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**Discourse, Narrative and Agency: A contribution
of Local Stories to Disability Theory, Research
and Professional Practice**

A thesis submitted in fulfillment
of the requirements for the degree of

Doctor of Education

in

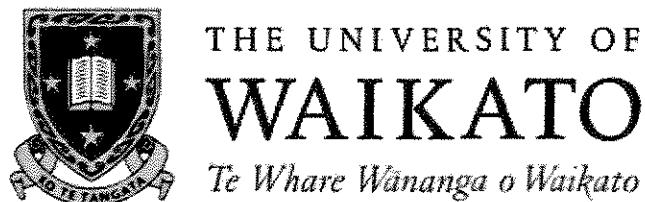
Disability Studies

at

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by

J. L. Arkwright



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ABSTRACT

The impetus for this study arose from a realisation that the post-structural concept of agency was relevant to disability studies. In locating this study as a contribution to the knowledge of disability and disablement, the initial chapters explore the theoretical genealogy of disability studies and the methodology for the study. In broad terms this has been a discursive and narrative research project, which sought to explore how discourse constituted the lives of six people with impairments and/or illness. Within this examination, specific attention was paid to those occasions in which the participants were able to take up alternative and preferred subject positions when they had been positioned in ways that removed or reduced their agency on account of their having an impairment and/or illness.

The six people who participated in the study are introduced at the end of Chapter Four and the next three chapters provide an account of their accounts. Overall, the participants' accounts of their experiences told how medical discourse positioned them in ways that removed their agency but not exclusively so. In contrast to medical discourse, disability rights discourses offered alternative subject positions because disablement is not constructed as an inevitable consequence of having an impairment and/or illness. In regard to the benefit of disability rights discourses for disabled people, two of the participants had been advantaged by the career opportunities available to them within the disability sector that arguably had been created by disability rights discourses. However, generally speaking, the participants' accounts of their experiences showed that disability rights discourses were not the only discursive option for them. On those occasions in which the participants took up

subject positions that afforded them agency, they were often calling on more than one discursive idea or practice, typically beyond both medical or disability rights discourses. The participants' lives were more diverse and complex than the reproduction of any one singular discourse. Hence, even between just six people's accounts, there was significant difference between how each person called on and negotiated discourse so as to take up subject positions that offered them agency.

In considering the participants' accounts, a number of generic storylines have been generated from the research process. In particular, these were: the negative impact of deficit discourse on disabled people's lives, the advantages and limitations of disability rights discourses, the complex and person-specific processes of taking up subject positions that afford agency for the person, and the experience of silenced, subjugated and contradictory subject positions. These quite specific understandings about the processes of disablement for people who have impairments and/or illnesses, and their corresponding actions of agency, are discussed in more detail in the concluding chapter in regards to implications for future research, theory and professional practice.

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CONTENTS

	PAGE
ABSTRACT	i
ACKNOWLEDGEMENTS	iii
CONTENTS	v
1 INTRODUCTION	1
Two assumptions about disablement	1
Narrative, discourse and the constitution of self	2
Discourses construct disability	5
Relating the concepts of discourse, subjectivity and agency to disability	6
2 DISABILITY: MODERNIST THEORIES, CRITIQUE AND RESEARCH	9
The biomedical model	9
Sociological critique of the biomedical model	15
Disability rights and the disability movement	20
Diversity and conceptual differences within the disability movement	28
Two versions of disability rights	31
The modern – postmodern divide within Disability Studies	36
Searching beyond modernist theories of disability	40

3 CRITICAL REALIST AND SOCIAL CONSTRUCTIONIST PERSPECTIVES WITHIN DISABILITY STUDIES: THEORIES, CRITIQUE AND RESEARCH	42
The critical realist contribution to Disability Studies	45
The discursive turn in Disability Studies	48
The rise and relevance of narrative studies to Disability Studies	51
The power relation of discourse and the construction of subjectivity	62
Negotiating agency in response to position calls	69
4 THE RESEARCH METHODOLOGY	73
Narrative therapy and thickening the alternative story	74
Narrative research and the storied self	78
Discursive analysis of position calls, subject positions and agency	84
The research process	88
Accessing participants	89
Ethical considerations and process	91
Engagement with the participants and the interviews	93
The analysis of the interviews	100
Introducing the participants	105
5 INTO, THROUGH AND BEYOND DEFICIT DISCOURSE: DAVID RE-NEGOTIATES HIS PARENTS' LEGACY	107
Early years: The practice of “hanging out” with friends	108
Teenage years: Positioned as “the spastic”	111
Teenage years: The subjectivity of “rebel”	121
Teenage years: Practices of “finding comfort” and “connection”	124
Later years: The new narrative of empowered and aware	133
Later years: The interplay of different storylines	138

6 THE POLITICS OF DIFFERENCE: FAY AND JOHN SHAPE INTENTIONAL IDENTITY CLAIMS	139
Fay and John take up medical and/or rehabilitation discourse	139
Fay's refusal of the illness subject position	141
John's identity claims of being "a hard nut" and "a bloke on the ground"	143
Fay negotiates new body/self narratives	146
John's multiple subjectivities	152
Fay negotiates the power relation within medical discourse	158
John is offered inclusive and affirming subject positions	160
Fay and John's positive identity claims	161
7 STORIES OF DEFICIT AND LOSS: CAROLE, JAN AND RON'S JOURNEYS TO RECOGNISE AND CONTEST POSITION CALLS	163
Medical discourse constructs impairment and illness as a problem	164
Ron's story of experiencing discriminatory actions within education	166
Jan's account of how she storied herself as a "complete failure"	168
Carole's protest against disempowering practices of "kindness"	169
The construction of illness as "less than" produces Carole's "secret world"	171
Male sex drive, gender and Christian discourses position Jan to fail	175
Carole, Jan and Ron contest deficit and loss position calls	179
8 THE COMPLEXITY OF DISABLEMENT AND AGENTIC ACTION: A CONTRIBUTION OF LOCAL STORIES TO THEORY, RESEARCH AND PROFESSIONAL PRACTICE	193
The dominance of medical discourse	196
Advantages and limitations of disability rights discourses	201
Processes of agency	210
Secret, subjugated and contradictory subject positions	217
Negotiating the power relation and agency	220
Constructing narrative and discursive change	223

9 BIBLIOGRAPHY	228
10 APPENDICES	251
Appendix 1: Consent form	251
Appendix 2: First letter to participants	253
Appendix 3: Practice questions before first interview	257
Appendix 4: Letter to participants after second interview	260
Appendix 5: Letter to Carole, after first interview	261
Appendix 6: Letter to Ron, after first interview	263
Appendix 7: First analysis guide	266
Appendix 8: Second analysis guide	268
Appendix 9: Third analysis guide	269
Appendix 10: Discursive maps	272

1

INTRODUCTION

This study engaged with six people who identified as having ‘a long-term illness or health problem’, ‘an impairment’ or ‘a disability’. Of interest to this investigation were the meanings the participants took up about their lives. In regard to their meaning-making, I was curious to learn the extent to which the discursive subject positions offered to the participants constructed problematic realities for them. Furthermore, I wished to investigate when the participants were positioned in ways that were disadvantageous for them, were they able to take up alternative subject positions, thereby resisting disabling ideas and practices.

Two assumptions about disablement

A Foucauldian analysis of discourse has informed the study, in that “words and phrases have meanings that are organised into systems and institutions... [and] discursive practices that position us in relations of power” (Parker, 1999, p. 6). On this basis, my first assumption has been that some discourses did not benefit but rather worked to the detriment of those who were viewed as having an illness or impairment. For example, Western medical discourse not only creates the classifications of illness and impairment but in addition any bodily occurrence judged as representing the absence of health is assumed to create disadvantage for that person. The argument for how medical discourse specifically produces disadvantage for people with illness or impairment, from a disability rights discourse perspective, is discussed further in Chapters Two and Three.

Problematic as it is to be positioned in terms of the absence of health, Foucault (1980) did not believe that any experience was ever completely captured by the meanings held within any one discursive framework. In other words, despite being positioned disadvantageously by one discourse, other discursive meaning-making would potentially be available, offering alternative understandings of experience. Foucault referred to these alternative understandings as subjugated knowledges for “the power implicit in one discourse is only apparent from the resistance implicit in another” (Burr, 2003, p.69). Hence, the second assumption I have held is that whilst the participants’ lives would demonstrate disadvantage because of the presence of illness and impairment, their lives would also illustrate resistance to such disadvantage: there would be times when the participants attempted to gain agency, “to push at the limits of what is socially constructed and actively construct something different” (Parker, 1999, p.7). I was curious to hear about these stories of resistance; how these stories of exception to disablement were achieved; what discursive ideas and practices were taken up so as to enable the participants to story themselves beyond the familiar terms of deficit discourse.

Narrative, discourse and the constitution of self

Researching stories of disablement and stories of resistance to disablement reflects my interest in narrative, as well as my purpose in examining the discourses that have produced such narratives. It is prudent at this point to discuss my understanding and use of the terms ‘narrative’ and ‘discourse’ and their connection to each other. This discussion will be continued in Chapter Three, where I review discursive applications

to the field of disability theory and research, and Chapter Four in which I discuss the specific purpose and methodology of this study. Both chapters explore in more detail the discursive concepts of positioning, subjectivity and agency. And while these concepts have occurred within the domain of discourse analysis, they are also implicit, and explicit, within the field of narrative therapy. One of Epston and White's earlier texts on narrative therapy, *Narrative means to therapeutic ends* (1990), draws on the work of anthropologists Bruner and Brooks. According to Bruner (2002), a story is not about producing a convincing logico-scientific argument but about being characterised as life-like, a subjective account of experience that is a performance of meaning-making. Stories, therefore, are narrative mediums which are not descriptive but performative. That is, they have real shaping effects on what is constructed as reality:

Our lives are ceaselessly intertwined with narrative, with the stories we tell and hear told, those we dream or imagine or would like to tell, all of which are reworked in the story of our lives, that we narrate to ourselves in an episodic, sometimes semi-conscious, but virtually uninterrupted monologue. We live immersed in narrative, recounting and reassessing the meaning of our past actions, anticipating the outcomes of our future projects, situating ourselves at the intersection of several stories not yet completed. (Brooks, 1984, p.3, cited in Epston & White, 1990, p. 80)

Epston and White go on to make the point that narrative "locates a person as the protagonist or participant in his/her world... a world in which persons participate with others in the 're-authoring', and thus the shaping of their lives and relationships" (p.82). Burr (2003) also attests to this theme of co-production, saying "the narratives

we construct about ourselves are not simply a private matter... [for] we are heavily dependent upon the willingness of co-actors in the construction of our story" (p.145).

People's narratives, therefore, are negotiated and re-negotiated within communities (White, 2001). As such, narratives do not stand separate from discourse but embody discursive ideas and practices, those underpinning values and worldview that have constituted and shaped the meanings the person has of experience (Weingarten, 1991). In this case, from a discourse perspective, who a person is, how they view themselves and how others see them, is not seen as fixed and independent from the social environment. Rather, the self, as constituted by various discourses in an on-going manner, is viewed as multiple, fragmented and incoherent (Burr, 2003). The stories we tell about ourselves and others are discursive acts:

One's being shifts with the various discourses through which one is spoken into existence. The individual or heroic "I" is understood as a discursive construction, not stemming from the particular characteristics of that person but from the subject position made available to him/her. (Davies, 1991, p.43)

If the narrative stories of the self are constructed within and limited by the subject positions available within discourse, then it is important to develop an understanding of the discourses that one is engaged with at any one time. For people who live with illness and/or impairment, this means understanding how discourses construct disability.

Discourses construct disability

Disability, as a construct of discourse, is an experience that I would argue is at the intersection of many discourses. Disability is a contested term and considerable debate and argument has occurred relative to disability theory, research, policy and practice. Different ideas have been proposed for what disability is, what causes it and how it should be responded to. The dominant discourse about disability continues to be that of Western medicine. In response to the biomedical model and respective critique of it, a number of alternative theories about disability have been developed. The social model of disability, minority group and feminist approaches, normalisation and social role valorisation (SRV), critical realist and postmodern perspectives, all continue to make significant contributions to disability studies.

As a person who has lived with spinal cord injury for twenty-three years, I can understand, and identify with the relevance of all these approaches to the field of disability. Without doubt, each of these paradigmatic agendas has, at different times, informed my thinking and shaped how I have engaged with health professionals, work colleagues, family and friendships. But in more recent years, my attention as a counselling educator and practitioner has turned more specifically to the postmodern concepts of narrative and discourse and related foci of positioning, subjectivity and agency. As my teaching and counselling practice have been informed by these narrative and discursive ideas, there has at the same time been a growing interest within disability studies to apply postmodern theory to the field of disability:

The global experience of disabled people is too complex to be rendered within one unitary model or set of ideas. Considering the range of impairments under the disability umbrella; considering the different

ways in which they impact on individuals and groups over their lifetime; considering the intersection of disability with other axes of inequality; and considering the challenge which impairment issues to notions of embodiment, we believe it could be argued that disability is the ultimate postmodern concept.

(Corker & Shakespeare, 2002, p.15)

Relating the concepts of discourse, subjectivity and agency to disability

Given my personal and professional background, this invitation by Corker and Shakespeare, to apply the pluralist scope of postmodernism to the complex experience of disability, was in effect an encouragement for me to continue the project I was already engaged in. In 2005 I wrote the article ‘Disability: Theorising experiences in the critical analysis of discourse’ (Arkwright, 2005), in which I argued and illustrated the theoretical relevance of the concepts of discourse, subjectivity and agency to the lives of disabled people. What I especially liked about these concepts is that they avoided the either/or binary of one model versus another, instead providing a framework with which to understand the respective relevance and impact of all theorising about disability. I then published a chapter in which I discussed the binary of ‘competent versus incompetent parent’ and how it was difficult for me as a person with an impairment to take up a position within the descriptor of ‘competent parent’. I illustrated how it was possible to draw on narrative therapy processes and disability rights ideas to refuse the discursive invitation of being a ‘less-than’ parent (Arkwright, 2008). Indeed, my understanding of discourse and agency is that it is possible to position oneself to “play with the different constitutive acts we might engage in” (Davies, 1998, p.135). The question then becomes less which discourse (medical model, social model, SRV, postmodern approaches and so forth) serves

disabled people best but more how each discourse “can be used in particular ways with powerful effects (one of which might be the constitution of ‘me’ as a particular kind of person)” (Davies, 1998, p.135). This means that all the efforts made by academics, health professionals and disability activists to theorise disability, alleviate impairment and emancipate disabled people have been potentially helpful to disabled people in understanding and negotiating life. In addition, while all these models are relevant, they are still insufficient to explain all disablement because discourses such as gender, ethnicity, class, age, education, work, sex, religion and so forth also intersect with and impact understandings of illness, impairment and disability. For this reason, I would argue that discourse analysis is especially relevant to disability theory. As Davies (1998) has stated, in this instance referring to Kristeva’s examination of feminist discourses, it is possible to see the value of all theories pertaining to people’s understandings of experience, rather than accepting the discursive invitation to be loyal to one over another:

Each of the competing [feminist] discourses have been generated over time, partly in reaction to the problems encountered in the one that went before. These discourses oppose and contradict each other in quite fundamental ways. Yet they are still necessary... as they can each achieve quite different and important things. (Davies, 1998, p.135).

If this is the case, that even quite different disability theories can achieve important things, then the question of what these competing discourses actually achieve for disabled people must be asked. And to what extent are the discursive concepts of positioning, subjectivity and agency useful for understanding the subject positions within discourse that disabled people occupy? These considerations have implications for future disability theory, research, policy and practice. They are the

central focus of this study. Indeed, the study suggests that at this point in time when the experience of disability is viewed as more complex than can be accounted for by any one theory of disability (Corker & Shakespeare, 2002), it is especially relevant to understand how different discourses position disabled people. Furthermore, what these subject positions mean for how people with impairments and/or illnesses can live and who they can be, but most importantly what ideas and practices disabled people call on as they resist those position calls which limit or remove their agency.

In this first chapter, I have briefly introduced the topic of my study, overviewed the concepts of discourse and narrative, and shared something of my own background that has influenced me to undertake the study. Chapter Two maps the historical dominance of medical discourse and discusses two counter discourses: the social model of disability, and the theory of normalisation / SRV. Disability theory, research and practice which utilises postmodern theory has emerged in recent years and signifies a new development within disability studies. Chapter Three reviews such literature and locates the place of this particular study within this wider pursuit, namely the current trend within disability studies to use postmodern theory to go beyond the medical versus social model dichotomy. The particular methodology, ethics and research process of this study are discussed in Chapter Four. The participants are introduced and the research findings from the participant interviews are discussed in Chapters Five, Six and Seven. Chapter Eight concludes with a discussion about some of the overall storylines that have been generated by the study, and suggests possible implications from the study for future disability theory, research and professional practice.

2

DISABILITY: MODERNIST THEORIES, CRITIQUE AND RESEARCH

Western medicine may seem an unusual place to start when reviewing disability literature, especially when much of disability theory has been established as a counter to the biomedical model. However, whilst disability rights, pioneered by the disability movement and furthered by the work of disability studies, has achieved much for disabled people, it remains on the margins of, and definitely a subversive alternative to medical science and medical practice (Bury, 2005). For this reason, I begin with the theory, practice and critique of biomedicine.

The Biomedical Model

Western medicine has a long history which can be traced back to Hellenistic times. Hippocrates, a physician in the fourth century BC, is most remembered for his oath of medical ethics. He stated, “I will use treatment to help the sick according to my ability and judgement, but I will never use it to injure or wrong them.” (Beauchamp & Childress, 2009, p.149). The Hippocratic Oath is still referred to and discussed in medical schools today which suggests that the underpinning philosophy of Western medical practice has remained similar for over two thousand years. However, diseases and medical practice have not remained the same. In the first part of this chapter, drawing initially on Foucault’s (1963) critique of modern medicine, I detail how medical practice changed from the eighteenth to the nineteenth century, and what these changes have meant for the construction of impairment and illness.

The social movements of the Modernist period, namely Colonialism, the French Revolution, the Industrial Revolution, the Enlightenment and the World Wars, created notable changes in both the types of illness and injury that afflicted people and the respective medical practices used to treat them. The European explorations to the New World and colonisation during the sixteenth and seventeenth centuries spread diseases from one continent to another. For example, up to ninety percent of native Americans are thought to have died due to European diseases following European settlement into North America. Smallpox killed millions in the Caribbean, Mexican highlands and South Americas during the early sixteenth century. In the Pacific Islands, smallpox, syphilis and other illnesses decimated the indigenous peoples. Europe also witnessed sweeping epidemics of plague, smallpox, typhus and syphilis, whilst scarlet fever, syphilis and diphtheria entered China with devastating consequences and India was ravaged by cholera. During the Imperial period, disease killed people the world over with alarming speed, but in addition to the spread of diseases created by Colonialism, the French Revolution (1789-1999) and the Napoleonic wars resulted in injuries and casualties on an unprecedented scale. Moreover, the Industrial Revolution's urban drift served to create even more health problems because cities became a breeding ground for infectious diseases (Porter, 2004).

During the eighteenth century, medical practitioners were facing the challenge of trying to treat illnesses that killed people but they still had very little knowledge about what caused disease. Bloodletting and purging remained the dominant treatment for

infection, only years later revealed as an ineffective and problematic practice. By the nineteenth century, hospitals and medical laboratories had become widespread.

Medicine began to shift from a focus on holistic health practices in local settings to the diagnosis and treatment of pathology within hospitals and clinics, what Porter (1999, 2004) has referred to as the shift from ‘dis-ease’ to ‘diseases’. By the end of the nineteenth century, knowledge about illness and its treatment had increased substantially. In the Age of Science, medicine became more like a science. Training from a university became necessary in order to hold a medical license. Laboratories produced aspirin, a safer pain relief than opium’, and nitrous oxide and chloroform were used for anesthesia during surgery and childbirth. The stethoscope had been invented and even more significantly, Pasteur had proposed his ideas about germs carrying diseases, resulting in a focus on hygiene, which did reduce the rate of infection. The development of vaccines began, as did the use of sulphur drugs during the 1930s; then penicillin and its purified forms led to the first effective antimicrobial drugs. The tide began to turn in medical care: doctors were no longer the listening ear of the 1800s with no real cure for the diseases that killed. Biochemical and pharmacological research expanded exponentially following World War Two, enabling doctors to effectively treat a wide range of both traditional illnesses, such as polio, as well as more modern illnesses such as heart disease and high blood pressure, including the development and use of intensive care units, laser and keyhole surgery (Porter, 2004).

However, modern medical practice still faces many challenges, not least of which are new infectious diseases such as avian influenza, and the continual decimation of

populations in developing countries by Human Immunodeficiency Virus (HIV). The new frontiers in medical research, stem cell research and gene based therapy are hoped to offer solutions to such illnesses and some injuries such as spinal cord and neurological problems.

However, as Watts has noted “two things that have not changed over the past decade are medicine’s capacity to devise new and more costly remedies and the uncertainty with which so many of us view the entire enterprise” (Watts, 2006, p. 332).

Uncertainty about the enterprise of medicine is not a new phenomenon. For example, by the mid twentieth century antibiotics had transformed the possibilities of recovery from many infectious diseases but it was during this very period that despite the rise of medical efficacy, or perhaps because of it, Foucault was critical of the institution of medicine. In *Birth of the clinic* (1963) he began his critique of the development, ideology and impact of modern medicine by tracking the changes in medical practice from the eighteenth to the nineteenth century:

Generally speaking, it might be said that up to the end of the *eighteenth century medicine related much more to health than to normality*; it did not begin by analysing a ‘regular’ functioning of the organism and go on to seek where it had deviated, what it was disturbed by, and how it could be brought back into working order; it referred, rather, to qualities of vigour, suppleness, and fluidity, which were lost in illness and which it was the task of medicine to restore; to this extent, medical practice would accord an important place to regimen and diet, in short to a whole rule of life and nutrition that the subject imposed upon himself. This privileged relation between medicine and health involved the possibility of being one's own physician. *Nineteenth century medicine*, on the other hand, was regulated more in accordance with

normality than health; it formed its concepts and prescribed its interventions in relation to a standard of functioning and organic structure, and physiological knowledge – once marginal and purely theoretical knowledge for the doctor – was to become established (Claude Bernard bears witness to this) at the very centre of all medical reflexion.

(Foucault, 1963, p.35, my emphasis)

The shift from ‘a rule of life for all’ that people ‘imposed upon themselves’ to an analysis by the physician of what was deviant or not normal, was significant. The patient was more pathologised in the latter. At the same time the status of the doctor had become more elevated because *le regard* (the medical gaze) of the doctor became a privileged and exclusive knowledge:

Description, in clinical medicine, does not mean placing the hidden or the invisible within reach of those who have no direct access to them; what it means is to give speech to that which everyone sees without seeing – a speech that can be understood only by those initiated into true speech. ‘Whatever precepts are given about so delicate a matter, it will always remain beyond the reach of the multitude’. (Foucault, 1963, p. 115)

As the knowledges informing medical practice became less visible and accessible to ‘the multitude’, people’s dependence on the expertise of the doctor inevitably grew. In the industrial age of the nineteenth century, illness detrimentally impacted the economics of local and national bodies, since a healthy population made for a productive labour force. Hence, it was in the interest of both the economy and the medical establishment for people to be well because a healthy person could sustain employment and afford medical care for both themselves and family members. Not surprisingly, health evolved into “the duty of each and the objective of all” (Foucault,

1980, p. 170) and it became a state policy priority, whereas previously only the concerns of war and peace, order and lawlessness had been state concerns. Foucault (1980) termed this evolving “the great medical edifice” and his critique was that whilst medicine was “explicitly moral and scientific” it was also “secretly economic” (p.166). He argued that due to a number of texts in the nineteenth century on the care of children, families were positioned by “new and highly detailed rules... [and] the health of children [became] one of the family’s most demanding objectives” (Foucault, 1980, p.172-3). Unchecked as a means of social control, by the twentieth century medicine had become “a world power” (Starr, 1982):

From a relatively weak, traditional profession of minor economic significance, medicine has become a sprawling system of hospitals, clinics, health plans, insurance companies, and myriad other organisations employing a vast labour force. This transformation has not been propelled solely by the advance of science and the satisfaction of human need... the profession has managed to turn its authority into social privilege, economic power, and political influence... the pattern has been one of professional sovereignty. (Starr 1982, p.4-5)

The rise of medicine to hold such power within society occurred because medical practice became the legitimate body for defining what disease, illness and impairment were, while at the same time it was also the profession that was engaged in curing and/or reducing disease, illness and impairment. Medical practice by definition then, created the distinction between those who were the consumers of medical practice, people who had diseases and problems with their bodies, and those whose work involved them treating such persons (Nettleton, 1998). The distinction meant people with impairments and illness were constructed as having conditions which were

undesirable, whereas those involved in medical research and practice were positioned to be respected for the knowledge, skills, social status and influence they had. The power of discourse, like medicine, to privilege one group of people but disadvantage another was what Foucault (1963, 1973, 1980) took exception to when he referred to “the tyranny of globalising discourses with their hierarchy and all their privileges of a theoretical avante-garde” (Foucault, 1980, p.83). As a counter to such dominant knowledge/power, Foucault advocated the emergence of alternative knowledges:

It is through the re-emergence of these low ranking knowledges, these unqualified, even directly disqualified knowledges (such as that of the psychiatric patient, of the ill person, of the nurse, of the doctor – parallel and marginal as they are to the knowledge of medicine – that of the delinquent etc.)... it is through the re-appearance of ... these disqualified knowledges, that criticism performs its work. (Foucault 1980, p.82)

Sociological critique of the biomedical model

Subsequent to Foucault’s theorising the insurrection of subjugated knowledges, Medical Sociology and Sociology of Health and Illness emerged as separate academic disciplines from either medicine or sociology, each focused on providing a response to and a critique of medicine. It is not my intent to explore comprehensively the history and work of these disciplines but to briefly scope key aspects of their critique of medicine. Sociologists within these disciplines continued Foucault’s lead of deconstructing the ideas and practices of medicine:

The [biomedical] model is based on five assumptions. First, that the mind and the body can be treated separately; this is referred to as medicine’s mind-body dualism. Second, that the body can be repaired like a machine; thus medicine adopts a mechanical metaphor

presuming that doctors can act like engineers to mend that which is dysfunctional. Third, and consequently, the merits of technological interventions are sometimes overplayed, which results in medicine adopting a technological imperative. Fourth, biomedicine is reductionist in that explanations of disease focus on biological changes to the relative neglect of social and psychological factors. Finally, such reductionism was accentuated by the development of the ‘germ theory’ in the nineteenth century, which assumed that every disease is caused by a specific, identifiable agent, namely a ‘disease entity’ (such as a parasite, virus or bacterium). This is referred to as the doctrine of specific aetiology. (Nettleton, 1998, p.3)

These five assumptions of medicine, underpinned by the positivist paradigm, gave authority to medical practitioners; so that “the story told by the physician becomes the one by which others are ultimately judged true or false, useful or not” (Frank, 2002, p. 16).

A critical analysis of medicine began to erode the unequivocal dominance and ideal of the modernist medicine project. Frank (1995; 2004c), a sociologist who had personal experience with cancer and a heart attack, advocated that people had accounts of illness which were beyond the confines of that which the medical story could tell. He stressed the importance of hearing the story of the person living with the illness (or impairment) separate from medical analyses and agendas. He illustrated his point with a poignant illustration:

I met a man who had cancer of the mouth that required extensive reconstructive surgery to his jaw and face. His treatment had been sufficiently extraordinary for his surgeon to have published a medical journal article about it, complete with pictures showing the stages of the reconstructive process. When he told me about the article and

offered to show it to me, I imagined that article might actually be about him: his suffering throughout this mutilating, if life-saving, ordeal. As I looked at the article I realised his name was not mentioned. Probably the surgeon and the journal would have considered it unethical to name him, even though pictures of the man were shown. Thus in “his” article he was systematically ignored as anyone – actually anything – other than a body. But for medical purposes it was not his article at all; it was his surgeon’s article. This is exactly the colonisation that Spivak speaks of: the master text of the medical journal article needs the suffering person, but the individuality of that suffering cannot be acknowledged.

(Frank 1995, p., 11-12).

It is stories like this one, where the person, whose body is ill, injured or impaired, is irrelevant in the treatment of that body, which have become less acceptable. No longer is illness viewed as the sole product of disease but mediated by “the role played by the mind, emotions and social processes [and] always created at the crossroads of biology and culture” (Morris, 2000, p.8).

Under the strongly pluralist postmodern landscape of the twenty first century, the determinist, dualistic, reductive and mechanistic practice of modernist biomedicine has been both challenged and complemented by other understandings about health, illness and disability. Space has been created for the validity of other stories and discursive practices, such as the patient’s experience and alternative therapies. Frank’s example of how the surgeon’s article omitted the experience of the man whom the article’s treatment documents, is testimony to the growing demand for the patient to be respected, informed and empowered in the treatment of his or her body. In regard to the rise of alternative therapies (their colloquial name depicting their position as counter to traditional medical practice), Morris (2000) mentioned how

people are showing their loss of faith in biomedicine by their “huge out-of-pocket investment in so called non-traditional or complementary therapies” (p.8). And whilst medicine, not alternative therapies to medicine, might still be the dominant discourse in understandings about health, illness and disability, how that model is enacted within the doctor-patient relationship has changed considerably in recent years. Rich, Simmons, Adams, Thorp and Mink (2008) made the point that “physicians are expected to behave according to a postmodern ethic... recognizing patient autonomy, sharing authority with various third parties, and managing their practices using a business model” (p. 235). Without question, post industrial consumerist culture has changed power relations within health services as “patients qua consumers are urged to refuse to accept paternalism or ‘medical dominance’ on the part of the doctor, to ‘shop around’, to actively evaluate doctors’ services and to go elsewhere should the ‘commodity’ be found unsatisfactory” (Lupton, 2004, p.198).

The shift to viewing medical services as a commodity in the market place, with medical practitioners competing with one another, supplying medical services to the paying and rights-orientated customer, has arguably ushered in some new health ideologies and practices. Rose (2007) and others have suggested that the normative agenda of biomedicine, as in medical practice aiming to return the deviant organism to biological normality, has been superseded by ‘customisation’ (Clarke, 2003; Rose, 2007). That is, the customer drives the technological advances of medicine so as to improve upon biology, creating a new era in which medical necessity is no longer the only reason why people receive medical treatment. Cosmetic surgery, gender

reassignment, facial remodeling, extending sexual capacities of aging men, and post menopausal women having babies, are current trends within the age of medical customisation (Rose, 2007, p.21). The question then shifts from ‘can the doctor help me’ and ‘will I still be able to do what I used to do’ when sick or injured to ‘how would I like to be’ and ‘can I afford this’ when neither sick nor injured. In this case, the dilemma for the medical profession centres on the ethics of such choices being made available to people, simply because first, they want it and can afford it and second, medicine can apply its technological research and advances to such agendas.

Not surprisingly, neuroethics and bioethics have become sub-disciplines within medicine because the agenda and practice of medical treatment is less clear than it used to be. Rose (2007) says the border between life and death has become open to negotiation and dispute, as has distinguishing the difference between addressing illness or impairment versus improving biological capacity. Certainly, the potential of applied bioengineering to intervene with and even improve human biology has captured people’s imagination. For example, in 2000, the English Prime Minister Tony Blair said “biotechnology is the next wave of the knowledge economy and I want Britain to become its European hub” (cited in Rose, 2007, p.35). The 2003 United States (US) President’s Council on Bioethics Report, suggested that enthusiasm for biotechnology rested on people’s desire for better children, superior performance in sport and ageless bodies (as cited in Rose, 2007, p. 77). Given these ideals, it is interesting to speculate about what biotechnology represents, who will benefit and who will be disadvantaged by it. Some ethical dilemmas have been raised, such as “why should the ‘dignity’ of the person at the end of life be a

bioethical issue, but not the massive ‘letting die’ of millions of children under five years of age each year from preventable cases” (Rose, 2007, p.31). Hence, despite the rush to invest human resources and funds into biotechnology, some are cautious, even critical.

Disability rights and the disability movement

Disability rights campaigners have been especially critical of biotechnology becoming the means to improve or eradicate congenital impairment. Given that many disabled people might have been terminated prior to being born if the technology to detect the impaired foetus had been available while they were embryos, it is hardly surprising that disabled people have been strongly opposed to such technology. For example, Rock (1996) stated: “Disabled people know only too well they are not welcome in society, but the active promotion of abortion on the grounds of disability and determining that euthanasia is a viable proposition for the disabled foetus/child – is fascism” (p.124).

Hence, quite separate from Medical Sociology and Sociology of Health and Illness, disability rights activists have also been active in critiquing the biomedical model. The disability rights movement is often associated with having its roots in the United Kingdom (UK) during the 1960-70s. For example, the Disablement Income Group (DIG) worked toward improving benefits for disabled people, and the Union for Physically Impaired Against Segregation (UPIAS) focused on independent living, participation, inclusive education and productive paid work for disabled people. The members of these groups (during the 1960-1970s) were typically disabled people who

lived in segregated institutions and were unemployed. In comparison to academic critique of medical discourse, the spoken and written protests from DIG and UPIAS represented those who had little power within society. In Foucauldian (1980) terms, the knowledge they held about disability was “low ranking and unqualified”. The work of the disability movement has very much been an illustration of what Foucault (1980) referred to as the “insurrection of disqualified knowledges”.

UPIAS spoke of the segregation that disabled people experienced on a daily basis and stated, “We find ourselves isolated and excluded from such things as flights of stairs, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and a lack of up to date aids and equipment” (UPIAS Aims para 1, cited in Shakespeare 2006, p. 11). The fundamental principle of UPIAS was that disability was not caused by impairment, but by social conditions that disadvantaged and discriminated against disabled people. This principle was, and still is, a radical reframe from the biomedical model. From UPIAS’ perspective,

Disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people... 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 (UPIAS, 1976, p.3, cited in Shakespeare, 2006, p.12).

Renaming disability as a social oppression caused by social barriers, not illness or impairment, was indeed a complete paradigm shift but it did not in itself explain how it was that medicine was responsible for the exclusion of disabled people. For this to occur, a deconstruction of medical discourse was needed, extending from Foucault's (1963) *Birth of the clinic* and specific to disability. Zola, a disability rights' activist and medical sociologist, wrote about the medically created apartheid between healthy and ill people that had become a familiar cultural practice in the West. Zola noted that illness was rarely contextualised but always located within the individual:

My concern is what happens when a problem and its bearers become tainted with the label ‘illness’... as a disease is by definition not social and at the same time the expected level of intervention is also not social. If it has to be handled anywhere or if anyone is to blame it is individuals – usually the carriers of the problem – and certainly not the rest of us, or society at large. (Zola, 1977, p.62-63)

Hence, Zola made the link more overtly than UPIAS, that medicine marginalises people with impairment and illness, views the problem and solution resting with the treatment of the individual, and absolves the social environment for any accountability in either creating or fixing the problem of disability.

Zola was one of a number of disabled activists and academics (Barnes, 1990, 1991; Finklestein, 1980; Oliver, 1990; Shakespeare, 1993, 1994) who began to critique and look for an alternative to the medical model. Oliver's first text, *The politics of disablement* (1990), stands as the academic entry point for Disability Studies. As a paraplegic and sociologist, Oliver was concerned that there was no social theory of disability that was in the best interest of disabled people and he began theorising the

experience of disability. His starting point was the impairment/disability distinction already established by UPIAS (1976). Drawing on the work of Brisenden (1986) and Finklestein (1980), Oliver noted that medical definitions of disability were not helpful for disabled people because the underpinning meaning of disability was that it was a personal tragedy. As evidence of this, he noted how the OPCS (British Office of Population Censuses and Surveys) 1986 survey of disabled people created disability as a personal problem thereby re-enforcing the identification with individual deficit. He prepared an alternative survey that positioned disability as caused by a disabling environment, as in a problem of social oppression (see Table 1):

Table 1

OPCS Survey of Disabled Adults	Oliver's Alternative Questions
<ul style="list-style-type: none"> • Can you tell me what is wrong with you? • What complaint causes you difficulty in holding, gripping or turning things? • Are your difficulties in understanding people mainly due to a hearing problem? • How difficult is it for you to get about your neighbourhood? <p>Cont....</p>	<ul style="list-style-type: none"> • Can you tell me what is wrong with society? • What defects in the design of everyday equipment like jars, bottles and tins cause you difficulty in holding, gripping or turning them? • Are your difficulties in understanding people mainly due to their inability to communicate with you? • What are the environmental constraints which make it difficult for you to get about in your immediate neighbourhood? <p>Cont...</p> <p>(Oliver, 1990, p.7-8)</p>

Oliver then linked the way disability is produced as a medical and individual problem to the structural, ideological and cultural features of capitalism. In this materialist explanation for disability, Oliver discussed Foucault's critique of psychiatry (1965) and criminology (1977), especially how the category of pathology was a social

concept produced by the discursive knowledge of psychiatry. Oliver focused especially on the economic structures and conditions that made possible the rise of institutions after the industrial revolution, such as prisons, asylums, workhouses, hospitals, factories and schools. He argued that disability as individual pathology only arose as distinct from individual ablebodiedness because of the development of wage labour (Oliver, 1990, p.47). Disability, therefore, was socially created, produced in the context of capitalism through the rise of medicine. The medical model was the problem, whilst the answer was full inclusion and non-discrimination of disabled people. Shakespeare (2006) noted that this conceptual move gave the disability movement a political focus, namely the removal of disabling barriers. It also had the secondary effect of liberating disabled people from negative identity conclusions:

Suddenly people were able to understand that it was society which was at fault, not themselves. They didn't need to change: society needed to change. They didn't have to be sorry for themselves: rather, they could be angry. Just as with feminist consciousness raising in the 1970s, or with lesbians and gays 'coming out', so disabled people began to think of themselves in a totally new way, and to become empowered to mobilise for equal citizenship. Rather than a demeaning reliance on charity, disabled activists could now demand their rights.

(Shakespeare, 2006, p.30)

The combination of disabled people not having to feel sorry for themselves and being legitimately angry about disablist discrimination meant the social model became a powerful force within disability politics. By the 1990s, the disability movement was challenging the observation made by Hunt (1966) twenty five years earlier, that

disabled people are “unfortunate, useless, different, oppressed, and sick” (Hunt, 1966, pp.6 & 155, as cited in Barnes, 1996a, p.46). The movement also disputed ableist assumptions about the experience of living with impairment, as in:

Disabled people feel ugly, inadequate and are ashamed of their disability; their lives are a burden, barely worth living; they crave to be ‘normal’ and ‘whole’; are asexual or at best sexually inadequate; able-bodied partners are doing them a favour and the disabled person brings nothing to the relationship; if they were particularly gifted, successful or attractive before the onset of disability their fate is infinitely more ‘tragic’ than if they were none of these things; their need and right to privacy isn’t as important as able-bodied people’s needs and rights; their lives need to be monitored in a way that deprives them of privacy and choice.

(Morris, 1991, p.19-20)

Informed by the social model of disability, disability activists argued that impairment was not the problem, but that what caused disablement was social restrictions and oppression of people who had impairments. This argument that disability was caused by societal oppression of people with impairments, quickly became an ideology in itself, which has strongly influenced policy, practice and research, especially in the western world. For example, eleven years after Oliver wrote *Politics of disablement*, New Zealand’s national policy on disability was based on a social model philosophy and agenda. The introduction of *The New Zealand disability strategy*, published by the Ministry of Health in 2001, stated:

Disability is not something individuals have. What individuals have are impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have. (The New Zealand disability strategy, 2001, p.63)

The fact that New Zealand (NZ) even has a national disability strategy and one which is so clearly based on the social model, stands as testimony to the success of Disability Studies and disability activist groups such as NZ's Assembly of People with Disabilities (DPA) who have politicised and promoted the social model. Civil rights for disabled people, primarily through anti-discrimination legislation and barrier removal, became the essential goals of disability rights. Political battles for disability rights legislation have been fought and won, as evidenced by the United States of America's (USA's) Disabilities Act (ADA) in 1990, the disability amendment to NZ's Human Right's Act, 1993, and the UK's Disability Discrimination Act, 1995.

In conjunction with campaigns for anti-discrimination legislation, social model advocates have been critical of medical model informed research that has reduced disability to individual pathology, caused by an organic problem which requires a cure (Llewellyn & Hogan, 2000). Social model advocates have argued that research which focused on reducing or curing impairment was directly related to a vested interest in rehabilitation outcomes, meaning non-disabled professionals set the agendas for the research projects (Bury, 1996a, 1996b; Oliver, 1990, 1992; Scotch, 2002). Such an emphasis means the disabled subject is always viewed as a patient, precluding any understanding of disabled people beyond the role of dependence on others' support and treatment (Scotch, 2002). In contrast, social model research has investigated disabling social and cultural conditions and promoted the ideal that disabled people should control, not merely participate in, the research process (Walmsley, 2001). For example, early research of disabled children, informed by

medical discourse, positioned disabled children as vulnerable, passive, and isolated (Priestly, 1998) whereas more recent research has emphasized disabled children's ability to resist social stigma and oppressive social practices (Davis & Watson, 2002). Such research was emancipatory in design because it intentionally sought to construct disabled people as having value, rights and expertise and be deserving of full inclusion within society (Barnes, 1996; Barton, 1998; Fine & Asch, 1993; Oliver, 1992, 1993). Such research, which identified and campaigned against oppressive societal structures, produced positive outcomes for disabled people. In particular, personal accounts of disablement, once told and heard, furthered the cause for inclusive living arrangements and inclusive education:

The telling of their experiences by people who lived for years in the large, segregated institutions has been one of the most powerful arguments for deinstitutionalization during the past 20 years... Parents' descriptions of their experiences and perspectives about raising their children with severe disabilities in the community, in the local school, and with other children have been one of the primary forces toward integrated, inclusive education. (Ferguson, Ferguson & Taylor, 1992, p.300).

Researching social barriers for disabled people became the primary focus of Disability Studies and the disability movement. For example, Harris (2003) explored the experiences of disabled refugees and asylum seekers in the UK, from the perspective of barriers to health, barriers to safety, barriers to social services, barriers to the benefit system, and barriers to social contact.

Through the disability rights' movement, disabled people began to have opportunities to tell their stories and promote their views (Ferguson, Ferguson & Taylor, 1992;

Oliver, 1996; Moore, Beazley & Maelzer, 1999). Discussing and researching the experiences of disabled people in regard to schooling (Fergusson, 1992; Higgins, 1992; Swain, 1993), media and film (Davidson, 1994; Shakespeare, 1994; Zola, 1992), community integration (Briggs, 1993; Morris, 1993, 2004; Reynolds & Walmsley, 1998; Silburn, 1993), intellectual disability (Booth & Booth, 1996), sexuality (Brown, 1994; Earl, 1999; Hahn, 1993; Shakespeare, Gilleppe-Sells & Davies, 1996), parenting (Kaluanes & Rubenfeld, 1997; Keith & Morris, 1995; Reinelt & Fried, 1993), employment (Barnes, 2000; Drake, 2000; French, 1995) and aging (Todis, 1992; Zarb, 1993) became grist to the mill for disability rights promotion and research during the 1990s. It was essentially a minority group action, fighting to end “disablism – unfair discrimination against disabled people” (Shakespeare, 2006, p.65).

Diversity and conceptual differences within the disability movement

As the social model was being used as a platform to campaign for the removal of social barriers, through protest action, academic writing and research, there was a growing awareness within the disability movement during the 1990s that not all disabled people were discriminated against equally. Nor would disablement end if discrimination of disabled people ended because there were further minority groups within the minority group of disability, such as disabled women, non-white disabled people, and gay disabled people. Furthermore, due to the presence and impact of impairment, disabled people were not a minority group in the same sense as other minorities were on the basis of gender, ethnicity and sexuality. That is, while “disability discrimination [does] parallel racism, sexism, and other social

exclusions... in most cases, disabled people are experiencing both the intrinsic limitation of impairment, and the externally imposed social discrimination” (Shakespeare, 2006, p.41). Women became the first minority group within the disability movement to speak and write about the distinguishing features of their experiences and views. They had realised that they had unique experiences as disabled women and that impairment did contribute to their experiences of disability (Corker & French, 1999; Morris, 1991, 1996; Thomas, 1999). Moreover, the social model was accounting for neither reality.

Morris' (1996) edited text *Encounters with strangers: Feminism and disability*, was a significant volume for its elucidation of women's experience of disability. In the introduction, Morris highlighted the need and desire of disabled women to no longer be victims of social oppression. A key aspect of disabled women's experience was that impairment did disable. Morris (1991, 1996) and others (Crow, 1996; Corker & French, 1999) challenged the impairment/disability distinction established by UPIAS and later promoted by Finklestein (1980), Barnes (1991) and Oliver (1990, 1996):

While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is to it is to deny the personal experiences of physical and intellectual restrictions, of illness, of the fear of dying.

(Morris, 1991, p.10)

French (1993) similarly argued that the removal of social barriers would not eliminate all her disablement. She described how her visual impairment did in and of itself cause problems, including an “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" (1993, p.17). Crow's (1996) critique of the social model's simplistic exclusion of impairment as a causal factor of disablement has perhaps been the most remembered. She declared:

The experience of impairment was not always irrelevant, neutral or positive... As individuals, many of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence so much of our lives. External disabling barriers may create social and economic disadvantage but our subjective experience of our bodies is an integral part of our everyday reality. What we need is to find a way to integrate impairment into our whole experience and sense of ourselves for the sake of our own physical and emotional well-being, and, subsequently, for our individual and collective capacity to work against disability. As a movement, we need to be informed about disability and impairment in all their diversity if our campaigns are to be open to all disabled people. (Crow, 1996, pp.209-210).

Crow's challenge and invitation was met with resistance by pioneers and staunch stalwarts of the social model. Authors such as Barnes, Finklestein and Oliver (1996) remained convinced that any deviation from the impairment/disability distinction would ultimately weaken the efficacy of the social model to reduce ableist discrimination. Oliver (1996), for example, did not deny the reality of impairment for some disabled people but did not think that the social model needed to be altered so as to include the experience of impairment:

The social model is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability... [It is a] pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or professional treatment.

(Oliver, 1996, p.38)

Finklestein's argument was similar, although a little more caustic, when he described criticism of the social model as "juvenile... aris[ing] because it [social model] is frequently used as if it explains our situation rather than as a tool for gaining insight into the way that society disables us" (2001, p. 10). What then emerged in the UK was a defensive position taken by social model advocates, critical of any theorising that ran counter to social model ideals.

Two versions of disability rights

A difference of approach began to develop between Disability Studies and the disability movement in the UK and the USA. Significant USA texts, such as Rioux and Bach's (1994) *Disability is not measles: New research paradigms in disability* (1994) and Wendell's (1996) *The rejected body* (1996), received criticism from Barnes (1995). In his reviews of both texts, Barnes found fault with any foci which contradicted or did not promote the views which were dominant within UK Disability Studies at that time. He was positive about the non-medical orientation of Rioux and Bach's research emphasis but saw limitations in the book's Eurocentrist worldview, lack of reference to multiple oppression experienced by minority group disabled people, inaccessible academic language for non-academics within the disability movement, and blurring of the impairment/disability distinction (1995, p.380).

Barnes (1998) was especially scathing of Wendell's book, citing a lack of reference to UK Disability Studies writers and ignorance of the crucial distinction between impairment (biology) and disability (social barriers) (p.145-146). Yet Shakespeare (2006) and others have accorded value to Wendell's book and given it a place within their discussions of Disability Studies' literature. Wendell's discussion of the cultural

construction of the ‘rejected body’, the body in pain and transcendence from it, are arguably very relevant to disabled people but of course much less so, or even not at all, if impairment is not seen as a disability issue.

In comparison to the proponents of the UK social model, the disability movement with the USA has been more open to seeing beyond an antagonism for anything that resembles a medical model orientation. For example, rehabilitation has received considerable research by USA disability rights researchers, who wished to highlight and improve the experience of rehabilitation for people with disabilities (Albrecht, 1992). In addition, the preferred term by dominant USA disability rights researchers and authors has been ‘people with disabilities’ (Hahn, 1988; 1993; Rioux & Bach, 1994; Zola 1994) compared with the UK description of ‘disabled people’. ‘People with disabilities’ recognises that both impairment and society are disabling (Bury, 2005), in the experience of disability, whereas ‘disabled people’ or ‘disabled person’ is an identity descriptor, positioning people with impairments as a minority group alongside other minority groups. Moreover, Nirje’s (1969) normalisation theory and Wolfensberger’s (1985) social role valorisation (SRV) approach have been significant and influential within the USA disability rights’ movement, but ignored and critiqued as an extension of medical model ideology by many UK social model advocates (Barnes, 1999; Stalker, Baron, Riddell & Wilkenson, 1999). Having said this, Shakespeare noted that “despite early criticism from social modellists, more recently there have been signs of a growing interest between social model and normalisation approaches” (Shakespeare, 2006, p.22).

Normalisation as a concept evolved in Scandinavia during the 1960s and was developed by Nirje during the 1970-80s. He defined normalisation as “making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of the life of society” (Nirje, 1976, cited in Perrin & Nirje, 1989, p. 220). Initially normalization was a theory that focused on people with intellectual disabilities but later it became broader in its application, being used as an underlying principle for people with all types of impairments. It focuses on ending segregation on the basis of impairment and creating opportunities for community-integrated independent living for disabled people. As the following table depicts, normalisation has always had a rights based agenda:

Table 1

Item	Rehabilitation Paradigm	Independent Living Paradigm
Definition of the problem	Physical impairment; lack of vocational skill; psychological maladjustment; lack of motivation and co-operation	Dependence on professionals, relatives, and others; inadequate support services; architectural barriers; economic barriers
Locus of problem	In individual	In environment; in the rehabilitation process
Social Role	Patient/client	Consumer
Solution to problem	Professional intervention by physician, physical therapist, occupational therapist, vocational counselor, and others	Peer counseling; advocacy; self-help; consumer control; removal of barriers and disincentives
Who controls	Professional	Consumer
Desired outcomes	Maximum ADL; gainful employment; psychological adjustment; improved motivation; completed treatment	Self-direction; least restrictive environment; social and economic productivity

(DeJong, 1983, p.23)

Hence, normalisation and its practical outworking of independent living, does not follow the ‘individual tragedy’ association of the medical model but focuses on

disabled people being able to have more control, opportunity and autonomy in their lives. Wolfensberger (1985) developed normalisation further by introducing the concept of social role valorisation (SRV), which is “the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people” (Wolfensberger & Tullman, 1989, p.211). In practice this development meant disabled people were to be given ‘normal’ or ‘ordinary’ (as opposed to special or segregated) roles and skills thereby enabling them to be integrated into the everyday run of education, employment, community and family activities.

Integration and independent living, the normalisation agenda, have been very influential in the Western world. For example, New Zealand’s education, welfare systems and workplace accommodations of people with impairments are a testimony to the principles of normalisation, as legislation and social policies have facilitated mainstream integration for disabled people. Examples include the 1972 Accident Compensation Act (ACC); the 1975 Disabled Persons’ Community Welfare Act; the 1989 Education Act establishing mainstreaming in schools for students with disabilities; the restructuring of the Rehabilitation League into Workbridge in 1990, and the 1992 ‘New Deal (support for independence for people with disabilities’ regulation) which replaced institutional residential care with community living. The impact of such restructuring has been very significant in terms of the service provision options and opportunities for disabled people in New Zealand. For example, numerous policies have been written and studies undertaken which reflect a commitment to disabled people’s participation as respondents, evaluating disability services’ quality and outcomes, comparing policies and practices against

normalisation ideas, and advocating for positive images of disabled people (Walmsley, 2001). In addition, there has also been research upholding and investigating the concept of ‘partnerships’ between consumers and providers of special education, rehabilitation and disability respite services (Appleton & Minchom, 1991).

However, while normalisation and SRV theories have been influential in the shaping of education and community living policies and practice, especially in the USA but also in other Western countries like New Zealand, social model advocates in the UK were critical of this development. Barnes (1996) and Oliver (1995; Campbell & Oliver, 1996) in particular, argued that normalisation and SRV theories were exclusionary and paternalistic due to their overarching accent on achieving able-bodied norms and the philosophy being driven by non-disabled people acting on behalf of disabled people (Barnes, 1996; Campbell & Oliver, 1996; Oliver, 1996). As a result, what has emerged has been a degree of difference between the parameters and focus of disability rights in the UK and US:

One distinct version of the Social Model is the crypto Marxist version found primarily in the United Kingdom, but used in other countries. It states that the organization of society produces discrimination experienced by people with disabilities... This social organization, it says, must be changed in order to end discrimination based upon disability. The other version of the Social Model is found chiefly in the United States, but it is also used in other countries. It states that fulfilling the "normal" role models in society helps constitute a person's identity, at least as seen by others... Researchers using the UK Social Model will analyze social structures and their impact on people with disabilities. Researchers using the US Social Model will analyze

social roles and attitudes toward failure to fulfill them. (Pfeiffer, 1992, p.234)

New Zealand has benefited from both versions of disability rights. However notably, in regard to the UK social model and the USA normalisation/minority group rights model combination, both have been found to be limited in regard to accurately representing and making an impact for all disabled people. A number of social model orientated studies have findings which are inconsistent with the model itself. For example, Lock's (2005) study of stroke survivors, found the participants were significantly disabled by their impairment but also experienced social disadvantage or discrimination. Similarly, Humphrey (2000) argued that the separatising dichotomous nature of the social model served to privilege some impairment minorities over others and excluded non-disabled from being allies of disabled people in their fight for their rights.

The modern – postmodern divide within Disability Studies

Oliver's response to those who considered the experience of impairment needed to be accommodated within the social model was to suggest a social model of impairment be created to complement the social model of disability (Oliver, 1996). For Oliver, impairment was simply not a disability issue as "it is not individual limitations, of whatever kind, which are the cause of the problem, but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation" (Oliver, 1996, p.32). Such a stand only served to fuel the determination of a growing number of people within the disability movement and Disability Studies to explore other ways of understanding disability

than the classic UPIAS impairment/disability distinction. Shakespeare and Watson, for example, began to shift allegiances, from 1997 when they co-authored a paper entitled ‘Defending the social model’, to 2001 when they wrote a chapter titled ‘The social model of disability: An outdated ideology?’ By then a number of people had begun to turn away from materialist accounts and explanations of disability, to relating some postmodern concepts, such as discourse, to disability. *Disability discourse* (1999), edited by Corker and French, became a text which began to spark a new direction within Disability Studies. In their introduction, Corker and French stated:

Social model theory rests on the distinction between disability, which is socially created, and impairment, which is referred to as a physical attribute of the body. In this sense it establishes a paradigm for disabled people which is equivalent to those of sex/gender and race/ethnicity. However, though it is a groundbreaking concept, and one which has provided tremendous political impetus for disabled people, we feel that because the distinction between disability and impairment is presented as a dualism or dichotomy – one part of which (disability) tends to be valorized and the other part (impairment) marginalised or silenced – social model theory, itself, produces and embodies distinctions of value and power... In saying that ‘people with impairments’ and ‘disabled people’ are ‘quite distinct things’, the conceptual link between impairment and disability oppression is broken because it could be construed that disability and impairment are not related. To paraphrase Ingham (1996; 183), this ‘reinforces the nature/culture binary’, opening the study of impairment to the domain of science and closing off consideration of how ‘biology is linked to culture.’ Impairment as a biological category escapes the realm of construction or achieved status, even though it is, itself, ‘defined’ or ‘constructed.’ (1999, p.2)

The idea emerged that the social model had relegated impairment to biology and therefore the meanings found within medicine about impairment, rather than impairment being a social category which is constructed and therefore value laden (Corker & French, 1999; Hughes & Paterson, 1997; Paterson & Hughes, 1999; Tremain, 2002). This idea gained momentum as a new genre within Disability Studies; that is, that the “disabled body is a site of discursive production and consumption” (Corker & French, 1999, p.2). More detail of particular writing and research about the body as a site of discursive production will be discussed in the next chapter. Needless to say, the critique of the social model was clear: disability and impairment are both socially created, not just the former, and as constructed categories they both interface and influence each another; they simply cannot be separated as distinct or unrelated from one another (Corker, 1999; Corker & French, 1999; Shakespeare, 2006). Again, social model enthusiasts were not receptive and so the division within Disability Studies grew. Barnes, for example, warned against and attacked the cultural turn of liberal arts and cultural studies within Disability Studies, as opposed to upholding the social model of disability:

The bulk of the work coming out of these disciplines, certainly over the last few years, seems to be written by a particular breed of academic luvvie who write mainly for themselves and other academics rather than for a wider audience: consequently, it is replete with obscure and esoteric jargon, virtually inaccessible to all but the most dedicated of readers and, most importantly, politically benign and pragmatically irrelevant. (Barnes, 1999, p.580)

Despite Barnes' protest, postmodern analyses of disability continued, such as Corker and Shakespeare's (2002) edited text *Disability/Postmodernity: Embodying disability theory*. In the foreword to this book, Young (2002) noted that "the social model of disability seems necessary for activists to maintain in their arguments with employers, educators, legislators and judges [and] that a postmodern approach to Disability Studies [should] not be concerned as a displacement of the social model of disability" (p.xiv). In other words, as a political tool for campaigning against discrimination, the social model was still relevant. However, within a few years Shakespeare (2006) had decided otherwise, stating that "the social model is wrong" (p.53). His basis for this conclusion undoubtedly drew on the discursive literature and scholarship within Disability Studies during the previous half-decade or so, as well as his recent work in the bioethics field. He concluded that the social model's reductionist persuasion was too problematic, as it homogenises the experience of disability and disability identity and separates impairment from disability. In short, the disability experience was not universal but varied, nor was people's sense of identity ultimately captured in the disability movement's 'different but proud' mantra of disability identity politics, and that impairment, as well as social arrangements, disabled people.

Just as postmodern critique highlighted problems with the UK social model, the same can be said for normalisation/SRV theories. Several studies found the ideas inherent within normalisation and SRV too complex for professionals in the disability field to either understand and/or implement successfully (Wilson & Bartak, 1997). Furthermore, it has been argued that normalisation theory has had

little positive impact on the sexual options open to people with intellectual disabilities because professionals deny and limit their understanding and expression of their sexuality (Brown, 1994; Williams & Nind, 1999).

Searching beyond modernist theories of disability

From a postmodern perspective it is not surprising that neither the social model or normalisation/SRV theories have been able to adequately capture and reflect the complexity of the disability experience or consistently advance the disability rights' agenda for all people who experience disablement. Hence, while social model and normalisation/SRV theories have made extremely significant contributions to the theory and practice of disability rights, there has continued to be a call by people within Disability Studies to keep searching for further conceptual frameworks. For example, Shakespeare (2006) said:

Disability studies should work to provide rich empirical studies, both quantitative and qualitative, of how disabled people experience barriers, and how they experience their impairments. In particular, the differences between disabled people are as important as the similarities: for example, examination of the role of class is paradoxically absent, even from materialist disability studies. Rather than being restricted by social model orthodoxy, disability studies should be pluralist, valuing analytical rigour and debate. Disability researchers should look outwards and engage with medical sociology, bioethics and other areas of academia. (Shakespeare, 2006, p.198).

In this chapter, having offered an overview of the biomedical model and critique of it by Medical Sociology and Sociology of Health and Illness, the disability movement and Disability Studies, I now go on to discuss how critical realist and social

constructionist perspectives of disability have added to the theoretical pluralism within Disability Studies.

3

CRITICAL REALIST AND SOCIAL CONSTRUCTIONIST PERSPECTIVES WITHIN DISABILITY STUDIES: THEORIES, CRITIQUE AND RESEARCH

In considering how Disability Studies became broader than the social model of disability, relating social constructionist and critical realist perspectives to the experience of disablement, it is relevant to briefly discuss Shakespeare's journey within the disability movement and Disability Studies. The purpose here is not to focus specifically on Shakespeare or his life's work; rather, his philosophical shifts in regard to Disability Studies do embody something of the changes that have occurred within the discipline. Shakespeare has always been at the leading edge of new developments within the disability rights campaign. When the social model of disability was new and represented freedom for disabled people, Shakespeare (1993, 1994) was a staunch advocate but, as mentioned earlier, toward the end of the 1990s this position began to change. He and others were questioning the impairment/disability split forged by the social model. Postmodern philosophy was considered to hold possibilities for disability theory and Shakespeare was one of a number who contributed to Corker and French's edited text, *Disability Discourse*, published in 1999. The volume was separated into three sections: personal narratives, the social creation of disability identity, and cultural discourses. The poignancy of subjective accounts and the value of discursive analysis for Disability Studies are heralded in the book. In 2002 Shakespeare positioned himself strongly with those who were looking for alternatives to the social model, when he joined with Corker and together they edited the book *disability/postmodernity*. The areas of debate within Disability Studies, such as the impairment/disability divide, the experience of

body and sexuality for disabled people, the relationship between ethnic culture and disability, and disability sub-groups such as intellectual and psychiatric disability, were examined in light of a range of social constructionist conceptualisations.

Disability/postmodernity, more than any previous text, expanded considerably the social constructionist and feminist analysis of disability by relating critical postmodern source texts, such as the work of Foucault, Derrida, Lyotard, Lacan, Butler, Merleau-Ponty, Kristeva, Haraway, Giddens, Price and Shildrick – to name a few, to the subject of disability. Then in a further development, in 2006 Shakespeare published his text *Disability Rights and Wrongs*, which takes an even more strongly oppositional stance to the social model than *disability/postmodernity*, but from a critical realist, not a social constructionist viewpoint. For several years Shakespeare had been working as a bio-ethicist and was, among other things, critiquing the debates concerning the early detection and choice about termination of embryos that were diagnosed as having some sort of pathology. Such debates have been especially topical in recent years, as medical advancements have increased the chance of identifying problems with embryos prior to birth. Responding to bio-ethical dilemmas, it would seem, led Shakespeare to take up a critical realist position. This stance, while being broader than any one ideology such as the social model, involves a more materialist ontology than the postmodern philosophy contained within *disability/postmodernity*. Shakespeare's theoretical continuum to date, from the Marxist-inspired social model, to a postmodern analysis considering narratives and discourse, to his more recent critical realist approach, shows the shifting search within Disability Studies for ways to represent and theorise disablement. The social

model became the inaugural theoretical tool for fighting against oppression of disabled people. Relating postmodern philosophy to the experience of disablement meant the introduction of narrative accounts and discursive analysis for resisting the narrow strictures of the social model that denied the problematic realities of impairment and marginalised the experiences of a number of groups within the disability population. The critical realist position, which still embraces an emphasis on diversity and complexity of experience, is arguably more user-friendly and relevant to policy and practice than the social constructionist-influenced discussions within *disability/postmodernity* and other texts.

In this chapter I suggest that critical realism, whilst appearing eminently pragmatic, runs the risk of returning to and relying upon positivist analysis, discounting disabled people's subjective accounts of living with illness or impairment. I also review the discursive turn in Disability Studies, considering a number of discursive and narrative studies pertaining to the experience of impairment and/or illness. I then go on to discuss how discourse positions people in power relations, constructing what subject positions are available for them to take up. The concept of agency is further detailed, with a fictitious example given of a person respectively accepting and then refusing a subject position call constructed by medical discourse. This chapter finishes with a question about disabled people's experience of agency that guided the purpose and process of this research project. I now return to Shakespeare's work in which he has related critical realism to Disability Studies (2006).

The critical realist contribution to Disability Studies

Shakespeare explains the critical realist position in relation to disability:

Critical realism attends to the independent existence of bodies which sometimes hurt, regardless of what we may think or say about those bodies. Critical realists distinguish between ontology (what exists) and epistemology (our ideas about what exists). They believe that there are objects independent of knowledge: labels describe, rather than constitute, disease. In other words, while different cultures have different views or beliefs or attitudes to disability, impairment has always existed and has its own experiential reality. Within disability research... [critical realists] seek to avoid arguments over medical model versus social model perspectives by demanding an approach that gives weight to different causal levels in the complex disability experience... which combines the best aspects of both the traditional [medical model] and the radical [social model] accounts. (Shakespeare, 2006, p.54-55)

Shakespeare draws on a number of writers and researchers to support the relevance of critical realism for Disability Studies, offering a multidisciplinary approach. For example, Williams (1999) stated:

Disability is neither the sole product of the impaired body or a socially oppressive society. Rather, it is, as we have seen, an emergent property, one involving the interplay of physiological impairment, structural enablements/constraints and socio-cultural elaboration over time. Moreover, within such a model, the conflational traps of structuration theory are avoided, yet a critical view of agency is still retained, including the transformatory potential of embodied social praxis. ‘Personal tragedy’ and ‘social oppression’ therefore, on this reading, become extreme models and overly drawn contrasts between what is, in fact, best seen as a dynamic, dialectically unfolding process

between body and society, located within a temporal frame of reference (both historical and biographical). (p. 813)

Gable and Peters' (2004) application of resistance theory to disability paradigms takes a similar multidisciplinary approach, in that the paradigms are involved in a dynamic with one another thereby creating a mediating interplay of any extreme. Danermark and Gellerstedt (2004) map their critical realist perspective in terms of "injustices to disabled people [that] can be understood neither as generated by solely cultural mechanisms (cultural reductionism) nor by socio-economical mechanisms (economic reductionism) or by biological mechanisms (biological reductionism)" (2004, p. 348). Their table replicated below, demonstrates the use of different disciplines in the analysis of the multi-causal nature of disablement:

Table 2
Analytical levels in disability research

Levels	Examples of mechanisms	Examples of contexts	Examples from a particular context: a specific work site	Examples of negative outcomes
<i>Culture</i>	Negative evaluation of a characteristic	Law	Employment procedures	Denigration, exclusion
<i>Socio-economic</i>	Profit, exploitation	Labour market	Organization of work tasks	Unemployment, slimmed organizations
<i>Psychosocial</i>	Relation-to-self	Social interaction	Relations in work team	Lack of self-esteem
<i>Psychological</i>	Feelings of pride and shame	Communication	Conversation during breaks	Withdrawal
<i>Biological</i>	Genetic factors	Noisy surroundings	Shop floor	Sensorioneural hearing loss

(Danermark & Gellerstedt, 1994, p.349)

Shakespeare (2006) refers to this approach as an “interactional model”, studying disability on a number of different analytical levels and understanding disability as a combination of disadvantages within cultural, socio-economic, psychosocial, psychological and biological domains (Shakespeare, 2006; Gustavsson, 2004; Ven den Ven, Post, de Witte, & Van den Heuvel, 2005).

The interactional model does address the exclusionary aspects of both the medical and social models, allowing for both impairment and disability (as defined by the social model) to be causal of disability. The interactional approach places responsibility on both the individual and society in regard to taking actions that reduce disablement. Therapy to improve self-esteem and/or anti-discrimination legislation (Shakespeare, 2006, p.62), is an example of this. The pragmatism and pluralism of the interactional model is a welcome relief from the ideological battles of social versus medical model, or the UK social model/disability rights versus the USA normalisaton/disability rights theory/practices. In this sense, it could be argued that critical realism is less modernist, with its emphasis on multiplicity and fragmentation (Burr, 2003), but the critical realist preference for ontological objectivity, and the desire to describe and establish what is ‘real’, gives it a stance of certainty which is less postmodern. This is not to suggest that the interactional model is not relevant or useful to Disability Studies; it is arguably the most balanced and encompassing model to date. But as a model that defines and takes a position of authority from a largely static epistemological body of knowledge, the interactional model runs the risk, like all of the disability paradigms to date, of becoming rigid and inflexible. There is also the concern that the causal nature of the critical realist

approach will ultimately produce another deterministic and reductionist analysis of disability. On this point, one of Hughes (2007) concerns about the recent shift to utilize critical realist approaches within Disability Studies, is there tendency to “universalize ontological lack and attribute deficit to us all” (p.682). In other words, the particularity of subject positions that people with impairments and/or illness take up in respect of their bodies / selves and others, disappears and is lost as a resource for countering disablement, when the universalist interactional model proposed by Shakespeare and others (Shakespeare, 2006; Shakespeare & Watson, 2002, 2002; ;Turner, 2003) is applied to disability. If this is the case, the question arises who will be most privileged by the assumptions that govern the critical realist interactional model, and how well will it serve those most likely made subjects of and objectified by such analyses? It is on the basis of this question, that I now turn to discursive approaches in which discourse is understood to construct subjects and constitute their meaning-making.

The discursive turn in Disability Studies

Interest in and concerns about how discourse produces identity for disabled people became part of new focus in Disability Studies beginning, in the main, during the 1990s. Danforth and Rhodes (1997) advocated discourse analysis for Disability Studies, describing deconstruction as “an aggressive, political mode of critical analysis that strips conventional and assumed truths down to their logically insubstantial bare bones [so that] the constructed reality of [disability] would no longer continue in its present form” (pp. 358-359). Winslade (1994), for example, deconstructed the ways in which lay, medical, charity and disability rights’

discourses impacted on identity conclusions for disabled people and how an understanding of this might be utilised to construct specific ways of providing professional support to disabled people. In regard to the impact of medical discourse on disabled people's identity, Tremain (2002) concluded that medicine, rehabilitation, and psychology have "produced subjects who have impairments because this identity meets certain requirements of contemporary political arrangements" (p. 42). Paterson and Hughes (2000) argued that by not considering the historical, social and cultural constructions of impairment, disability rights (social model) discourse had effectively relinquished impairment to medicalisation, thereby leaving "the body deficit, stripped of agency and conflated with sickness and invalidity" (p. 41-42). Watson's (2002) study of disabled people's sense of self-identity furthered criticism of the social model because in its conclusion he stated that "there appears to be little support for an identity politics built on the notion of a common group of identity of disabled people" (p.527). Watson concluded that Disability Studies acts as "a regulatory regime that inadvertently constructs a 'normal' body and in endorsing the existence of such an identity, Disability Studies perpetuates the notion of difference between disabled and non-disabled people, reinforcing the dichotomy" (p. 524). Islam's (2008) study was also interested in the construction of disabled subjectivity, when he explored the lives of thirteen young Pakistani and Bangladeshi disabled people, who were invited into different discursive constructions according to ethnicity, disability and gender. Bowkin and Tuffer (2002), in taking into consideration the impact of the internet in regard to subject positions made available to disabled people, explored how on-line conversations

became a discursive context which created non-disabled identity possibilities for disabled people.

In addition to studies and discussion which explored the discursive positioning and construction of identity for disabled people, a number of studies have related the work of discourse theorists, especially Foucault, to disablement. Priestly (1999) studied the discursive norms for disabled high school students, finding that “the language of ‘special need’, and the discursive practices used to police it, continued to construct disabled children as other” (p.102). Heaton (1999) analysed the discursive construction and expectations inherent in informal care of people with dementia. Goodley and Rapley’s (2002) research on discourse pertaining to intellectual disability pointed out that assumptions of intellectual disability being acontextual, as in a “naturalized, individualized and embodied pathology” (p.138) was damaging for those labelled with intellectual disability, and moreover that the social model contributed to these damaging effects by “ignore[ing] the socially contexted nature of impairment” (p.138). Speed (2006) explored how the practice of mental health in Northern Ireland conceptualised mental illness as an individual dysfunction that did not take into account the contribution culture and the social environment make to the construction of disability. Galvin (2005) explored the stories of ninety two people from four countries who had an illness or disabling condition. She found that major areas of a person’s identity, such as independence, work and appearance/sexuality, were heavily influenced by the negative attitudes of others in response toward the person with impairment and/or illness not having a normative identity. Galvin (2005) drew on “Foucault’s (1980) understanding of power and resistance” when she

concluded that people with illness and/or disabling conditions “ultimately wield more power to disturb the status quo... because... the oppressed occupy a location which lends itself to the disturbing of these boundaries” (p.410).

In respect of disabled people challenging the normative assumptions that marginalise people with impairments and/or illness, Wilson and Beresford (2002) in their deconstruction of psychiatry, stated:

The challenge we now face as mental health service users/survivors is to make it possible for our own critiques and discussions to develop and counter the dominance of existing medicalized and ritualized individual discourses. Until we achieve this, the likelihood is that, ironically, modernist explanations of madness and distress will continue to flourish in an age of postmodernity.

(Wilson & Beresford, 2002, p.156)

However, while discursive studies have often portrayed how discursive norms constitute the disabled subject and been interested in how disabled people resist the normative processes that disable them, few studies have researched effective resistances of such positioning. Davis and Watson's (2002) study is noteworthy in that they found disabled children did resist social stigma and oppressive social practices, and had complex identities, as opposed to a singular negative perception of themselves as a disabled self.

The rise and relevance of narrative studies to Disability Studies

In contrast to a social model agenda, the discursive turn in Disability Studies was further demonstrating that the feminist mantra, ‘the personal is political’, had much to offer. Disabled women within the disability movement began to illustrate how

disabled people's stories, especially those of women and ethnic minority groups, were relevant to disability rights and Disability Studies (Morris, 1991; Corker & French, 1999). However, Barnes and social model exponents were critical. Barnes referred to those who wrote personal narratives as "the true confessions brigade; those intent on writing about themselves rather than engaging in serious political analysis of a society that is inherently disabling" (Barnes, 1998, p.146). Barnes' comment makes sense if self-disclosure is viewed as apolitical and not embedded within broader social processes. However, narrative, when considered from a social constructionist perspective, is a "cultural creation... [for] the stories within which we live our lives always draw from the cultural stories of the world around us... [and contain] cultural imperatives" (Winslade & Monk, 2000, p. 53). As we hear disabled people's stories we are engaging with the politics that determine their lives, revealing the very assumptions and social conditions that create disablement. Indeed, one of the main arguments for listening to people's narratives is to learn what they tell us about socio-cultural life (Frank, 1995, 2005; Nelson, 2001; Reissman, 1993, 2003; Smith & Sparkes, 2006, 2008a, 2008b). Goodley, Lawthom, Clough, Moore (2004) have even suggested that "narratives may be our *best hope* of capturing structures that continue to shape, divide and separate human beings (2004, viii–ix, my italics).

Corker and French (1999) in believing there was much to be gained from hearing accounts of illness and impairment, provided space for five personal narratives, each a separate chapter, in their edited text *Disability Discourse* (1999). Their purpose was to "giv[e] 'voice' to many of the silenced, 'borderline' or unfamiliar stories of Disability Studies, for example, the voices of disabled children, disabled women,

non-Western perspectives on disability, acquired disability, and congenital, intellectual, sensory and social disabilities” (p.11). Almost every type of impairment grouping, other than white males with physical disability, are depicted by Corker and French as having narratives which are silent, borderline or unfamiliar. At the time of their writing of *Disability discourse*, many of the historically dominant voices within Disability Studies advocating the social model were white males with physical disability. This dominance might suggest that not all narrative accounts are accorded equal value, and Corker and French, both disabled women with sensory impairments, were endeavoring to address the imbalance through their edited text *Disability discourse*. In this text, Corker and French were engaging in the postmodern shift within sociology and research, where people’s narratives are viewed as cultural reproductions. As Frank (2005) has said:

The most consequential work we do, every hour if not every moment, is to decide which stories we will allow into our lives and which we will refuse. We choose which stories will compel us and which we will dismiss as not compelling. We choose among stories, but the principles of our choosing are not themselves chosen. Stories attract us, or they strike us as unimportant to our lives, or they actively repel us. We humans take up and reject stories, but the stories too, are active as they affect our choices. These choices make crucial differences to the lives we lead... Our affiliations with other people – the basis of our social lives – are chosen according to principles that are unchosen. (Frank, 2005, p.1)

Frank’s use of the word “choice” here is similar to the way in which Davies views “choice... [as] more akin to ‘forced choices’.... because one has been subjectively constituted through one’s placement within that discourse to want that line of action” (1991, p.46). If we relate this to Barnes’ criticism of personal narratives, we could

say that Barnes had “taken up” a “position”, to use Davies’ (1991) terminology, or was “caught up”, to use Frank’s (2005) term, within the social model story. This cultural story or discourse constituted him to like stories that targeted societal barriers as the cause of disablement but dislike stories that suggested disability could also be an individual experience related to the problems associated with having an impairment or illness. On the other hand, Frank’s experiences of cancer and a heart attack led him to get “caught up” in challenging the way medical discourse positions patients, situating himself within the alternative account of the embodied subject who is living, as opposed to treating the illness or impairment. He said,

The stories that ill people tell come out of their bodies. The body sets in motion the need for new stories when disease disrupts the old stories. The body, whether still diseased or recovered, is simultaneously cause, topic, and instrument of whatever new stories are told. These embodied stories have two sides, one personal and the other social.

(Frank, 1995, p.2)

For Frank (1995), the personal story of illness is always in relation to the broader cultural, societal stories about illness or impairment. He highlighted the dominance of medical discourse when he said “the story told by the physician becomes the one against which others are ultimately judged true or false, useful or not” (p.5).

Frank’s (1991, 1995, 2004b, 2004c, 2008) narrative approach, in which he has often been critical of medical practice, while relevant to and sometimes drawn on by people researching disability (Smith & Sparkes, 2008a; Whitehead, 2005), should not be conflated with social model-informed criticism of the medical model. Frank’s emphasis on people’s accounts being both personal and social highlights how a

narrative approach to research is more than generating personal accounts of disabling experiences, it is also about making visible those ideas and practices which have become subjugated and less heard due to the power of dominant discourse. Many illness and impairment narratives that have been reproduced in the literature have been an attempt to research how discourses, such as medicine but also the social model, play out in disabled people's lives. For example, Kinavay (2006) explored narrative self-understandings for three adolescents born with spina bifida. She discovered that each made meaning of their impairment in different ways. One person had taken up an understanding that it was important to overcome the adversity of the impairment/disability, becoming a courageous person with spina bifida. Another separated himself from the impairment, as if that wasn't a problem in itself and focused on other problems he experienced, such as depression. The first person was performing medical discourse in storying spina bifida as an adversity to be overcome. The second person also took up medical discourse but only in relation to depression, not his impairment. The third person's approach was to integrate disability within a sense of self-identity, such as being disabled and proud, which is a more social model interpretation of what it means to have an impairment. In another study, Phillips (2007) interviewed twenty two older women with intellectual disability and found that "women labelled as having 'learning difficulties' [intellectual disability] are also assumed to have a bodily impairment; a bodily impairment which was sometimes considered dangerous or promiscuous but also vulnerable, child-like, asexual and in need of care and control" (2007, pp. 518-519). These findings are significant for they illustrate how the participants actively resisted

deficit ideas about their bodies by finding ways to choose what they liked, concerning how they dressed and looked.

McDonald, Keys and Balcazar (2007) explored the narratives of non-white men and women who had learning disabilities, finding that the participants could pass for non-disabled but when named as having a learning disability were perceived as not having a legitimate impairment, being of lower intellect and not having positive gender experiences. The participants were constructed in deficit terms by medical and White ethnicity discourses but they demonstrated resistance to the racism and ableism they experienced by either withdrawing from those environments where the discrimination was prevalent or by reframing the negative messages and assumptions about learning disability. French and Swain (2006) undertook a oral history project, in which sixty people with visual impairment were interviewed about their experiences as children when they lived in residential facilities for blind children. The study uncovered how the participants suffered abuse when they were lived in the residential facilities. The research highlighted the very strong friendships the children developed with one another while living in the residential facility. French and Swain (2006) emphasised how personally transforming the interview process had been for the participants, in having the opportunity to tell their stories of what it was like for them as children living in the residential facility. Several themes emerged from the study: the abusive environment of the residential facility for blind children, the helpfulness of strong friendships for blind children when surviving an abusive environment, and the value for the participants in being invited to discuss past experiences and having someone act as a witness to those stories.

In considering his own and listening to other people's illness and impairment stories, Frank (1995) suggested that people's accounts could be categorised according to three types of narrative: restitution, chaos or quest. The restitution narrative involves the idea that wellness will return because due to treatment, primarily medical, sickness is not lasting. The chaos narrative is something of the antithesis because there is no order to the narrative, nor is there any sense of life getting better, the person is suffering and wounded and their story provokes anxiety both for themselves as others who witness it. The quest narrative is different from both the restitution and chaos narratives; the person may not get better but neither are they forever overwhelmed in suffering and loss. Through their illness the person finds some kind of gain, whether it be personal transformation, a career change, or advocating for others, or some other type of ascendancy; a quest narrative offers the person a voice. Whitehead (2005) called on Frank's narrative typologies in her analysis of her interviews with seventeen British people who had chronic fatigue syndrome (CFS) or myalgic encephalopathy (ME). She said that it was common for the participants of her study to start with a restitution narrative, move to a chaos narrative and, for the most, shift back to a restitution narrative and then on to a quest narrative. She proposed this was a different narrative trajectory from people who were HIV positive or had been treated for breast cancer, where the restitution narrative was more dominant.

Smith and Sparkes (2008a) drew on Frank's (1995) narrative typologies and Norrick's (2005) theory of tellability, when they interviewed Jamie, a man who had a

spinal cord injury at the level of the second cervical vertebrae, leaving him paralysed beneath his neck-line and requiring a ventilator to help him breathe. By surviving the injury and believing for a full recovery, Jamie initially engaged in a restitution narrative, but when it became harder for him to hold onto the hope of becoming “able-bodied again” [he experienced a] “rapid descent into… the chaos narrative” (p.223). In this narrative Jamie had no control over his body or his life. He said “his life had ended” and he “may as well be dead” (p.224). The more Jamie engaged in a chaos narrative, the less tell-able his story became. His chaos narrative created anxiety and fear for others because he never experienced any physical recovery, nor did his responses to his spinal cord injury lead him to experience any kind of personal transformation. Chaos narratives are difficult to tell or speak of because the plot “lacks any coherent sequence” (p.232). They are “told on the edges of speech, in the silences that speech cannot penetrate” (Frank, 1995, p.101, as cited in Smith & Sparkes, 2008, p.231). Chaos narratives, because they are hard to speak and hard to hear, produce lives of an increased isolation, as was Jamie’s testimony: “It’s a different world now. The accident has changed everything. I’m a stranger. It’s horrible living like this. I mostly stay inside” (Jamie, as cited in Smith & Sparkes, 2008, p.226).

The environmental barriers experienced by Jamie when he was unable to visit his children because of physical access problems, and the impact of a C2 level complete spinal cord injury on his biological body, were the concrete factors that led to Jamie not being able to take up a quest narrative. The article concluded that in time “Jamie may have to tell a range of body stories, need people to listen to them, be offered

consolation... be left alone... [so as] to help alter the trajectory of his life and infuse his history with new meaning" (p.234). However, infusing history with new meaning is not an easy project for people to engage in. As well portrayed in this example, Jamie's disablement was produced by significant social barriers and consequential impairment-based limitations, including the absence of biological function of his body, limbs and hands, and the daily experience of extreme pain and tiredness. But in addition to these material conditions, Jamie was a man who prior to his spinal cord injury had lived his life through his body. He had played sport all his life and had always worked physical jobs. His strong and active body was inseparable from his subjectivity of who he knew himself to be. As he said, without his body he was dead. At least the Jamie who he had always known was no longer available to him. Unless there was some kind of reconstruction of self, Jamie's life had metaphorically ended when he became paralysed. The meanings Jamie engaged with about his spinal cord injury constituted his responses to having a spinal cord injury.

Prior to this account of Jamie's life, Smith and Sparkes (2005) had previously discussed Jamie's 'chaos narrative' in an earlier article that featured him alongside the stories of thirteen other men with spinal cord injury. In this research, the interviews explored the meanings of hope in the men's lives. Eleven of the men had remained engaged with a 'restitution narrative', believing in physical recovery being possible on the basis of advances occurring in "medical technology" and the nature of "the restorable body/self" (p.1096). Smith and Sparkes (2005) referred to this kind of hope as a "concrete hope" (p.1097). Two of the participants had taken up a quest narrative. One of the men said, "I don't view disability as a crisis. I'm on a different

path" (Doug, as cited in Smith & Sparkes, 2005, p.1099). The other man stated, "I don't have much of my able-bodied self left because I've changed so much as a person... and become a better person" (David, as cited in Smith & Sparkes, 2005, p.1099). The quest narrative in the lives of these men, according to Smith and Sparkes (2005), embodied "a transcendent hope" (p.1099). Jamie, as discussed, was engaged in the chaos narrative, where there was a loss of hope. He said, "I'm no one. [7s silence] I have no future... My life, it's, it's, not here. It's over. I have nothing left to live. I have no hope of a life. I have nothing. There is no hope for me" (Jamie, as cited in Smith & Sparkes, 2005, p.1101).

Previously I have explored how the meanings people hold about their spinal cord injury produces how they respond to their injury:

For some people, spinal cord injury meant intense shame that precluded rehabilitation because being sick and bed-ridden was preferable to being visibly disabled. For others, paralysis was a heart wrenching confirmation about wrong choices that they had made in life; for others it was a tragedy that they were undeserving of; or alternatively it may have simply represented another one of life's challenges or even symbolised an opportunity for a new chance at living better. These ways of viewing disability are cultural stories: one discourse positions paralysed people as less than human, another as tragic but courageous, while another views them as possibly fortunate.

(Arkwright, 2005, p.35)

In another narrative study on a person with spinal cord injury, Bergen (2004) tells the story of Melvin, a Chicago gang member turned world-class wheelchair athlete. Wheelchair basketball and disabled sport became an avenue in which Melvin was able to succeed in after his spinal cord injury, both as an athlete and in becoming a

role model to others. Melvin's journey from gang member to disabled sport athlete, on the categories of Frank's narrative typologies, could be storied as him moving from a chaos narrative when he first became paralysed to a quest narrative when he became accomplished in disabled sport. Such a story is much more tell-able than Jamie's chaos narrative because it provides hope and inspiration, it does not create despair. Melvin, being young at the time of his spinal cord injury, being active and independently mobile through using a lightweight wheelchair, and presumably having already been produced by his involvement in a gang to be resilient and competitive, was well placed to take up and succeed in wheelchair sports after having a spinal cord injury. Melvin's involvement in wheelchair sports became a narrative story that was very tellable, perhaps being storied as something like: gangster survives, succeeds and reforms. Melvin's "paraphrase of Goethe – 'It's not doing what you like to do but liking what you have to do that makes a world of difference'" (Melvin, as cited in Berger, 2004, p.805) – invites admiration.

Many narrative studies have explored the meanings that disabled people have engaged with concerning their experience of having an impairment and/or illness. Ohman, Soderberg and Lundman (2003) interviewed five women and five men with different kinds of serious chronic illnesses and concluded that living with a serious chronic illness meant shifting between enduring and suffering but in that process the self was reformulated. Driedger, Crooks and Bennett (2004) studied the narratives of fifteen men and women who had multiple sclerosis (MS), addressing the questions of how the participants had coped with their disease, and how they engaged with disablement over space (environment) and time (past, present, future) as a result of

changing social and spatial relationships. From the study, they recommended that more attention be paid to the role of time and space so people with MS can re-negotiate time and space and develop a process of adaptation. Shuttleworth (2002) explored the search for sexual intimacy by fourteen men with cerebral palsy. This study revealed the pre-requisite of cultural stories of support and acceptance for the men if they were to engage in sexual relationships with others, finding that “several aspects of self and society helped facilitate their establishment of sexual relationships with others, including cultivating supportive and communal contexts, expanding the masculine repertoire and defusing the adverse structural and symbolic context of disability and desirability” (2002, p.112).

A number of narrative studies have researched the impact of environmental and social barriers on disabled people’s lives. For example, Roesta, Kristiansenb, Van Hovea and Vanderplasschena (2007) explored the stories of people with “mental health problems” who were looking for employment on the open labour market and concluded that “psychiatric discourses, what we term toxic psychiatric orthodoxies, silence, disable and construct [mental health] survivors as unemployable” (p.267). Nelson, Clarke, Febbraro and Hatzipantelis’ (2005) exploration of nine women and eleven men with mental illness was that supportive housing, when previously they were homeless, made a significant difference to their lives.

The power relation of discourse and the construction of subjectivity

Discursive and narrative studies of people’s experiences of disability have often explored how the truth claims of medical discourse, and sometimes the social model,

are dominant in people's meaning making about their experiences. However, the studies have also given voice to those accounts that have been constructed by discourses beyond the medical or social model of disability.

Disabled people are positioned in relations of power by multiple discourses. Jamie, for example, in Smith and Sparkes' (2008a) research, as a consequence of his spinal cord injury was positioned as failing within medical, social model, sports, employment, masculine, parenting, and marriage discourses. He gained no biological recovery from his spinal cord injury, he experienced significant social and environmental barriers as a person with a spinal cord injury, and he was unable to return to the practices he had assumed as a man, husband and father prior to having a spinal cord injury. It is not surprising he described his life in such disparaging terms. From a discursive perspective, his hope lies in him being able to take up a subject position in which he could succeed on the terms of discourse he is being subjected by. Smith and Sparkes (2008a) imply that such a process may occur in time for him.

In other studies discussed, a number of them described people with impairments and/or illness showing resistance when they had been marginalised and discriminated against. For example, Phillips' (2007) study in which twenty two older people with intellectual disability were found to resist deficit ideas about their body. However, few of the discursive and narrative studies explored in detail what enabled people to refuse those discursive practices that positioned them in ways they did not like, what discourses they were calling on in their dislike of how they had been positioned. It is this analysis which is a key focus in this study, understanding how discourse

positions and constitutes subjectivity, and the corresponding processes of agency people negotiate in responses to such positioning.

In an earlier article (Arkwright, 2005), I explained how discourse constructs truth and enacts power relations, often creating multiple but contradictory subject positions for disabled people. I detailed a personal story of how I was often late to a work meeting and initially an individual behaviourist discourse invited me to think I needed to improve my time management and organisational skills. However, as I re-examined my being late to this particular meeting from a discursive viewpoint, I was able to see that my late attendance was a product of a number of competing discourses:

I ran over time with my students because I valued the interactive nature of the discussions and the chance to have input into their lives. These are products of trying to do well within relationship and teaching discourses. I prioritised going to the toilet because I was afraid of having a bladder accident and getting a urinary tract infection if I didn't; hence, the outworkings of appearances and health discourses. I usually walked to the toilet using my walking sticks as this was good for my body: rehabilitation discourse. However, I used my wheelchair to get to the meeting as walking would be too tiring and time consuming; I didn't want my impairment to disadvantage: social model discourse. Sometimes on the way to the meeting I would get caught briefly having to chat with someone, as well, but I viewed being late to administrative meetings as the lesser of many evils because people are more important than administration; a view that is no doubt sustained within many counselling and people helping discourses. However, out of respect to my colleagues I did wish to attend the meeting on time, meaning I was also endeavouring to comply to relationship discourses but this time in relation to my peers not my students. And even when at the meeting, I was usually concerned that I had not managed to have

had a drink; evidence again of health discourse. Clearly, I was unable to simultaneously occupy the multiple subject positions on offer. It was impossible for me to act on all the subjectivities produced by those discursive contexts, such as being a relational person, committed and genuine teacher, responsible rehabilitated person, empowered disabled person, and an acceptably presented professional. (Arkwright, 2005, p. 45-46).

Once I could clearly see the discursive position calls I was being invited into then I was able to choose which ones I would engage with and which ones I would refuse and the respective merits of making these choices.

The above example demonstrates how “discursive practices... position us in relations of power” (Parker, 1999, p.6). Discursive ideas and practices, whether medicine, disability rights, feminism, ethnicity and so forth, become the basis by which we language and interpret experience, make sense of ourselves, other people and think about the world. Our languaged statements, involving meanings, metaphors, representations, images, stories, emotions and actions (Burr, 2005), therefore belong within discourse; they are never outside of discourse, and as such we are subjects of discourse, positioned according to the discursive ideas and practices by which we have become subjected. It is for this reason that Foucault (1980) reasoned that knowledge and power were inseparable, preferring to write them as “knowledge/power”. The unique point about this notion of knowledge/power is that power is not relative to hierarchical authority in the traditional sense of holding a certain role or being in charge of a line of command:

This form of power is thought of as “capillary”, that is, it is not held in some social nerve centre, but is everywhere around us and is

constituted, reproduced in every action or utterance. It exists most subtly in our sense of self-discipline, whereby we take messages given to us from the social environment and monitor our own behaviour in accordance with these messages, or act as if we are constantly under surveillance. We are all both subjects to it and subject of it (in the grammatical sense of being active in its production).

(Winslade, 1994, p.45-46)

However, because people are subjected to more than one discourse at any one moment in time (although one discourse is likely to be much more dominant than others), then alternative subject positions within other discourses are potentially available. When these alternative subject positions are taken up, they become the means of resisting the positioning power of the dominant discourse. It is on this basis, that Foucault (1980) believed that within a given power relation, power is never completely dominant" (Winslade, 1994), and that where there is power, there is always resistance to that power relation.

The social model illustrates how this concept of power/knowledge relation works in practice. It was started by a group of people with impairments who did not work and lived in institutional care. They redefined what disability is and in time that description became "a structuring principle in society which gave form to institutions, patterns of social interaction, knowledge and ideas and individual subjectivity" (Winslade, 1994, p.45). As a result, the disability rights' movement began, law and social policy were influenced, disabled people viewed themselves as a minority group entitled to equal citizenship and the same rights as all other people, and began insisting non-disabled people saw them similarly. In New Zealand today, our parliamentary disability strategy is a reproduction of the social model, when it

describes disability as “not something individuals have... [but] a process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have” (The New Zealand Disability Strategy, 2001, p.1). There is little doubt that Paul Hunt and his peers who made up UPIAS have made a huge impact that has nothing to do with their status, position or professional role in society, as they were on all accounts not positioned favourably within their social contexts. The point is, it is not them *per se* that have been a powerful force in the emancipation of disabled people but the new knowledge they created about disability. It has been this knowledge, taken up and reproduced, which has created influence.

It is this very story about the social model that typifies and holds the key for me concerning why discourse and the allied concepts of positioning, subjectivity and agency, are critical for Disability Studies. The ideas inherent within the social model are not the answer; they provide one of a number of answers for disabled people. However the way that those people’s ideas developed into a practice, which contain a set of values, constructing and reflecting a worldview that then constitutes and shapes how people interpret, make meaning of, and act in regard to disability, is an answer. If we put our faith in the people who originally developed the social model, or alternatively the ideas and practices reflective of the social model, then we too are subjects of those ideas and practices, constructed by their relative merits and limitations and reproducing of them. But if our hope is based on the notion that “discourses are practices which form the objects of which they speak” (Foucault, 1972, p.49) then we are aware that it is critical to understand which discourses our

meaning-making reproduces, and what the respective implications are for the realities we will live out, in accordance with the discursive terms of reference we have taken up. If people were only ever subject to one discourse then having this awareness would not be critical, but as we have seen with discourses that construct disability, people constantly live at the intersection of multiple discourses. As Burr (2005) said “numerous discourses surround any object [for example, illness or impairment] and each strives to represent or ‘construct’ it in a different way” (p. 65). Medical discourse constructs illness and impairment as pathology requiring treatment. Social model discourse constructs illness and impairment as separate from disability, the latter caused by disabling social arrangements. Normalisation/SRV construct illness and impairment as creating disadvantage that becomes less if the person can be supported to participate in the social roles and activities than people without illness and impairment routinely engage in. A narrative discourse constructs impairment and illness as story which is both personal and social, shaping “what we seek, what we fear, what possibilities we can imagine life holds for us, and what part we believe we can play in bringing about outcomes, for ourselves and others” (Frank, 2005, p.8). Discourse analysis deconstructs impairment and illness as the objects of discourse, exploring how discourse has constituted the way disabled people make sense of and live their lives. Critical realism discourse depicts impairment and illness as the outcome of multiple causal factors: biology, psychology, culture, socio-economic, psychosocial, and responses should be appropriate and relative to each domain. But, as highlighted in Chapter Two, these are only the discourses predominately discussed within Disability Studies and many other discourses also construct particular ideas and practices about illness and impairment. In my view there is merit in disabled

people developing further understanding for how any discourse, not just those traditionally taken up and reproduced by Disability Studies, produces people with illness and impairment. For example, exploring what a particular discourse constructs as important, how the discourse positions disabled people, and what invitations are made possible by the discourse's ideas and practices for the kind of person the disabled person can be.

Negotiating agency in response to position calls

Positioning oneself to be a critical analyst of discourse is akin to what Davies (1991) describes as agency:

When a person has access to a subject position in which they have the right to speak and be heard... is author of their own multiple meanings and desires (though only to the extent they have taken on as their own the discursive practices and attendant moral commitments of the collective(s), of which they are members)... a sense of oneself that can go beyond the meanings in any one discourse, and forge something new, through a combination of previously unrelated discourses, through the invention of words and concepts that create a shift in consciousness that is beginning to occur, or through imagining not what is but what might be. (Davies, 1991, p. 51)

Seeking to understand how discourse is positioning us, what subject positions are available to us at a given moment and what the implications are for us in engaging with those subject positions, is the process whereby we might negotiate agency as we live out the moments of our lives. When we can do this, for example, by understanding what the social model means for what we can and cannot say and do, and what impact that has on us and our relationships with others, I suggest that we are

conscious enough of our subject positions within discourse to be able to experience agency. If we find that the subject positions which are available to us are not ones we would like to choose, then it is helpful for us to understand what discourses are producing this desire for difference. We can then identify the meaning-making assumptions that will enable us to refuse or resist those discursive positions, what Drewery, Winslade and Monk (2000) refer to as refusing those “position calls” which we do not prefer.

However, because of the taken-for-granted status of dominant discursive meaning-making, refusing discursive position calls is challenging but not impossible:

People are bringing to a particular situation their history as a subjective being, that is the history of one who has been in multiple positions and engaged in different forms of discourse [so that the person] is not inevitably caught in the subject position that the particular narrative and the related discursive practices might seem to dictate. (Davies & Harré 1990, p.48)

An example of two options for a disabled person inevitably caught up in a subject position produced by medical discourse, is to accept the position call or refuse it, as the following example demonstrates:

Position Call (made by pool attendant speaking to a disabled person going swimming): “*It is good that you come swimming, it will help you a lot*”

Accepting Position Call (reply made by disabled person, accepting the pool attendant’s meaning of swimming for disabled people being about rehabilitation and getting better – the medical discourse): “*Yes, I think it’s helping*”

Refusing Position Call (alternative reply by disabled person, choosing a different discourse, such as disability rights): “*Thank you for your encouragement but I do not come swimming to get better; simply to swim like anyone else, for enjoyment and exercise.*”

It is this particular understanding of agency, in relation to disabled people’s experience, that this study has set out to investigate, the extent to which a disabled person understands the subject positions she/he is being called into and is able to take up an alternative and preferred subject position. Laws and Davies (2000, p.206) refer to the dual nature of subjectification, which they say is hard to grasp because:

One is simultaneously subjected and at the same time can become an agentic, speaking subject. The speaking/writing subject can go beyond the intentions of powerful others and beyond the meanings of the discourses through which they are subjected while necessarily and at the same time being dependent on their successful subjection for becoming someone who can speak/write meaningfully and convincingly beyond the terms of their subjection. Laws &

Davies, 2000, p.206)

Paul Hunt and his comrades within UPIAS are an example of how the dual nature of subjectification can work in practice. By redefining the terms of reference for disability, from ‘caused by impairment’ to ‘the result of societal barriers’, the members of UPIAS became agentic speaking/writing subjects, going beyond their positioning as residents in institutional care not able or permitted to live like non-disabled people in ordinary homes. It was their experience of that very subjection that legitimised their resistance of the discursive positioning that was so marginalising of them. Their resistance was so convincing that in effect an

alternative discourse about disability was established, with its own production of subjections, ones that in years to come other disabled people, like French, Corker and Shakespeare took up a speaking/writing position against.

By researching accounts of agency in the lives of disabled people, this study is not restricted to examining the prescriptions and effects of one or another disability discourse, such as the medical or social model of disability. Rather, I have been interested in the stories that people with illness and impairment tell about their lives for the purpose of understanding their views about what positions have been available for them to take up. In particular, my interest has focused on what discursive conditions have produced those subject positions and what those constructions have meant for their experiences of what is expected and possible (or not). It was my expectation that the stories people told of their lives would display more complexity than subjectification within any one discourse, such as medical or social model of disability. Given this complexity, I also wanted to explore how and when people changed their experience of disablement by becoming agentic speaking/writing subjects going beyond the terms of one (or more) discursive prescriptions, thereby representing and (re)-producing an alternative discursive subjectification. Hence, a key focus for me with this study has been:

In the stories and accounts told to me by six people who identified themselves as having either an illness, long-term health problem, impairment or disability, what did agency mean, and what enabled them to find ways to negotiate agency in their lives?

4

THE RESEARCH METHODOLOGY

In this chapter, I continue the story, begun in Chapter One, of how my background as a Narrative Therapist created my interest in the ways in which disabled people are discursively positioned and how they negotiate subject positions so as to take up agency in their lives. However, narrative therapy does not have an exact research methods equivalent, as narrative research is not as discursively orientated as narrative therapy. A narrative therapist typically seeks to understand how a person's story has been produced by discourse (Bird, 2004; White, 2007; White & Epston, 1991), whereas narrative research rather examines how an idiosyncratic story has been produced and what that story suggests about the social world (Frank, 2004a; Josselson, Lieblich & McAdams, 2003; Smith & Sparkes, 2008c). On the other hand, discourse analysis (Davies & Davies, 2007; Davies, Browne, Gannon, Hopkins, McCann & Wihlborg, 2006; Parker, 1999) does not take up the centrality of story and narrative in the creation of experience in quite the same way as narrative therapy, but focuses more exclusively on how power relations in language produce actions. Given my commitment to narrative therapy ideas and practices, I called on and brought together the concepts of both narrative research and a critical analysis of discourse when selecting and interviewing the participants, hearing their stories and bringing a discursive reading to their accounts. This chapter details the conceptual tools from both narrative and discursive research methodologies employed in generating and analysing data in this study, including an outline of the research process undertaken.

Narrative therapy and thickening the alternative story

Narrative therapy is a relatively new counselling approach, developed during the early 1980s by White and Epston, from Australia (White) and New Zealand (Epston). In contrast to the psychoanalytic, humanist, and cognitive-behavioural therapeutic movements, narrative therapy is postmodern. White and Epston brought a combination of ideas from family therapy, anthropology, discourse theory, literary studies and feminism to their practice of therapy. At the risk of oversimplifying the theoretical antecedents of narrative therapy, White and Epston (1990, 1992) applied Bruner's (1987, 1990, 1991) notion of "storied experience", Bateson's (1979) ideas about "news of difference", Foucault's (1980) thesis about "power/knowledge", and a feminist theory interest in power and minority group politics, to the therapeutic encounter. They argued that experience is subjectively storied, producing narratives that constitute how a person makes sense of experience and acts (Epston 1989, 1996; White, 1997, 2001, 2004, 2007). They took up Foucault's (1980) argument about subjugated stories, suggesting that for every problematic storying of experience produced by dominant discourse, there would be other stories that would provide an exception to the problem story. They externalised the problems in people's lives, avoiding language that internalised the problem within the person, thereby creating a linguistic space between the person and the problems affecting him. A common mantra in the early years of narrative therapy was the person is not the problem, the problem is the problem (Morgan, 2000).

Narrative therapists focus on constructing lines of inquiry that support people to take up and thicken alternative and preferred accounts of their lives (White,

2007), discovering those instances when the person has already taken up a discursive idea/practice that offers her resistance to that which is being experienced as problematic. As these re-positioning moments are paid attention to in the therapy, they can be constructed as part of a new story about who the person is, what she values, and how she can act. Narrative therapists also seek to deconstruct what specific discursive norms have constituted a person's problems and difficulties. For example, how Western ideals of success within contemporary society invite people to take up ideas and (re)produce practices of personal failure (White, 2004). From a post-structural perspective, identity is constituted by language, where demarcations of either/or differences enact a power relation (Derrida, 2000). For example, the language of medicine produces the category of illness as the absence of wellness. Within this binary, wellness is privileged and illness is not desirable. Indeed, Bird (2004) has noted that "people who belong to marginalised groups... find limited belonging [within dominant discursive norms, instead]... the descriptor which is readily available to them within the binary constructed world is an absence" (Bird, 2004, p. 6). Once positioned in absence or deficit, it becomes difficult to re-position oneself so as to take up alternative subject positions that no longer disadvantage the person.

People, in my view, are often aware when they are being positioned in a power relation that disadvantages them. Typically the person does not want the discursive line of action that is being offered by the discourse but are subjected by it and take up the position offered by the discourse nonetheless. Parker demonstrates the difficulty

for disabled people in resisting those subject positions that construct them to experience discrimination and disadvantage. She said:

I was relieved when I saw an old friend in my gym class... I walked up to her and asked her if she remembered me. I hoped that she did. I almost died when all she answered was, ‘Yeah, aren’t you that epileptic?’ I just knew all the girls around us heard it and I could hardly speak. *I was humiliated, but said, ‘Yes’.* (emphasis mine) (Parker, 1975, p.261)

I have had similar experiences (see Arkwright, 2005, p.10) of finding myself disconnected from those discursive ideas which would enable me to refuse position calls which marginalise me on the basis of my having an impairment. However, I have also shown (Arkwright, 2008) that whilst the privileged subject position is typically not available for disabled people to take up, it is possible even when invited into a deficit position to negotiate moments of agency, thereby taking up a subject position of presence within a discursive expectation. The illustration I have previously used was how I took up an idea of being a “less than” Dad, because due to my impairment, I could not play sport with my children. The discursive ideas that produced such a singular and problematic description of my parenting ability was the assumption that “good fathers” are physically active with their children. In this deconstruction, other information about my parenting came forward, which challenged the conclusion of my being a less capable Dad than non-disabled fathers, such as my listening well to my children and giving great wheelchair rides to them and their friends. These parenting competencies were invisible and silenced under the dominant discursive expectation that Dads must be active and play sport with their children. The shift from being a “less than” Dad, to a disabled Dad who

fathered capably, but differently from non-disabled fathers, meant that I was no longer only positioned in the absence of parenting competencies. Taking up a subject position of presence within the binary of good/not good fathering was made possible by the back and forth exploration between the stories I was reproducing and the discourse(s) which produced such stories. It was this process of paying attention to the relationship between discourse and narrative storylines that was important for me to replicate in my research approach so that my inquiry and analysis processes were consistent with the discursive ideas I had become committed to in my professional practice.

In regard to extending my interest in narrative and discourse from narrative therapy to research, case studies, biographies and life histories, inspired by Bruner (1990) and Polkinghorne (1988) and continued by others (Chase, 2003; Riessman 1993), have focused on the relevance of the subjective story for research. Post-structural philosophers (Derrida, 1977; Foucault, 1972; Lyotard, 1984), and others taking up the post-structural perspective (Burr, 2003; Davies, 1991, 1998; Davies et al., 2006; Davies & Davies, 2007; Davies & Harré, 1990, 1999; Drewery, 2005; Drewery, Winslade & Monk, 2000; Laws & Davies, 2000; Parker, 1992, 1999; Wetherall & Potter, 1992) whilst not uninterested in the content and structure of people's stories, have been more concerned with the discursive production of subjectivity and the role of language in the reproduction of discursive power relations. Given the overlap but also distinctions between the concepts and practice of narrative research and the critical analysis of discourse, I now examine more fully how each informed the methodology of this study.

Narrative research and the storied self

Narrative research, like narrative therapy, considers the narration of story as a primary way that “people make sense of experience, construct the self, create and communicate meaning, [and] that personal narratives, no matter how unique and individual, are inevitably social in character” (Chase, 2003, p. 79). Central to the process of narrative and story narration is how the meaning made of events creates a narrative theme or storyline, which is organised according to a plot with a beginning, middle and end (Polkinghorne, 1988). Storylines are organising structures through which experiences are made sense of. In the interpretation of experience, an unfolding dialectic occurs between the person’s storylines and the social world the person is engaged in. Often events, such as a grief experience, disturb or disrupt the ideas and practices of a narrative storyline, in which case a storyline may change or a new storyline may emerge (Neimeyer, 1998). The new or changed storyline then (re)constructs how events are understood and responded to. Frank (2005a) terms this understanding “thinking *with* stories, as opposed to thinking *about* stories” (p.3) (emphasis in text). Narrative storylines therefore are cultural constructions; they are not fixed or unchangeable cognitive structures separate and distinct from the social world.

The interplay between a person and the social world occurs as the discursive subject positions made available to the person within any given moment, construct what the person, as subject, can take up and reproduce. At the same time, the narrative storylines of the person constructs his engagement with events, the how and why he responds the way he does to the subject positions made available to him by discourse.

But in this engagement, new storytelling occurs, which can affirm or challenge existing storylines. This understanding of self, as involving both narrative and discursive actions, resonates somewhere between the “thicker individual / thinner social relational” and the “thick social relational” typologies on Smith and Sparkes (2008b) continuum for viewing narrative identities and selves. The mid-point in Smith and Sparkes’ (2008) typology continuum is the “thicker individual / thinner social relational” view, which they name as the “the storied resource”. In this typology, “while narratives are personal, they are thoroughly shaped by socio-cultural conventions” (p.17). A more discursive category of identity within the continuum is “the dialogic” typology, which is when “culture [is] ‘speaking itself’ through the stories people tell” (p.20). The most discursive view of identity on the continuum, is the “performative perspective” where “narratives, selves, identities, mental processes, emotions and so on is derived from social and relational processes... realized as a by-product of relatedness... [and] are viewed as multiple, fragmentary, unfinished, always changing” (p.24).

In terms of how narrative and discursive views of the self were called on and brought-together in the analysis the participants’ account-making, a three layered approach was used. The first analysis guide relates to the “storied resource” typology, where “individuals draw from a cultural repertoire of available stories larger than themselves that they then assemble into personal stories” (p.19). The second analysis guide was discursive in orientation, theorising the participants’ accounts on the basis of their moment by moment response to subject positions and how position calls were accepted or resisted: the “performative perspective” typology. The third analysis

guide combined aspects of the first and second analysis guides, and as such more depicted the practice of “the dialogic” typology.¹

In the “performance perspective” and “the dialogic” typologies, narrative storylines are viewed as dialogic acts. Stories are told to an audience, even if that audience is oneself, and both the teller and the audience are taking up discursive subject positions in respect of how each tells and responds to the telling. Stories, therefore, as individual narrative reproductions of discursive ideas and practices, intersect with the listener’s or reader’s narratives “creat[ing] a space that truly is liminal: neither here nor there, but *between* the teller’s *here* and the listener’s *there*... stories work by effecting shifts in listeners’ paramount reality” (emphasis in text) (Frank, 2005a, p.18). In addition then to narratives ordering and constructing experiences (Bruner, 1986), stories are the medium by which we can learn about others’ experiences and the social/cultural/political discursive constructions that have produced them. As the medium by which we learn about others’ experiences, stories contain drama. They often provoke and challenge our sense of reality, in effect changing our own narratives (Frank, 2005a; Mattingly, 1998).

When people are deeply in plight, what they have as their perhaps last, perhaps best resource is a capacity to tell their story. The least that might be expected from those of us for whom plight is still over there, still a background to our lives, is to hear their stories. We may also need to send food, medicines, and tools for rebuilding, but first we have to be willing to hear the story. (Frank, 2005a, p.20)

¹ Further details of the analysis processes used in this study are discussed later in this chapter.

Stories require engagement by another. As a counsellor I am aware of this, but qualitative research also provides a context for people to tell their story and be heard, for “what cannot be said cannot be acted upon... what is inarticulate cannot be protested and changed” (Frank, 2004a, p.437). Furthermore, even in a person telling her or his story, it is not only her or his personal story for “no one existence is ever clearly bounded... each voice is permeated with the voice of others” (Frank, 2005b, p.969). One person’s story about having an illness or impairment is greater than that person’s life, it is a site of encounter for coming to further understanding about disablement, beyond the realm of that one person’s narratives.

Developing understanding about society through the study of people’s stories is not a neutral or objective process but a subjective co-production between the research participants and the researcher (Burr, 2003). Narrative research focuses on the “discovery of meanings that both constitute the individual participant and are co-constructed in the research process” (Josselson, Lieblich & McAdams, 2003, p. 259). On this basis, the discovery of meanings that the participant holds about his or her life are not “gathered” but “generated” (Crocket, 2002). My expectation was that the participants’ stories would help me gain an understanding of how they understood and accounted for some of the events they had experienced, but that the account-making they did with me would also be a response to how they viewed me and my research. The interview process whilst sometimes referred to as a dialogue between the researcher and the participants, also contains a power relation that privileges the researcher’s priorities, objectives and process over the participant’s interests and commitments. “The qualitative research interview entails a hierarchical relationship

with an asymmetrical power distribution of interviewer and interviewee. It is a one-way dialogue, an instrumental and indirect conversation, where the interviewer upholds a monopoly of interpretation” (Kvale, 2006, p.484).

Given the value of researching disabled people’s stories but the problematic “asymmetrical power relation of the interview” (Kvale, 2006, p.484), some uncertainty remained for me in regard to how to investigate, interpret and write about what the participants have said in their conversations with me. Such uncertainty is common in narrative research data generation and analysis for “clear accounts of how to analyse the data... are rare.. [with] no overall rules about suitable materials or modes of investigation, or the best level at which to study stories” (Squire et al., 2008, p.1). Frank has argued that clinicians and researchers might listen for his typologies of restitution, chaos and quest narratives as a means of providing a thematic framework, as otherwise “a story can be easily dismissed as a one-off occurrence, a sad tale that has little claim on the listener” (Frank, 2004b, p.211). Other narrative tropes in addition to Frank’s triad have previously been proposed. These include Gergen’s (1991) “progressive”, “regressive” and “stability” narratives or Frye’s (1990) “comedy”, “romance”, “tragedy”, “irony and satire” narratives. However, none of these narrative typologies were likely to provide the focus and detail I required in my hope of researching the discursive concept of agency, in relation to disablement, through an analysis of how discursive subject positions became available and were negotiated in the moment by the participants. In questioning and analysing very specifically for narrative themes or tropes, there was a risk of presupposing what the participants’ stories would tell, thereby losing the

particularity, complexity and richness of the narrative stories (Riessman, 2008). Squire, Andrews and Tamboukou (2008) have articulated well why people commit to narrative research when the process itself is not necessarily well sign-posted with clear maps for the process:

Despite these [investigation and analysis] difficulties, many of us who work with narratives want to continue to develop this work. Most often, perhaps, we frame our research in terms of narrative because we believe by doing so we are able to bring them into useful dialogue with each other, and to understand more about individual and social change. By focusing on narratives, we are able to investigate not just how stories are structured and the ways in which they work, but also who produces them and by what means; the mechanisms by which they are consumed; and how narratives are silenced, and even explain important aspects of the world.

(Squire, Andrews & Tamboukou, 2008, p.1-2)

Narrative research certainly suited my purposes for this study, especially my interest in making sense of people's storylines and understanding more about individual and social change. However, from a discursive perspective, the focus is less "who" produces stories but rather how discourse produces the stories we tell, which become the narratives that frame what subject positions we take up and how we take them up. In order to research how this process works, in this study I also engage in a critical analysis of discourse by employing the concepts of position calls, subject positions and agency to participants' stories and accounts of experience.

Discursive analysis of position calls, subject positions and agency

Critical analysis of discourse is a form of social critique because it looks for explanations of people's experiences and actions as the product of social, cultural and historical contexts (Burr, 2003). It is well suited to the emancipatory agenda of Disability Studies.

In Chapter Three, using the example of a disabled person going swimming (page 71), I showed how position calls work in practice, producing the subject. I gave an example of the swimmer accepting the subject position of being helped, in terms of disability by swimming, and I gave a counter example of the swimmer refusing the position call, stating that the meaning of swimming for him was about "being like everyone else, swimming for fun and recreation". I then suggested that the acceptance of the position call illustrated the swimmer reproducing medical discourse in terms of disability, whereas the example of refusing the position call demonstrated the swimmer reproducing social model discourse. In reproducing medical discourse, a subjectivity is produced that involves the person wanting to get well, to engage with rehabilitation and medicine. In reproducing social model discourse, a subjectivity is produced that involves the person viewing social barriers as what disables him, not his illness or impairment. In regard to these processes of subjectification, Drewery stated:

Once we understand how different forms of subjective experience are produced, it seems to me we have a responsibility to move forward to thinking about what forms of subjectivity would be preferred, and how different ways of speaking produce more or less preferred subjectivities. (2005, p.306)

Understanding what form of subjectivity is preferred will depend on the degree to which it is possible for the person to take up a position of presence within a discursive expectation or position call. If, for example, the swimmer is rehabilitating well, then accepting the pool attendant's position call may serve him well. On the other hand, if the swimmer only finds a position of absence in the expectation of swimming helping him to get better, then the preferable subject position is likely to be refusing the pool attendant's position call. Taking up a subject position within social model discourse will enable the swimmer to refuse the medical discourse position call of "swimming will help a lot", but it may not be the only discourse which offers a subject position of resistance to the pool attendant's position call to the swimmer. It is not necessarily obvious and requires deconstruction to establish what subject positions are preferred and how different ways of speaking may produce more or less preferred subject positions for a person living with illness or impairment.

In the scenario of the swimmer and the pool attendant, the swimmer has been portrayed as taking up only one discursive subject position at any one time but the person as subject is less rigid than this and is always in a process of change:

The new subject is theorized as fluid, fragmented, with more open boundaries (Davies, 2000), as co-existing with texts in which it is constituted, texts in which contradictions can be embraced (Cixous & Derrida, 2001), as texts that one can play with, and, through that play, generate new possibilities of being (Barthes, 1977). (Davies et al., 2006, p.88)

In other words, it might well be that the swimmer's subjectivities are not a simple representation of either medical discourse or social model discourse. The subject

positions the swimmer takes up each day, including each moment, might well be some kind of intersection between a number of discursive possibilities, some of which could contradict one another. The swimmer might easily be swimming to get better, taking up medical discourse, and with a statement about having the right to swim and have access to swimming like non-impaired persons, taking up social model discourse. Hence, whilst Disability Studies has traditionally positioned the social model in contestation against the medical model, and established each as opposites of one another, both discourses might be considered as co-existing and co-shaping within a subject's subjectivities. And it is these kinds of narrative contradictions, the juxtaposition of multiple positionings and selves (White, 2007), that has been of interest to me as a narrative therapist which I wished to also explore in this study. Furthermore, the swimmer is not just discursively "constituted by multiple discourses [but] a subject who is in process, a verb rather than a noun, a subject with boundaries permeated by others, by discourse, a subject identical with the text through which it is being constituted" (Davies et al., 2006, p.93). Both the swimmer and the pool attendant are constituted by the experience of each other; their engagement with each other is a discursive and narrative performance, which potentially produces new discursive and narrative performances. The possibility of new discursive and narrative productions by either (or both) the swimmer and the pool attendant come through each person's later storying of the encounter with each other, as well as in the moment of the encounter. As they tell stories about the encounter (to self and others), each person's narratives will be reconstructed, which in turn will shape how they respond to future position calls. Davies refers to this as "mo(ve)ment", signify[ing] the simultaneity of specific embodied *moments* and the

movement toward the subject as a process that can come about through the mode of telling” (emphasis in text) (Davies et al., 2006, p.92). It was my hope that this research would deconstruct both the “embodied moments” and the corresponding “mo(ve)ment” that had occurred for the participants through the processes of their discursive sense-making and storying of experience – those “moments” when new narrative and discursive subject positions had been taken up, or were even being taken up – through their experience of participating in this research.

The process of deconstruction, as introduced in Chapter Three, is a process that reveals how discourses produce subjects (Davies et al., 2006). I wanted to hear the participants' stories with a discursive ear that showed how discourse constructed the subject positions they took up but also showed the moments of agentic action, when they resisted position calls that had positioned them in disadvantage. The point of such deconstruction, is that when the process of subjectification is made visible to the subject, the person is no longer the “subjected subject” (Drewery, Winslade & Monk, 2000). Davies et al. (2006) call this “decomposition[:] the name we might give to subjective movement through which we unmoor our embodied selves from the discourses we have worked deconstructively to make them unthinkable” (p.99). On these terms, the UPIAS group experienced this “subjective movement” when they made medical discourse “unthinkable” by their reframing of what caused disability, namely social barriers not impairment. Similarly, I hope that this study’s deconstruction of disabled people’s stories and accounts of their lives generates new understandings about disabled people’s narratives, impacting on how we theorise the discursive production of disablement. Hearing the participants’ stories was critical

for achieving these understandings because “life continues to unfold in the account of it, and the account making is, in that sense, always a new event, a new experience” (Davies & Davies, 2007, p.1141). Given my agenda of researching agency in the lives of disabled people, I was especially seeking to inquire about moments or events when “habitual ways of thinking are dislodged, are pulled out from under” (Davies et al., 2006, p.99).

However, the inquiry process by which to achieve a deconstructive discursive reading of the participants’ narratives appeared no clearer than the data generating process for narrative research for “as any kind of text may be made a subject of deconstruction, there are no specific requirements for interviewing... [there is] no worked out practice of deconstructivist interviewing” (Kvale & Brinkmann, 2009, p.232). In practice, I drew on the kinds of inquiry processes that I had learned as a narrative therapist. I now discuss in more detail the interview and analysis processes I engaged in for this study.

The Research Process

There were three aspects of the research process. First, a plan of inquiry that enabled me to engage with the participants’ stories and accounts about their lives. Second, a critical discursive analysis of the participants’ accounts of their experiences, particularly in regard to what discursive subject positions have been available to the participants to take up, the effects on their lives of taking up those subject positions, and to explore the extent to which the participants took up subject positions which indicated actions of agency. Third, develop a view of the study as a discursive co-

production between myself as researcher and the participants of the study. The power relations and corresponding subject positions made available to the participants in the process of participating in the study, needed to be made visible and considered in light of the analysis I was making of the participants' stories and accounts of their lives.

Accessing participants

Six people who self-identified as having an illness, long-term health problem, impairment or a disability, were interviewed. In my invitation to participants, the wording of each description for disability was deliberate in that it was assumed that the very way each participant viewed their body/mind status would reflect the respective discursive production they were caught up in. Those persons who had taken up social model understandings of disability would be likely to see themselves as 'having an impairment', and a disability only if their impairment needs were not accommodated. If the participant took up the meanings inherent within the minority group model of disability, they may perceive themselves 'a disabled person', an identity description distinguishing them from non-disabled persons. On the other hand, those persons who were less involved in the disability movement and had taken up a construction of themselves as unwell were more a production of medical discourse and as such were more likely to see themselves as 'having an illness or long-term health problem'. Other people might view themselves as 'a person with a disability', which was the languaging of disability during the 1980-1990s when the normalisation/SRV philosophy of disability was quite dominant and influential, especially taken up by non-disabled people advocating for and working with disabled

people. Having said this, while each participant had probably taken up one dominant discursive subjection, they were also likely to have been produced by some combination of more than one discourse. Indeed, the degree to which this was or not the case was of interest to me as part of the study's exploration.

The study was promoted through posters at a small tertiary education institute, where I work, that stated:

- Are you interested in being part of a collaborative project about disability?
- Do you have experiences of disabling social stories?
- Do you have experiences of standing up to disabling social stories?
- If you have answered 'yes' to any of these questions then you may be interested in participating with James Arkwright in his doctoral research project.

Three students from the small tertiary education institute made up a "convenience group" (Cohen, Manion & Morrison, 2001) as they were selected for the study on their ability to be available for the time required for the interviews and their level of interest in the study. I interviewed each participant on two separate occasions, with each interview being up to one and a half hours in length. A further three people from elsewhere in New Zealand were selected by me from my personal and professional knowledge of the disability field in New Zealand, and invited to participate in the study. Those three participants were "purposively" selected on the basis of being prominent within the disability field and/or their profession (Cohen et al., 2001). In making this selection I assumed that community, if not nationwide,

prominence may indicate that the individual had negotiated moments of agency in their lives. The three people whom I approached to participate in the study accepted my invitation.

Ethical considerations and process

Prior to the study commencing, an ethics application for the study was submitted to the University of Waikato, Faculty of Education Ethics Committee. The committee approved the study as a supervised postgraduate research project.

The ethics application detailed how the participants would fill out and sign an informed consent form (see Appendix 1). Within the consent form it stated that all information about the participants gained from the research would be kept strictly confidential and the participants would remain anonymous within the thesis, other public documents and public presentations, unless someone specifically requested that she or he did not want to remain anonymous. In writing the thesis, it became clear that it would be challenging to keep the identity of one of the participant's anonymous. After consultation with my supervisors, it was decided that I would contact the participant to talk about my writing of their account in the thesis and the challenge of ensuring that the person would not be identified as one of the participants in the research. The participant replied that everything that had been told to me during the interviews was "on public record anyway" and that in this person's high profile role "it comes with the job that people write about me; it is fine with me, James." In writing my account of what the participant said to me during the interviews, I have still endeavoured to protect the participant's identity as much as

possible given the constraints of keeping the account appropriately specific to the social contexts that are a critical part of the person's story.

Part of the ethics application explored the potential for harm to the participants. Of concern was my dual role with the participants. Three of the participants were envisaged to be students at the tertiary education institute where I worked, and the other participants I would have had, to varying degrees, a relationship with them prior to their involvement in the study. The ethics application outlined several steps I would take as an attempt to reduce the extent to which participants might feel vulnerable or experience harm as a result of becoming involved in the study. First, no students who were currently studying in the courses I taught would be able to participate in the study. Second, with each participant I would discuss the nature of my dual role with them, what vulnerabilities this might bring forward for them and what would they need to know from me or have so as to feel less vulnerable². Third, my letter of introduction to the participants outlining the purpose of the study, and the consent forms, clearly outlined that participants could withdraw from the research at any time should they choose to do so. Fourth, a clear complaints process, should a participant wish to make a complaint about any part of the research process, was outlined to participants within my letter of introduction to the participants and the consent forms, and the complaint process was also discussed during the first interview.

² Further details on aspects of my conversations with the participants about my dual role with them, as in my knowing them beyond the context of the researcher – participant relationship, are discussed in Chapter Eight when I review the researcher – participant power relation

An ethic of collaboration and respect was prioritised in the ethics application. All participants were informed at the beginning of their involvement in the study that they would receive: a letter of introduction about the research and a consent form, copies of his/her interview transcript (for review), copy of my analysis of their interview with me (for review), a summary of the final research report, and a copy of any resultant article/presentation from the study up to 2 years after the study was completed. The participants were also informed that the thesis, when completed, would be held as a public document in the University of Waikato library.

Finally, due to the study being conducted by myself as a lecturer at the tertiary education institute where I worked and involved three students studying at the institute, the institute required that I submit a research ethics application to the research ethics committee at the institute. This ethics application was undertaken and was approved by the committee.

Engagement with the participants and the interviews

All six potential participants received a letter from me, informing them about the study, and preparing them for being a participant in the study. In the letter, I asked each person before the first interview to:

Reflect on experiences when you think an idea or a practice has positioned you in ways that meant you had to reflect on how to respond, either at the time or after the event. I am very interested in hearing your stories about these times.

(extracted from first letter to participants – see Appendix 2)

Examples were then given regarding a wide range of responses that a person with an impairment or illness might have to a situation in which a disabled person was subjected to a pejorative and exclusionary position call (see Appendix 2). When the interviews began, each participant had appeared to understand the scenarios portrayed in the introductory letter and had been reflecting on experiences which had some kind of parallel or link from their life to the examples I discussed in my letter.

In order to maximise the opportunity for a dialogic encounter between myself and the participants, I followed an informal, unstructured ethnographic interview process (Cohen, Manion & Morrison, 2001). My initial letter was the starting point for the interview. In keeping with a narrative research interview, I asked questions that invited the participants to tell stories about and give accounts of their lives. I also asked questions that invited the participants to think about interactions with people or situations that they had found difficult, to make sense of what was difficult for them, and how they responded in those times. In these stories I was listening for and asking about the ways in which they had been positioned by discourse, as well as the discursive subject positions they took up in their responses to the positioning they had found difficult. I was interested in how they made sense of these experiences, notably the assumptions and norms that produced them.

I prepared questions for the interviews in advance, not to be used in a structured way during the interview process but in order to provide something of a background practice template for the inquiries, a practice that is consistent with narrative research methodology:

I tell [the students] that a well constructed interview guide prepares them to be open to a wide range of stories their interviewees may tell, and it helps them know what in general they want to hear about. But once they are prepared in this way, inviting and listening well to this person's particular story should be their main goal. Many of their interview questions will be answered without even being asked.
(Chase, 2003, p.83-84)

A sample of some of the questions I crafted prior to the interviews are listed below:

- What might be some of the things which stand behind you deciding to participate in this research project?
- It is my idea to research the concept of agency as it relates to disabled people's lives. What do you know about the concept of agency? What would you like to know about the concept of agency?
- I wonder if I shared a story of agency operating in my life if that would be helpful in terms of orientating us in this discussion?
- As you have heard that story, has it connected to any stories of your own for you?
- If so, can you share those stories with me?
- Could we discuss now about some of the ways you have been positioned because of your disability?
- How did the positioning influence what you felt, thought or did?
- What might support you or has supported you in the past to resist that positioning which you don't like?

(extracted from the full version – see Appendix 3):

In preparing these questions I was particularly interested in taking into account the power relation of the research process; how the researcher and research participants

are respectively positioned in relation to each other. I wanted to position myself as interested in their views, their stories and their accounts of resistance to disadvantageous position calls, as a person who might have similar stories and subjective experiences. Reflecting on my position as researcher has been important because within Disability Studies there has been discussion about research dis-empowering disabled people further, primarily benefiting the researcher rather than participants or the collective of which the participants are a part (Barnes, 1996; Oliver, 1999). In response to this criticism that research in the disability field has taken advantage of disabled people, I have had an ethical commitment to work collaboratively and respectfully with the participants, as detailed in the ethics section of this chapter.

In the interviews, I endeavoured to ask mostly open ended questions and reflect and clarify what the person had told me in a similar way to having a counselling conversation with a person (client). Reflecting statements, clarifying questions and open ended questions are conversational skills often used by counsellors to generate rapport and explore the person's thoughts and feelings (Davis & Buskist, 2008). As a narrative therapist, I place an emphasis on using the person's (client's) own language and to ask questions that focus on their meaning-making (Bird, 2004; White, 2007). An important skill is to ask questions that are connected to what the person had just said to me. Such questions can draw out more of the story the person is telling, exploring the meaning-making that accounted for how she has storied experience the way she has. In the interviews I paid particular attention to those words and phrases the participants used which appeared to indicate a discursive subject position they had

been positioned by or had been invited to accept. For example, one participant said “I’m sort of one that doesn’t like to use the words ‘unwell’ or ‘sick’ because I don’t actually know what determines sickness for me. So sometimes I just think ‘not firing on all four cylinders’ or eight or twelve or whatever”. My question in response to this statement was “do you have any ideas about the preference for the words ‘not firing on all four cylinders’ as opposed to not saying ‘sickness’ or ‘illness’?” My intent in asking this question was to see how the person accounted for her refusal to take up the subject position of being ill or sick.

After the first interview I sent the transcript to each participant for her or him to review, and I enclosed a letter. The letter began with a general statement that was very similar for all the participants:

It is my belief that conversations are never neutral or remain in a vacuum but continue to act in our lives both during and after a conversation has occurred. Therefore, I would like to suggest that we begin our next conversation by reflecting on any thoughts you have had since our last conversation together. For example, perhaps you have considered some aspect of our conversation further or maybe some part of the transcript has stood out as interesting or significant to you. (extracted from second letter to participants – see Appendix 4)

After this general statement, I wrote some very specific questions in relation to the first interview I had had with the participant. Typically I was curious to know a little more about what the story suggested about her or his narrative storylines and the subject positions taken up in the production of such narratives. These questions served to alert the participant to the kinds of accounts of experience and sense-

making I was interested in hearing more about in the second interview. For example, in the letter to one participant I said:

On a number of occasions you said you “were working on it” or “it’s a work in progress” in relation to finding ways of disclosing the effects of illness in your life without being positioned as “less than”. The word “work” indicates intentionality to me as in being proactive rather than reactive and I’m wondering if the word “work/working” has the same meaning for you? I am interested in uncovering the thinking and activities that go along with the word “work” for you, such as the history and effects of “working at things” or things being “a work in progress” in your life. And of course, I’m interested in what the thinking and activities of “work” have meant for how you have responded to the effects of illness in your life.

(extracted from letter to Carole – see Appendix 5)

In posing the above questions, I was hoping to gain more understanding of the person’s narrative responses to how her illness positioned her. In the second interview, I explored what discursive ideas she took up in her refusal to be positioned as “less than”.

In other letters, I deliberately invited the participant to consider what discursive assumptions they had reproduced or had refused. For example, for another participant I asked questions in the letter that invited him to explore his views about being referred to as “whose is that?” by a senior doctor when he was in hospital as a child:

What do you think [name of Doctor] words “whose is that?” might indicate about how children were positioned within pediatric hospital wards prior to 1969?

Would you refer to a child as “whose is that?” now that you are an adult? If so, why? If not, why not?

(extracted from letter to Ron – see appendix 6)

The rationale for the letters I wrote to the participants between the first and second interview was based on my knowledge and use of narrative therapy “therapeutic letters and documents” which are designed to thicken the person’s (client’s) alternative and preferred storying of experience (White & Epston, 1991). And whilst the research letters were not intended to be therapeutic in themselves but more a process for furthering my understanding about the way the participant had been constituted by discourse, in effect they often did appear to support the person in taking up a preferred account of their life. For example, one person, at the start of the second interview said:

Something that I did find interesting was that how strong the family discourses were. I hadn't even picked them up or recognized them before we talked so that was really really good for me... it was interesting to see how many strengths my family did have and a lot of it was actually in my very younger years.. I think it's helped me understand my mother and my family a bit more.

For some of the participants, prior to the second interview, I drew what I referred to as a ‘discursive map’ as a way of wondering about the relationship between their stories and accounts and the discourses which produced them (see Appendix 10).

The purpose of the map was to orientate me to asking specific questions which might lead to the generation of more understanding about the discursive position calls

experienced and the subject positions taken up by the participants. The second interviews were again informal and unstructured. In the second interviews I again sought to clarify and understand more about the specific meanings the participant had made in relation to how they had storied experience. For example, in the second interview with another participant I was curious to know more about these subject positions that were available to him in the early years of his life:

Q: What do you mean by that – ‘honouring the impairment?’

Q: How have you concluded that because people ran to the finish line together with you at a cross country race and because people passed you their pencils when you ran out of your own, how has that led you to conclude that your impairment itself was likeable and intriguing?

At the conclusion of the second interview with the six participants I had many stories and accounts to make sense of in regard to my topic of interest, namely the narrative and discursive production of disabled people’s lives, including their actions of agency. The next step was to develop some processes that would help in this task of analysis. The analysis of the interview transcripts was explored through three separate interpretation guides that I developed as a means for providing different sets of lens by which to understand the participants’ accounts.

The analysis of the interviews

Initially, in seeking a way to analyse the data, I followed an approach similar to grounded theory, where “the researcher simultaneously codes and analyzes data in order to develop concepts. By continually comparing specific incidents in the data,

the researcher refines these concepts, and integrates them into a coherent theory” (Taylor & Bogdan, 1988, p. 137). Narrative researchers, Chase (2003) and Riessman (1993) suggested looking for narrative themes in the participants’ stories, first coding the different kinds of content discussed, and then categorising the codes into broad groupings. Accordingly, I explored the participants’ accounts in light of what they had indicated as important and meaningful to them and what that suggested about the discursive subjections available to them. A number of categories and codes were developed as a grid for interpreting the transcripts, such as the following:

Table 3: First analysis guide (extracted from the full version see Appendix 7)

Discursive Categories	Narrative Thematic codes
Medical Discourse	Receiving medical treatment Becoming less ill or impaired Feeling less than/a failure
Disability Rights Discourse	Refusing to be less than Disability caused by society Disabled and proud Desiring to make a difference for other disabled people
Normalisation / SRV Discourses	Career/work is very important Social roles are valued Feels there is a place for her/him in society
Family/ Whanau Discourses	Relationships and family are important
Faith/Spiritual Discourses	Faith and spirituality support individual Feeling blamed for not being healed

The categories and codes were very helpful for establishing the common ground between the participants’ accounts, but there were two problems with this approach. First, the distinctiveness of each person’s narratives was being lost; and second, the relationship between the codes and categories did not match very well with discourse theory ideas about fluid, fragmented and multiple selves. The categories and codes became too reductionist, creating simplistic connections between a discourse and subjective experience. For example, all “less than” thoughts/feelings/actions were

viewed as produced by medical discourse because that discourse typically produces illness and impairment as abnormal, as in need of fixing. However, to collapse all “less than” or failure experiences as a product of medical discourse is problematic. A finer discursive reading of participants’ stories was required. Furthermore, the category and code analysis was not providing very clear understanding about the participants’ processes of agency, the focus of my research. As Carr (1997, pp. 98-99) has said, “what is at issue in interpretive studies is the relationship between the data and the theory, the concepts, the conceptual framework or the model”, and these relationships between my conceptual framework and the analysis of interviews were not being achieved by the first guide I employed.

I therefore turned to a much more discursive analytic process. I focused on four aspects of discourse theory. These were: position calls; participants’ responses to position calls; the extent to which a participant took up multiple positions as a discourse user; the effects of the research process on researcher and participants. I also considered the degree of synchronicity between narrative therapy and narrative research. I crafted a series of open ended questions with the intention that they would form a kind of template by which I could make sense of the participants’ accounts of their lives. I asked, for example:

- What were the position calls that the participants were invited into?
- How are they called into existence for the different participants?

- What are the effects of these position calls on participants in terms of the participants' (and their friends/family) concrete actions and meaning making?
- What were the participants' responses to these position calls?
- What were critical moments or sites of resistance to discursive position calls, examples of refusing to take them up as a singular disabled identity?
- What were the effects of the research process on making visible the practices of agency?
- To what extent is the research process, itself a discursive practice, acting as an agent of change for participants thereby enabling them to experience moments of agency?

(extracted from the full version – see Appendix 8)

This second guide was especially useful for producing an analysis of the interviews that related to the study's focus on agency. However, this approach also had its own problems. The participants' narratives were not maintained and their stories became fragmented, as the analysis prioritised a deconstruction of the participants' accounts according to positioning theory. Such results seemed to contradict the philosophy of narrative research and therapy, which understands story as the mode of operation that produces experience. Given that I do take up this idea, it did not make sense to lose the sense of each participant's story within the discursive reading of the interview transcripts.

I then developed a third analytic process, one that could build on the narrative themes established in the first guide and include the concepts of narrative within the discursive analysis of the second guide. The new analysis remained concerned with discourse, positioning, subjectivity, agency and power relations but made room for the participant's storying of experience. The questions I asked in this third lens or layer of analysis were designed to read the participants' accounts as narrative and discursive performances. The questions kept much of the content material of the second guide but extended the questions to include the concept of story. For example, I asked:

- What might the participants' stories/responses say/indicate about the discursive position calls they have been historically invited into?
- What subject positions did the participants take up and what storylines did these subject positions make available for living their lives?

(extracted from the full version – see Appendix 9)

The advantage of this third approach to analysis was that it paid attention to three aspects at once. Firstly, it maintained some coherence of each person's story and account; secondly, it allowed for some thematic common ground between the participants' accounts; and thirdly, it focused on the detail of the shaping effects of language, and on moments of agency. Having said that, each of the three processes of analysis was useful as lens by which I made interpretations and came to make sense of the participants' accounts of their experiences.

The next three chapters offer my discursive and narrative reading of the participants' interviews, shaped by each layer of analysis. In this chapter, I have already drawn on small aspects of the data generated from my interviews as I illustrate the methods I employed. I turn now to a fuller introduction of the participants prior to my theorising of their accounts in the remaining chapters.

Introducing the participants

All of the participants described their ethnicity as either New Zealand European or New Zealand Pakeha. One of the limitations of the study was that nobody of a non-white ethnicity participated in the study. Of the six participants, three were women and three were men. With some reserve, I have decided to name what each person's illness or impairment is but I am very aware that I am taking up medical discourse in committing to such a practice. Given that impairment or illness is the only parameter by which people could be eligible to participate in the study, it does make sense to discuss, albeit briefly, each participant's respective illness or impairment. However, given the inevitable disadvantageous positioning that occurs whenever a person is identified as being ill, impaired or disabled, it is in itself quite problematic to introduce participants on the basis of their body status according to medical terms. I ask the reader to hold the medical description of each person lightly, and to look forward to my telling of each person's accounts as they respectively unfold in the next three chapters. In order to help protect each participant's identity, the names used for each participant are pseudonyms.

Chapter Five features David's story. He was born with an impairment that affected his movement and speech, in which a story of discrimination dominated his life for many years until some very particular experiences enabled him to develop a counter understanding of himself and his life. Chapter Six explores Fay and John's stories of turning illness and impairment into an opportunity for new life directions. Fay had experienced rheumatoid arthritis (RA) for over ten years and John lost his sight through trauma some twenty years earlier. Chapter Seven looks at how Carole, Jan and Ron took up a "less than" subject position on the account of having an illness or impairment but how they also were active in using discourse to refuse such positioning. Carole had for several years been living with systemic lupus erythematosus (SLE). Jan had for over ten years experienced significant medical conditions, such as diabetes, heart disease, high blood pressure and as result had developed a significant hearing impairment. Ron was born with some body deformities for which, during his childhood, he had many surgical reconstructions; he had a significant hearing impairment and a life long journey with speech impairment.

5

INTO, THROUGH AND BEYOND DEFICIT DISCOURSE: DAVID RE-NEGOTIATES HIS PARENTS' LEGACY

The stories David told about his life constructed him as having an “ever-fresh” childhood, while his teenage years were “stinky and dark”. The discourses which constructed David’s experiences during his childhood, where he was included and his impairment was accommodated, were very different than the discourses he was subjected to during his teenage years when he was positioned in deficit. In this chapter, I detail David’s account of his journey from being told by his parents he had “nothing wrong with him”, to experiences of being excluded and feeling “disdained” after the age of ten, to his re-description of what it meant for him to be termed “a spastic”.

In this account of David’s account-making, I especially focus on exploring the deficit position calls that David was subjected to and took up, and the events which occurred that led to David accessing subject positions that did not position him in deficit, and did enable him to act with agency. In his actions of agency, David re-negotiated his parents’ refusal to subject him to medical discourse. David took up a different version of “having nothing wrong with him” – which was his parents’ legacy to him – instead, David engaged with the idea that he was “a spastic with attitude”; a person with an impairment who would resist those practices that marginalised and excluded him.

Having briefly overviewed David's journey of 'into, through and beyond discourses that positioned him in deficit', I now turn to explore his account more fully, beginning with his childhood when he enjoyed practices of inclusion.

Early Years: The practice of "hanging out" with friends

David said that prior to ten years of age, he had not thought of himself as having an impairment or disability, or being disabled. He viewed himself more as "a guy that was uncoordinated" and "wobbly". David attributed these non-medical descriptions of himself to the influence of his parents, especially his mother, who he said "would never, period, ever talk about my impairment, ever". David's mother refused the position call within medical discourse to understand David as having an impairment and being disabled, which David said related to her own disabling experiences:

My Mum has polio...and she was in an iron lung and she's haunted by stuff... she used to associate anything to do with disability with her own bad experiences and she was vigilant about me, you know. I didn't know I had [type of impairment], I didn't know it was called [that] until I was 21, they would say to me it's a co-ordination problem.

The "co-ordination problem" description given to David by his parents to explain his impairment, worked well for him during his childhood. It was a subject position which constructed him as being like other children but likely to have difficulties with physical activities. This way of understanding David's impairment meant he enjoyed "a lot of interactivity and interdependence". In speaking about his primary school years, David selected stories that gave an account of him being included and receiving help from his friends regarding his physical needs. For example, he said "people saw that I needed a new pencil... so they would slip their pencils onto my

desk". David's friends also accommodated his impairment when he participated in sport, such as when running cross-country. He said, "I would be the slowest... but everyone would run at my pace so we'd all come in together".

David referred to the quality of relationship he had enjoyed with his friends to account for the sense of inclusion he experienced during his early years at school. He said, "they wanted to belong with me and I wanted to belong with them, so any barrier that came up, we just dismantled it fairly unconsciously because the sole desire was to maintain connection, unification and hang out together". In describing this experience of "belonging" David drew on the metaphor of 'family', saying "we were kind of like brothers". He also took care to distinguish the relationship of mutual belonging he had with his friends as being different from people having empathy for him:

The word 'empathy' is a bit too clinical, they would somehow have a connection to where I was at... like we would walk home together and there were often many ways to walk home, but we intuitively would take an easy way to walk home because they knew that I was having trouble with hills.

The word "connection" represented more inclusion for David than the description "empathy". It positions David as an equal rather than someone who required empathy from others. David's "connection" with his friends was like that found within families and as such, any impairment-related needs he had were "intuitively" dismantled.

David was unsure about what informed the “intuition” which guided how he and his friends undertook activities together. In considering this story, I wondered if there was a process whereby David’s friends learned what he was able and not able to do, perhaps by watching him or by talking together about what they were doing.

Regardless, David and his friends became aware that he could not walk up and down hills easily when going to school, and somehow, whether over time or almost immediately, they chose to walk the easy way home because that was less difficult for David.

In describing the relationship he had with his childhood friends, David said “they valued me, they desired my company and participation... my continuing co-operation and participation was cherished”. The discursive ideas David and his friends were taking up were those that esteemed the practices of “connection”, “co-operation”, “negotiation” and “interdependence” and any “block” that prevented that from happening was “dismantled”. David and his friends appeared to have not taken up any ideas that restricted disabled people from “connecting” to others and working together in an “interdependent” way.

David described the way his friends related to him and accommodated his impairment as “functionalistic” and “naturalistic”. David was passionate about the importance of replicating what he had experienced as a child. He said, “disabled people with non-disabled people, cherishing one another, honouring the impairment, honouring the impairment!... seeing it [the impairment] as valuable and likeable and kind of intriguing”. In other words, not only were David’s impairment related needs met

within his social circle but his point of difference was engaged with as something valuable. In referring to his childhood relationships, David said

They did recognise I was different and there was a lot of talk about it but in a neutral way. No, not in a derogatory or you're worse off kind of way... we would often talk about how I moved and how I did things but it was more from the perspective of that's the way you do it and how are we gonna work out how to etc... it was from that perspective, not a, oh you're in deficit kind of thing.

In selecting such stories to tell of his childhood, where he experienced a strong sense of “belonging” with his peers, David was promoting an idea and practice of how people “without impairments” and those “with impairments” could interact with one another. David’s parents refused to describe him as having an impairment or being disabled; these positive childhood experiences of David’s were presumably the social legacy they had endeavored to create for David. A boy with an impairment who was not storied as disabled; a boy with an impairment who felt he belonged, who viewed himself as likeable and valuable. Until the age of ten, David had been protected from any understandings and practices that would disable him. He had been offered only subject positions that interpreted the functional effects of his impairment as being about him having differences but not being positioned as disabled or in deficit because of those differences.

Teenage Years: Positioned as “the spastic”

The position calls that David was subjected to dramatically changed once he became ten years of age. One particular memory stood out for him as a turning point. He said it began as a playground “tussle” between him and his best friend but escalated

to name calling when his friend called him a “spastic” and then other children joined in and also called him “spastic” and “retard.” David said until that moment, he had never heard the word “spastic” before. The effect on him he said was “like a staple in my heart, it felt like a staple gun through my chest”. David said he got up and said “no way” he was “not a spastic”, he was “no different” but then they called him “a liar”. David said the group by then had “circled” him and one child said “you don’t belong with us anymore David, you belong in an institution”. He also recalled his friend throwing him to the ground and when he tried to stand up and hit back, he said another boy hit him back to the ground. David finished the story by saying that after being “hit down” he “stayed down”.

The event was extremely traumatic for David because he was no longer constituted as belonging and accepted. Previously David’s friends and peers had taken up discourse that produced them to value and prioritise “connection” with David but on this day they took up a competing discourse, one that had them objectifying David as ‘other’ to themselves. Critical in this telling is how David had no knowledge that his “coordination problems” and “wobbles” could call him into a position of being termed a “spastic” and a “retard”, thereby categorising him as no longer being one of the group, but someone who should live in an institution. However, David’s friends and peers, or at least some of them, were already familiar with discourse which positioned pejoratively people who had an impairment and on this occasion they shifted from merely thinking such ideas about David as ‘other’ to them, to performing actions that reproduced those ideas in practice. Any engagement with the notion of impairment was always likely to be problematic for David because of the extent to which medical

discourse as the constructing knowledge of impairment denounces it as a derivative, non-preferred embodiment.

In thinking about embodiment, if “subjecthood is granted... in recognition of the co-existence of oneself with the text... the sense that there is no fixed referent existing outside the text. We are the story happening to us, we are ‘freewheeling in language’ (Barthes, 1977: 56)” (Davies et al., 2006, p.96), then the story of who we are in any given moment is dependent on the discourse that is being taken up (in that moment) in the construction of us. And unfortunately for David, as he neared his teenage years, the discursive text by which his friends and peers were ‘reading’ him was changing, which meant the story of who he was, was also changing. David’s account illustrates how “the subject is always vulnerable to the possibility that the terms of its conferred existence might be disrupted by the withholding of recognition, or some kind of sudden break in the certainty of belonging (Davies et al., 2001, 2002)” (Davies et al., 2006, p.96). David’s friends and peers, in taking up ideas about what it meant to have an impairment on the terms of disabling discourses, namely to be constructed as “spastic” and “retard”, were no longer ‘recognising’ David as one of them. They had a new story of David as not having belonging with them. Moreover, the speed of occurrence and force by which David was exposed to the knowledge that he ‘was’ a “spastic” and “retard”, was especially positioning for him. Unfortunately, David had no alternative discursive understanding by which to resist the group’s meaning-making of him, even if only a silent protest in his own thinking. David’s only possible defense, that he knew at that point in time, was his parents’ construction of him that there was “nothing wrong” with him but when he voiced this

understanding that “no way” was he “a spastic”, they called him “a liar” and “hit him to the ground”. At that moment, David’s parents’ discourse, which constructed David in non-disablist ways, was subjugated and silenced. The dominant discursive understanding of David was no longer that he was valued, instead he was ‘other’.

In re-telling his story, David was aware of the subjectification process that had occurred in the playground that day, the labeling of him as “spastic” and “retard” which he then took up, owned and reproduced as a subjectivity (Davies et al., 2006). He referred to the experience as a “gateway... my birth into this new world of dual identity and disability”. David now had a sense of who he was according to two very different discourses, firstly, his parents wishing to position him in the presence of health, as someone who had “nothing wrong with him”, and secondly, his peers taking up a construction that positioned him in the absence of health, physical and mental, as someone who was “a spastic”. The impact of this discursive conflict on David was that he became confused and unsure as to which position call he should take up:

I'd get confused 'cos my parents were telling me you know, you've just got a co-ordination problem, there's nothing wrong with you, and yet at school they were calling me mental, retard, spastic and cripple, and so I became really confused about what was the truth.

Despite the competing subject positions, the ‘truth’ of medical discourse dominated. David said he was shifted from someone who felt “valuable” and “likeable” to somebody who was “ugly”, “abhorrent”, “disgusting” and “disdained”. In discussing this shift, David identified three contextual changes that he thought contributed to

him becoming increasingly positioned as a person who was different from and less acceptable than his peers. He identified these as the introduction in class of testing and grading; an increasingly competitive environment in the classroom and on the sports field; and being eligible for special needs or specialist disability services.

Achievement within the domains of the classroom and sport are key indicators of success within the majority of New Zealand schools. David's athletic and academic performances were well beyond the margins of what was considered normal and acceptable. For example, he said that by the age of ten, "exams came into the system and I started to get 9-10%... and the teachers became to speculate that I was retarded". Later, at secondary school, David's peers were no longer running the cross-country race at his pace, as they did in his early years of schooling when they all finished the race as a group so as to accommodate David's capability. Instead, David said "it was so competitive and nasty and cut throat that everyone's gone home and they're pulling down the track and I'm still running the fucking thing". The practice of competition, where each child is constructed in comparison with and measured against another, had significant effects for David. Not only was David clearly positioned to fail in comparison to all the other runners but it appeared there was no recognition of his effort in participating either. David re-iterated how different this was from his primary school years when completion was what mattered most. To emphasize this point, David told the story of how when he first went to school he participated in swimming races by doing "the whole length pulling myself along the railing and see if I could beat them. I never could but I could reach the other end and they would celebrate [and] I would celebrate by being at the end with them". Here,

David highlighted his enjoyment at being able to celebrate his successful reaching the other end of the pool. The story presents how both persons ‘with’ and ‘without’ impairment can participate alongside one another, respecting each other’s differences. David is not depicted as a failure or someone who does not belong. He succeeded on the terms by which he could compete, that is, pulling himself along the railing. However, such opportunities for participation and inclusion became rarer for David as he progressed through his schooling. Segregation occurred once David received additional tutoring. He noted “the more support I got from disability resource, the more my friends hated me”. David said his friends questioned why he needed disability resource support when previously they had helped him in the classroom. Hence, his position as ‘other’ was also a reproduction of special needs discourse.

Being excluded was a common experience for David during his teenage years, which was well captured in the number of stories he told that showed how he had clearly been discriminated against because he had an impairment. For example, David said prior to ten years of age he and his friends would play around the swimming pool, often pushing each other in and laughing when they did that to each other. However, at a friend’s eleventh birthday party, the boy whose birthday it was pushed David into the pool but this action was not responded to in the way it would usually have been with everyone laughing about it. Instead, the boy was reprimanded and sent him to his room for “push[ing] that handicapped boy in the pool”. This particular incident positioned David as not being like the boy’s other friends, with consequential effects on David’s friendships from there on. He said, the party was:

One of my last birthday parties I ever went to... my friends one by one deserted me... it was like a virus... and what really made me distraught, is it took just two years for the conversion to be complete and I'd basically lost most of my friends.

David's image of the virus is apt because his friends had become infected with ideas about David being "a spastic" and "not belonging" with them. These ideas effectively prohibited the possibility of David continuing activities together with them and the sense of "connection" with his friends that he had grown up with. David's life became dominated by experiences of exclusion. On another occasion, David spoke of how his younger cousin had referred to him as "eating like a pig" and to David's shock his aunt did not correct her son by saying David did not eat like a pig. Instead, she said David "could not help it". In saying this, David's aunt may have been attempting to be supportive of David, implying that his impairment precluded him from needing to submit to the same standard of table manners as other children. However, David did not interpret the comment as supportive. He "thought 'what! I can't help eating like a pig? (laughter), you bitch! (laughter). I expected her to say 'no he doesn't eat like a pig', you know, to validate me... the way I act and that sort of thing". In his response, David was positioning himself as the same as his cousins – they did not eat like a pig and neither did he – as in the narrative fostered by his parents, namely that he had "nothing wrong with him."

When people treated David on the basis that he did have something wrong with him, that he was not like other people, then the understandings David had of himself were in dispute. People could potentially be well meaning toward David but if they offered position calls that invited him into a subject position of being different and

less than other people, then it was an assault on his narrative of only having a “co-ordination problem” and some “wobbles.” One case in point, was when David was twelve years of age. His form teacher, whom David introduced as a “magnanimous” and “kindly” man, attempted to explain about David’s impairment to the class but it only served to emphasize David’s difference:

I remember one morning, my teacher, out of compassion, he said “now I want to share some ideas about David. David can you come up?” He starts off, he said, “I want you to know that David is a spastic”. He said it with good intentions, but I ran out of the room. I was so hurt and humiliated. I ran out of the room to my reader person who taught me to read and I cried and cried and cried. Now, he was trying to educate the kids but I mean the word “spastic” was like a staple gun in my heart, it was a punchy kind of word, punchy.

David’s hurt and humiliation related to how he had been positioned. Nobody else was called to the front of the class, with their point of difference being explained by the teacher, only David. All other children, irrespective of ethnicity, gender, size, age or ability were positioned as ‘the norm’, whereas David was positioned as ‘outside the norm’, his impairment needing to be explained. When this happened, school was not safe for David, and he experienced this event as if he had been shot through his heart by a staple-gun. David also spoke of another experience at school when a teacher’s words positioned him as being different. He remembered the teacher saying “this is a psychiatric thing David, your body’s... it’s a psychiatric thing, you might have to go to a mental ward”. In reflecting on this experience, David said “I was told that when I was ten and a half! Imagine my fucking horror leading to terror, I was terrorised and the thought of an institution would send me stiff!” “Horror” and “terror” are strong words. They illustrate how much fear David felt about the

prospect of having to live in an institution but perhaps the ultimate act of exclusion perpetrated against David was when a slightly older boy said to him “you should have been aborted”. The idea being privileged in this statement is that people with impairments are not entitled to life. It is this very eugenic notion that disability rights’ campaigners have advocated against, especially in regard to the detection and termination of human fetuses with birth defects (Rock, 1996). Unfortunately, only later in his life was David introduced to disability rights. At the time this childhood event occurred, David had no alternative discursive understanding about the value of his life, which would position him and others supporting him to advocate against the abortion of disabled people.

Of course, it is hard not to imagine David’s parents challenging abortion on the grounds of impairment, but their denial to David of his impairment meant David had no terms by which to make sense of his differences. All he knew was that his life had irrevocably changed and it was a very painful experience. He said,

I mean, as a ten-year-old boy I didn’t even know what was going on...all I knew was that my heart in my chest would ache. I remember having these real chest aches, heart aches, physical aches because everything seemed to be being ripped apart and I couldn’t...when I felt it, it was like a ripping apart of my citizenship, my identity, of how I had found myself, I mean, I’d found in myself, and now as I was growing and building a skyscraper of identity, now it was the... the foundation was being ripped apart and it was like ‘fuck’!, I had no idea’.

David’s words were that he had “*no idea*”. Indeed, he had no subject position available that would enable him to story people’s actions toward him as prejudicial

and discriminatory, and in the absence of such a position he was blaming himself for other people's negative responses to him. He said he kept "coming back to blaming my character, I always came back to that, 'oh you're a bad... it must be because you're evil, or it must be because you're nasty, or it must be because they can see that you're sinister or selfish". These ideas remained with David for many years, for which he went to psychotherapy as means of "weeding the weeds out of my character". And even many years later, David was still unsure as to why he was so ostracised during his teenage years. He said "as intelligent as I am, and as articulate...I don't know [why there could not have been] a continuation of what I had at ten?"

The effect on David of continually being excluded and positioned as different from others during his teenage years, was that he stopped taking up subject positions in which his contribution was legitimate and valued. Rather, he developed a practice of giving up competing, thereby accentuating his experience of exclusion:

I struggled at school... I didn't have any typewriters so I struggled through school and I would just turn up and listen.. and after a while to be honest with you, I was too frightened to compete, it was like I started to self-exclude you know what I mean, I started to think I don't want to compete, what if I fail, if I fail then I am a retard. You know like I started to self-exclude... do things like that.

Hence, the boy who pulled himself along the rail so as to "try and beat them" became the boy who did not compete because he was frightened of failing. Failing, fear of failing, no longer trying to compete, and losing his friends, became the new narrative in David's life, which was very different from the earlier story-line of having friends,

doing activities with his friends, and being helped by his friends. David had been treated as different from other people and so he took up that subject position of being different. He became aware of how he “had different social experiences... different public reactions [and] had lots of uneasiness around [him]”; and subsequently concluded he had a “mental problem”.

Teenage Years: The subjectivity of “rebel”

In being subjected to a psychiatric construction of his life, David said he began to act in the image of someone who was “mental”:

I started to swear a lot more and I remember writing ‘fuck you’ and passing it to someone and the teacher got it and he read it and I got on detention. So the only two words, you know if it was three words I wouldn’t have had enough coordination to write it, but the only two words I write and he has to find it. You’re suspended, not suspended, you’re detention. It’s interesting, I use the word ‘fuck’ at 10 and I used it because I felt disdained and I grew to feel disgusted about myself. It was like a stain and I still didn’t really get it. I thought they were angry at me because I had a fault in my character. I still didn’t really identify with my impairment at that time and because I didn’t, I got the message that they were doing this because they found something faulty in my character.

Marginalised by his friends, failing at school and believing he had something faulty with his character, David began engaging with others who were also disdained. He said:

The only friends that I maintained were the rebels, the trouble makers, the ones that were outside of the rules. I started doing really rebellious stuff, you know and that would serve me and my need to belong but at the same time they were calling me mental...

*oh look he's mental 'cos he's broken a window or he's doing this
or...*

David was disobeying the rules, which furthered his construction of being outside dominant social norms. First, he was the “spastic” boy, then he was the boy with psychiatric problems, the “mad” child, and now he had become the ‘bad’ student. However, in taking up the subject position of ““rebel”, David was positioned in the presence of the ““rebel” discursive expectation, which did provide some new narrative opportunities for him:

I was suspended from this private school, big scandal, you know. And it was all about being creative and it was all about using your imagination. I mean we would build elaborate labyrinths in the out-of-bounds bush. It was about using your imagination, it was about expressing anger.

According to this account, David was able to succeed as a “rebel”. He could get into trouble well, he could be imaginative in his rule breaking and he could perform anger well. Davies et al. (2002) drawing on Butler’s (1997, p.45-46) theory of subjection, have noted that,

Where one might expect submission to consist in a yielding to an externally imposed dominant order, and to be marked by a loss of control and mastery, it is paradoxically marked by mastery itself; the lived simultaneity of submission as mastery, and mastery as submission, is the condition of possibility for the subject itself.

(p.168)

By both submitting to and mastering the practice of rebellion, David enacted a subject position that created a new possibility for him. For the first time since the playground incident where he had been called disablist names and hit by his peers, David was

able to take up a position where he had an agency in his position of marginalisation for he had a place of inclusion within the “rebel” group. Davies et al. (2000, p.26) have referred to this as the “dual nature of subjection” where,

The speaking/writing subject can go beyond the intentions of powerful others and beyond the meanings of the discourses through which they are subjected while necessarily and at the same time being dependent on their successful subjection for becoming someone who can speak/write meaningfully and convincingly beyond the terms of their subjection.

(Davies et al., 2000, p.26)

The many interactions that produced David as the marginalised, excluded subject meant he was no longer able to occupy the subject position of being valued, connected and liked within the discursive practice that subjected him as a “spastic”. However, in being subjected to this position of ‘other’, David spoke and acted in ways that went beyond the terms of that subjection. His new subject position of the marginalised rebel made it possible for him to own, resist and critique the discourse that produced him as “other.” As such, he said,

In my teens when I started to get angry you know what they'd say. Oh you're angry 'cos you're a spastic, you know. So then it flipped around, oh you're angry 'cos of your impairment, oh you're angry 'cos you were born that way, oh you're angry 'cos you can't deal with your wobbles. And I'd say I'm not angry, I'm angry because you're a pack of fuckers.

David refused the invitation to view his anger as a sign that he had not coped with his impairment, preferring to understand it as his response to how he has been treated. David’s opposition to people’s interpretation and assessment of him continued the

new narrative of him being a “rebel”, a story-line which gave him a position by which to confront others. Such confrontation, though, only continued to invite David to be more subjected to the gaze of psychiatric discourse. By the age of twenty one he had been assessed as having a psychiatric diagnosis, which only confirmed the story for him that he was “‘mental’”:

Imagine how horrified I was finding out that I had regular depressions and they called it bi-polar 2 and they reckon that it's 'cos I've had some hard times you know. But imagine my horror because I've grown up with people calling me mental. So imagine that.

The construction of having a mental illness furthered David’s sense of disparity between the early years of his life before he was ten years old and how his life changed after this age. He said, “when I was a kid it was all ever-fresh and a wonderful environment and then it became just smelly, stinky and dark”. David’s images of “smelly, stinky and dark” captured how the deficit constructions of him as a spastic, mental, retard and cripple became the reality of who he was and how he experienced life. For example, despite never having been formally assessed as having an intellectual impairment or having ever been referred to live in a group home for people with intellectual impairment, when David left school he “volunteered to live in an IHC home for four months”.

Teenage Years: Practices of “finding comfort” and “connection”

For David, the discrimination and marginalisation he experienced after the age of ten had led him to feel like “a foreigner in my home land, a refugee, an outcast, a scapegoat”. He said, “the thought of going to school each morning after thirteen was quite scary, horrific, really uncomfortable”. However, his teenage journey with

sexuality became a comfort for him in the loneliness and fear of experiencing such exclusion. He said:

I did feel very traumatised and very discomforted and it was the start of my looking for comfort and issues around sexuality. It started after being so uncomfortable up until thirteen, from ten to thirteen, then when I found fourteen, sexuality was my comfort and I started to explore my sexuality to comfort myself. I remember waiting for the bus and women would walk down the street and I noticed that their breasts, that they would bounce when they walked down the street past my bus stop and I kind of liked looking at their breasts and it gave me some kind of enjoyment, some kind of comfort every time I looked at their breasts. And at the time as I was in such discomfort and then when I noticed that they had bras on, so I became fascinated with bras, so I'd see on the clothesline... you know... bras and I'd say wow! So I wanted to touch the bra... you know... I used to think the bra was silky and soft, so there's a softness against my skin and I'd put it against my cheek and it would feel soft, the silk of the bra and so here, I felt comfort and then I remember my brother had a room which I loved poking into and because he had all this illicit stuff around. He had this book called the "Little Red Schoolbook" and I was going through it and I got up to this page and I remember not seeing this word before, it was called 'masturbation'. It was very practical... that was my first masturbation session in my brother's room, reading this fucking' Little Red Schoolbook' and then I thought, 'my god! that pleasure is so great, it's a bit like the silk of the bra – it's soft and pleasurable'...you know... so that was my journey into comfort again... and I found myself when I hurt, masturbating a lot...so it was the way I comforted myself...

From David's account, sexual experiences became his first means by which he was able make a difference for himself when he felt in emotional pain due to the stigmatising subject positions he was constantly being called into.

By the time David was eighteen he had not been able to "follow in his brother's footsteps and have a girlfriend". He began to see women sex workers, which continued the narrative of sexual pleasure providing him with comfort. David said he tended to see one sex worker once a week for three years:

I was kind of honest enough about connection, making a connection, so sometimes we would cuddle and talk... a lot of times we would cuddle and talk and talk about our dreams and there was a lot of, you know, just feeling connected and so it wasn't just having an orgasm. I mean, that was part of it, but it was more about feeling connected again, and feeling comforted, and feeling cherished, and kind of warm, and feeling her breasts on my chest, that kind of thing.

Seeing a sex worker enabled David to re-experience connection again, a practice he had enjoyed prior to the age of ten and not dissimilar to him becoming part of the rebel group at school. As a result, David was able to reproduce the social experiences from his earlier years, namely inclusion, connection, comfort and creativity. Through the experience of seeing sex workers, David's confidence in his sexuality and relating to women grew. He said:

Well I noticed that up until [18 years of age] when I was with a woman I was very anxious and uptight and nervous but when I started exploring myself with escorts, even though there were rules, even though it was one hour and I was paying for it... so I didn't become disillusioned, I noticed that then in my day to day life I became more comfortable with women. I didn't get so nervous or anxious in their

presence. I could sit with a woman and kind of just get to know them as people.

David said he met his first girlfriend at twenty-one years of age. In this occurring some years after his brother entered into a relationship with a girl, David concluded that his pathway to sex and relationships was very different for him compared with his brother's journey with relationships. The subject positions available to David in respect to being involved in boyfriend-girlfriend relationships were limited by the power relations present within dominant disabling discourses, in which David experienced "much social uneasiness around [him]" and being told "you don't belong with us." On the terms of dominant teenage discourses, David was not constructed as an acceptable friend, much less as a boyfriend. However, discourse theory would suggest other subject positions would have been available for David to take up that did not position him so unfavourably. The "subject who could eclipse the conditions of its own emergence; [who] eclipses power with power... the subject emerges both as the effect of a prior power and as the condition of possibility for a radically conditioned form of agency (Butler, 1997, p. 14)" (Davies et al., 2000, pp. 206-207). The discursive conditions of David's sexual emergence were in respect of his construction as a "spastic", "retard" and so forth but he eclipsed these conditions even in being constrained by the subject position of being constructed as "other". David's experiences of exclusion did not preclude him from looking at women's breasts, touching bras, masturbating and seeing sex workers, which for the most part sit outside monogamous relationship discourse. However, in taking up sexual practices on the fringe of monogamous relationship discourse, David found a place by which to resist those position calls that constructed him as 'other'. In other words, subject

positions within monogamous relationship discourse were not available to David but in enacting alternative sexual practices, David was able to challenge the prior power of those discourses that had originally marginalised him as ‘other’.

Challenging the power of those discourses that constructed him as ‘other’ was something of an unfolding story in David’s life from his mid teenage years onward. There were a number of critical moments in which David took up agency which tended to have an accumulative effect of enabling him to refuse those position calls that constructed him as ‘other’. For example, David said that his mother would say to him, “David, the right woman will come along for you, the right woman will come along, she might not have two good legs or two good arms but the right woman will come along”. David said he loved the first part of the statement, ““the right woman will come along” but said he hated the second half of the statement “she might not have two good legs or two good arms, but she’ll come along”. In recounting this story, David said, “I hated that [second] side of the sentence, so I always cut her off [but] the first half of the sentence had so much promise to it... (laughter)”. David had not verbalised his refusal of the position call but in terms of his own meaning-making he resisted the idea that his partner might have to be disabled like him. In taking up this position, David was calling on ideas of disability rights discourse. He was asserting his right to not be prejudiced against because of his impairment and therefore be entitled to have a ‘non-disabled’ partner, but in taking up this position he also legitimised the practice of discrimination against disabled people; in effect, refusing himself as a disabled person. David has been constructed by medical discourse to desire a non-disabled partner, but in accepting this position call he is

participating in the very same disabling practice he is taking exception to. At the same time as being subjected by medical discourse, David is taking up disability rights discourse in refusing to be positioned by medical discourse as not eligible for a non-disabled partner on account of him having an impairment. In this example, medical and disability rights discourse are not clear compartmentalised separate practices, but co-exist and contradict each other within David's one response of refusing to accept his mother's statement that his partner "might not have two good legs or two good arms".

On other occasions, when David refused a deficit subject position, the position calls were less discursively complex. When David's cousin said he ate like a pig, as recounted earlier in this chapter, David expected his aunt to say "no he doesn't eat like a pig" but when she didn't, David said, "I thought, 'no I'm not going to accept that!'...(laughter)...". On other occasions, David resisted the position calls created by people who reproduced medical ideas and practices:

My mother had a friend whose son was training to be a physiotherapist and her son said "bring Dave down and we'll just work with him a little". And it was the first time I'd been involved with medical stuff since I was born you know.... And so I went down and he evaluated me and then they checked my balance and I was thirteen... they gave me an expectation list at the end of the evaluation and they said one thing, "given your balance don't try to ride a bike you know because it's just too dangerous." And I said "well, what am I going to do?" And they said "well, you can bus." I said "no, what am I gonna do with the bike outside 'cos I just rode here from school!" (laughter) Yeah it was another realisation actually that what medical people say is not entirely what will happen.

In addition, when David was a teenager overseas with his family, he had some experiences that contradicted and challenged the way he had been positioned in New Zealand. For example, one year when he was with his mother in Malaysia he received a very different response to his eating than he was used to; rather than his eating style being likened to how a pig ate, he was celebrated because his “messy eating” brought “great honour to the cook”. After the cook had hugged David because of the honour David had brought him, David said he began to realise that

what I was experiencing at school wasn't the absolute truth and so I had many experiences such as that when I travelled around the world that... I started to get an inclination that what was happening at school was not the absolute truth of the matter... I started to realise that other cultures had different ways of looking at me and that no one way was correct, that it was all independent of me, it wasn't me, it wasn't my fault.

The more David had experiences in which he was positioned very differently from how he had been positioned at school, the more David was able to refuse the ‘truth’ of those discourses that positioned him as ‘other’. A few months after the encounter with the cook in Malaysia, David had another very significant agency-producing interaction. He said:

One day I was in town and Dad was doing business and I was getting a little bored and I was only about fifteen. He said “well look, go to the arcade but before you do take my briefcase down to the car”. So I took Dad's... I had his briefcase like this, and I walked down, and as you do when you're a kid you never go straight to the car. I looked in some of the shops you know, and I've got this briefcase and I noticed the shopkeeper would come right up to me and say “excuse me sir can I help you, would you like to buy something?” And up until then they

would say quite the opposite you know, they'd think I was dumb and it took me a while to figure out, it was this god-damn briefcase! And what I figured out was they thought well there are... in there, intelligent papers, so he can't be too retarded if he's got intelligent papers in his briefcase, he must be a businessman. And here again another key moment like the cook, it changed my thinking about hey, it's not me, it's their interpretation it's their perception and not more than that, much less than that, it's over a bloody fucking briefcase which is \$11.50 in the shops. For \$11.50 I can change my whole sociological world for \$11.50.... so when I came to university I came with briefcase. I came with a god-damn briefcase and I would, even if I just had my lunch I would stick my fucking lunch in there and nothing else. And I did that right up till I was 26, I'd carry a fucking briefcase everywhere! That's the god-damn truth!

The briefcase became a concrete metaphor for David taking up the new idea “hey, it’s not me, it’s their interpretation, it’s their perception and not more than that”. By holding a briefcase in hand, David was no longer ‘other’. In carrying a briefcase David was taking up another narrative for his life, of being successful and confident. He was returning to the kind of subject positions that his parents had first introduced him to when they said there was “nothing wrong with him”, except that he first had to endure and negotiate past those discourses that constructed him as very much having something wrong with him. Constructed as ‘other’ by dominant discourse, David was positioned to engage with those also in the margins, such as the rebellious group at school and sex workers. By taking up these subject positions within “beyond the margins” discourses, David was able to refuse those position calls that constructed him as ‘other’ on account of his impairment.

During the years that David met with a woman sex worker, his relationship to the word “spastic” changed for him. Prior to this time he hated the word “spastic”, as he said it felt like a staple gun in his heart but when the woman he had sex with called him “spastic” during love making, his relationship to the word changed:

It took the power out of the language and I felt OK. It was okay to call me spastic when we were making love. I would sometimes hope that she would do that because I started feeling that that was OK. I was curious, actually wanting to connect with that word... like intercourse is about the ultimate connection maybe so like before say 16, 15, it would flare me up with anger, if I heard the word spastic, I'd kick a wall in, or I was really angry about that word...angered the fuck out of me but by the beginning of 21, someone would say 'oh you silly spastic' and it was kind of...it was kind of...I don't know if I ever liked it, but it was neutral, I didn't have any anger about it.

David had undertaken what Butler (1997) has referred to as “embracing the injurious term [because] it constitutes [him] socially [and] only by occupying – being occupied by – that injurious term can [he] resist and oppose it, recasting the power that constitutes [him] as the power [he] opposes” (p.104). David had taken up a social model understanding of himself, in which pejorative disablist labels are not rejected but inverted and purposely taken up as an identity marker of minority group pride (Crow, 1996). Once introduced to the idea that he could be a “spastic” but not be positioned detrimentally by that word but rather have it as defining feature of his point of difference, David began to use the word as a motivating force in his life. For example, he said:

I remember doing weight training...I was big on weight training and I remember pushing a bench-press, saying 'get that up you fucker get it up'...you know what I mean? Because if you don't push that weight

and you don't burn it... it would get me angry to push the weights... 'push that weight you big bad spastic mother fucker'... (laughter)... it would wind me up to push that weight, you know... [I was] a spastic with attitude! And... and that attitude was rebellion... I kind of owned the label now... it didn't own me, I owned it!

David re-positioned himself in relation to the word spastic. It no longer held meaning for him as someone who “did not belong”. Instead, he used his re-description of the word to represent and tell the story of how he had rebelled against those practices which positioned him in deficit. He had, to use Davies’ (1991, p. 51) definition of agency, developed “a sense of oneself as one who can go beyond the given meanings in any one discourse, and forge something new... captur[ing] a shift in consciousness that is beginning to occur, or through imagining not what *is*, but what *might be*” (emphasis in text).

Later years: The new narrative of empowered and aware

David’s twenties became a period where he shifted from his father’s mentoring of him into business, to his taking up a subject position within the disability movement where he engaged in disability advocacy work. He explained how an experience initiated and changed his thinking about what he wanted for his life:

I started to read books on perception and I left the business and it broke my Dad's heart. I was importing stuff. It was the late 80s and it was the thing to do, it was importing clock radios with TVs in them. We were quite wealthy and I was quite wealthy and I wanted to be a millionaire before I was 30. My Dad had financial goals for me. And I got this import into the harbour... and I got an order from a guy out at South Auckland. I got the TV and put it in the back of the van and got

out there and it was this guy with an intellectual disability and I went down this metal driveway and the place was really run down and really shabby. He said, “would you set it up in my bedroom”, and I said, “sure.” And I went in and the carpet was threadbare and it changed my thinking because I went away wanting to, wanting a better world for that guy. And that was the beginning of me getting involved with disability issues.

In this story, David is not positioned ‘in deficit’ but rather he takes up a subject position of assisting those who are positioned in disadvantageous ways. He was taking up the subject position of what Weingarten (2003, pp. 18-19) has termed the “compassionate witness”, a person who chooses to engage with another’s experience which in turn makes a positive difference. Weingarten (2000, 2003) named four witness positions: empowered and aware, empowered but unaware, disempowered but aware, disempowered and unaware. At the moment that David thought to himself that he “want[ed] a better world for that guy” he was shifting to the empowered and aware position. He recognised how the person was positioned in disadvantage and his response was to try and make a difference for him and people like him. As the boy who had previously been bullied in the playground, David had experienced the disempowered and unaware position. Later, he became the rebellious boy who called those who judged him “a bunch of fuckers”, which was more the disempowered but aware position. Now, David was taking up the preferential position, that of the empowered and aware witness, responding with compassion to others, aware of his own favourable positioning.

In taking up the empowered and aware witness position, perhaps David was engaging and reproducing his own parents' legacy for him. They had been compassionate, empowered and aware witnesses to his experiences of disablement. David's mother well knew the disadvantageous position of being institutionalised as a disabled person and she chose to protect her son from any such experiences. David's father had groomed him to experience financial success. Perhaps he even deliberately gave his briefcase to his son to carry, hoping that it would create positive social reactions for him from other people, as something of an antidote to the stigma and bullying he was experiencing at school during that time. His mother, perhaps deliberately, chose to take David to a restaurant in Malaysia where she knew the response to David's "messy eating" would be positive and in so doing challenge the way he had been told he "ate like a pig" by his cousins. Without asking David's parents, it is not possible to determine the extent to which David's parents sought to create these agency-producing experiences for him. Regardless, on Weingarten's (2000, 2003) terms, David's parents were empowered and aware of how David was positioned in deficit because of his impairment. They had always refused to respond to him in ways that conceded to any discursive practice that positioned David to experience disadvantage. They offered him two discourses. First, a non-medical discursive understanding that constructed him as only having "a co-ordination problem" and "having nothing wrong with him". Second, a business discourse, having the opportunity of being "wealthy", with the respective options and possibilities that can occur through having money. Neither discourse offered David the subject position of being a disabled person making a difference for other disabled people, a career involved in disability

politics, theory, rights and advocacy. However, this is precisely the discursive practice David went on to take up.

The disability rights advocate was a subject position that produced David as empowered and aware, no longer positioned in deficit. In many respects, this subjectivity of making a difference for other disabled people, was the legacy of confidence and success David's parents might have endeavoured to offer him, but their discursive construction was very different than which he went on to take up. By taking up disability rights ideas and practices, David was able to critique those discourses that positioned him, and others with impairments, in deficit. He was finally able to make sense of and dispute disablist discrimination.

David's accounts are told from the perspective of someone who has come to understand how having an impairment positions a person to experience discrimination. He became knowledgeable of what supported him to experience subject positions of privilege versus disadvantage. For example, the experience of a relationship altered David's social experiences so there was less "uneasiness" around him. He said:

Well people started to kind of... it was interesting, people started to see how connected and accepted I was with [girlfriend] and so that would give them a prompting to accept me...so relationship made me more acceptable in the community, they'd say, 'well if this girl, this non disabled girl, is living with me and loving me, then this guy must be okay'... 'you're okay, I'm okay, because you're okay with this girl'...so it made me kind of more connected to the community again... [The relationship] allowed me to go into circles and networks that I

normally was secluded from and I mean...I didn't consciously say 'yippee, she's my gateway to inclusion'...it was just...I loved her and as a result, as a natural extension of that I was involved with her family, her whanau³, her networks, they got to know me, they liked me and it blossomed...

However, the privileged position within discourse was not always available to David just because he was in a relationship. He did, however, learn to recognise when he was being constituted by ableism. For example, he said:

[my girlfriend] was Maori... and I remember this story... together we walked into a... café and there was a table right in front of us with two mature women there and the one mature woman looked at us and then quickly looked away, but then talked to the other one and said "don't look, but two...two people just walked in and...he must be from an institution and she must be his caregiver because she's a Maori girl and you don't see Maoris in this town and he's kind of crippled and he must be...here with his caregiver and that's her"...so we...there was racism, ableism, biculturalism... we had all this fucking coming at us, disableism...just from walking into a café and so...it kind of just summed up that sometimes the reality was too truthful for people's stereotypes, so they would make out that she was the caregiver and I was the cripple.

David's analysis shows how he has taken up the theorising of marginalisation processes, which equipped him to resist those very practices.

³ Whānau = Family in Māori

Later years: The interplay of different storylines

David's account is a powerful illustration of how discursive ideas and practices, as mediated by language, produce subjective experience and power relations. For much of David's early life, the subject positions available to him are only those which positioned him pejoratively, but as testimony to Foucault's thesis, alternative subject positions and storylines are also available for David. As David takes up the idea that how people treated him was just an interpretation, he is more and more able to refuse those discursive position calls which disability rights' discourse produced him to not like. Disability theorising becomes the meaning-making lens by which David gave an account of his life to me.

The teenage storyline of "not belonging" and concluding there was "something wrong with my character" was still an active narrative for David, as evidenced by him continuing to seek psychotherapy as a means to "weed out the weeds in my character". The purpose of this David said, was to restore his life to that of his childhood years, when he felt "valued" and 'liked'. These early narratives remained as something of an enigma for David, indicated by when he said "why could that have not continued?" They served as a driving force for David to escape "the dark stain" of exclusion that he suffered during his teenage years. In time, a new narrative emerged, which was the negotiation of his parents' discursive legacy to him. His engagement with disability rights, politics and theory, made it possible for David to take up his life as the politicised subject who advocates for social change against disablism.

6

THE POLITICS OF DIFFERENCE: FAY AND JOHN SHAPE INTENTIONAL IDENTITY CLAIMS

This chapter explores how John and Fay made sense of their lives and their respective impairments, reflecting on the different discursive subject positions they had each taken up and lived out since having an impairment.

Fay and John take up medical and/or rehabilitation discourse

Fay and John did not experience impairment until adulthood; their accounts suggested that they had come to understand quite quickly what their impairment and/or illness was and what it would mean for their lives. Medical and rehabilitation discourses had constituted John and Fay to live their lives in very particular ways.

After becoming blind, John engaged in the process of rehabilitation. The culture and practice of rehabilitation for persons with vision impairment provided him with a social environment, training, equipment, technology and a guide dog so he could develop skills in managing and succeeding as a blind person. In speaking about his life as a blind person, John used phrases such as “develop as a blind person”, “it’s my lifestyle”, “it’s part of who I am”, “access and independence”, “being one of the crowd”, “walking alongside my blindness and not being led by it”, “accept[ing] it [blindness]”, “assimilat[ing] into other communities”. John’s language conveyed the ideals of what life, according to the norms of rehabilitation discourse, could, or even should, be like for a blind person. The values and agenda of rehabilitation, normalisation and SRV that underpin the policy and practice of rehabilitation in

RNZFB were evident in the words that John used in his account-making about his experiences since becoming blind.

Fay was diagnosed with rheumatoid arthritis (RA) as an adult. On the terms constructed by medical discourse, she was positioned to adhere to the advice and medication prescribed by the medical professionals involved in her treatment, in order to manage and minimise the effects of RA on her life. When Fay described RA, she used language that embodied the diagnostic treatment model of medicine, which emphasises the importance of lessening and managing the effects of the disease:

Having RA or being diagnosed with RA, what that means, it is a muscular skeletal disease and it affects the connective tissue that connects the muscle to the bone, and it affects your bones as well. Long term, if it's not treated properly or quickly enough, then you can get a reasonable amount of your body being out of control 'cos it's an auto immune disorder and once that happens, you get impaired function and the bones tend to sort of crumble away. Then there's impairment of movement and surgeries and things like that... so [it's about] manag[ing] the disease's progress medically, physically and emotionally so that you can maintain an optimal wellbeing.

In speaking about some of her understandings and experiences since having RA, Fay often appeared to select stories that illustrated how she had been managing the effects of RA on her medically, physically and emotionally. For example, in referring to the use of medication to manage RA's disease process, Fay said: "I've had it [RA] for about ten years and we've [Fay and the rheumatologist whom she consults] really struggled to try and get it under control". Fay also discussed her cognitive and

emotional management of RA. She spoke of “not buying into unwellness”. She said, “yes, I have patches of it [RA] where it’s not very nice but I have managed to get myself through those patches... it’s very rarely like that and I know that my thinking and attitude plays a big part in that”. In this conversation, Fay is performing the subject of medical discourse, who has achieved well according to the terms of the discourse.

Fay, since being diagnosed with RA, had taken up medical discourse and John, when blind, had taken up rehabilitation, normalisation and SRV discourses. However, neither Fay, nor John’s storying of experience was exclusively dominated by these discourses, for both had lived for over twenty years without having an impairment. Unlike David, John and Fay had not always been positioned beyond medical norms, which meant to a certain extent they were able to call on those pre-impairment non-medical discursive ideas and practices in the ways they made meaning of experiences, and acted subsequent to having an impairment.

Fay’s refusal of the illness subject position

Fay accepted a medical diagnosis of her body, in respect of what that indicated for her in anatomical terms. However, in regard to what having RA meant for her personally, Fay’s account portrayed her as resisting RA impacting on her sense of identity. She said:

There’s a lot of fatigue associated with it [RA] and a general sort of feeling of not firing on all four. I’m sort of one that doesn’t like to use the words ‘unwell’ or ‘sick’ because I don’t actually know what determines sickness for me. Sometimes I just think not firing on all four

cylinders or eight or twelve or whatever... if I was to use the word 'sickness' or 'feeling unwell' or feeling 'rotten' that sort of says to me that there's, that I'm actually sick and in my mind I'm not. I'm sort of not admitting to that.

Fay used the mechanical metaphor of “not firing on all four cylinders or eight or twelve” as a way of understanding her body that enabled her to take up a position against a deficit construction of sickness and illness. She actively shaped her identity by refusing the position call of illness because she did not want the physical impact of RA to prescribe who she was or how people related to her:

I think emotionally I would tend to sort of slide into that mentality of being sick and what comes with that sometimes is a dependence or sometimes people start treating you differently. Sometimes people even play on the fact that they're not well and for me it's very much not about that at all so I tend to have that way of thinking as opposed to falling into that sickness category.

Fay’s “way of thinking” was a refusal to “slide into” the disadvantage of being positioned in the absence of medical discourse’s wellness ideal. She called on a non-medical metaphor to re-position herself against the deficit subject position that occurs for people diagnosed with a progressive illness.

When asked what informed her resistance to “slid[ing] into the mentality of being sick”, Fay responded by talking about her reaction to being diagnosed with RA. She said:

I knew there was something in my mind seriously wrong because I couldn't account for the reason why my body was in the state that it was in, so to hear the diagnosis in one respect was a relief and I

started thinking, “good, what we can do about it?” so that I could get some relief.

Fay’s sense of “relief” and proactive stance of “good, what can we do about it” are subject positions that, arguably, are produced by medical discourse’s diagnostic treatment model. Medical practice involves making an assessment so as to be able provide effective treatment. Diagnosis of pathology is the first step to recovery within medicine. However, in addition to re-producing medical discourse in her proactive response to the diagnosis of RA, Fay’s reaction was also constructed by what she described as “a dominant story… a deep understanding of myself as not failing”. This narrative had begun in Fay’s childhood. She said “there were lots of times of fear and uncertainty and not knowing what was happening, and not knowing if the decision I was making was right, [but] I pursued it anyway… and it panned out that it was [right]”. Fay said that because of these childhood experiences, she “had [over the course of her life] been successful [and] then instinctively I drew upon those skills to get me through having RA”.

John’s identity claims of being “a hard nut” and “a bloke on the ground”

Like Fay, John’s pre-impairment narratives continued to shape how he understood his blindness and responded to becoming blind. In describing his growing-up years, John said “my life as a kid, it was bloody tough. I mean we never had a telephone, we never had a fridge… my parents were divorced when it wasn’t fancy to be divorced”. In describing himself during his growing-up years and as a young man, John said, “I was a hard nut”. When asked if, over twenty years later from living in a single-parent,

poor family, the sense of being “a hard nut” was still an active part of his life, John said:

I'm more than happy to look across the table and say “no” and I do:

“If we have to do it this way, let's talk through how we get to this point but this is where we need to be”...so it [being a hard nut] does come through. You know I'm happy to say ‘no’.

John told other stories that illustrated how his sense of himself as “a hard nut” continued to construct how he engaged in his work as a “blind professional”. For example, he said:

Some people will sit down and write, they're wordsmiths but no, that's not me. I say that to my boss all the time, “look I'm not a wordsmith”, and she says “yes, you will” and I say “no you won't!”. Over the last three years she's realised I ain't a wordsmith and so she doesn't ask me to write things anymore. For monthly reports, what she's done is set it up so it's a bloody table, so it's a template, and I just fill in the blanks!”

John’s story of himself of not being a “wordsmith” might, perhaps, have also been linked to his family and work background prior to his impairment. After he left school, John said he “caught fish [as in he worked as a fisherman for his living and] played rugby”. The working class discourse of the fishing industry, and the dominant male masculinity discourse of rugby, were likely to have supported his identity claim as “a hard nut”, as well as produced the idea John had of himself as “a bloke on the ground”. In another story John told, he profiled his sense of identity by defining who he was not: “I am not an academic, academics get right up my nose... academics navel gaze all day, they just sit writing on bits of paper and get doctorates for it.” In

contrast to being an academic, John positioned himself as the “blind professional”, who was “trying to make a difference... hav[ing] a crack at changing society” by getting on “the soapbox with a megaphone.” John’s work often involved him undertaking public speaking in his role of raising disability awareness. The metaphor of being “on the soapbox with a megaphone” invokes a kind of union protest image, a reproduction of working class discourse and respectively; John’s storying of himself as someone who was “part of the groundswell”. In making the identity claims of being the “the blind professional”, who was “having a crack at changing society”, and in so doing was prepared to challenge others by “look[ing] across the table and say[ing] ‘no’”, John told stories that positioned himself as knowledgeable and sometimes critical of rehabilitation and disability politics practices undertaken by others. For example, in referring to people naming ‘disability awareness training’ as “impact training”, he said: “Impact training, I mean how wanky is that!? Look, it’s awareness training and they talk about oppression of disabled people. I mean, hello, you’re only oppressed because you let yourself be oppressed to some degree.” In another illustration, John told the story of a rehabilitation instructor whom he thought had been overly sensitive to the feelings of the blind person he was training. In this story and others, John in his account-making, often appeared to be reproducing the ethic of working class discourse, such as being prepared to be direct and pragmatic in his approach with others. For example, in response to aspects of current blindness rehabilitation practice, John spoke of not being over-protective of people when they were rehabilitating. He said, “I often tell people, look, if a blind person wants a cigarette, put them at the other end of the house and they’ll find a cigarette lighter in the kitchen all right!”

In their accounts, John and Fay recognised how their pre-impairment narratives continued to shape how they storied themselves and acted after having an impairment and/or illness. In addition, they both spoke of stories which suggested that they had developed new narratives since having an impairment and/or illness.

Fay negotiates new body/self narratives

Rheumatoid arthritis (RA) impacted Fay's sense of identity. Fay spoke of "doing a lot of physical activity and work" prior to having RA. Her initial response, she said, to having RA, was "trying to continue on with my lifestyle and trying to maintain who Fay was [because] I wasn't ready to change my identity". However, RA meant it was not possible for Fay to continue with her physical lifestyle. Unless she could recover from RA, successfully taking up the restitution narrative (Frank, 1995), Fay was positioned by medical discourse to experience a sense of loss. Fay had engaged with psychological theories of loss as a means by which to understand her experience of having RA. She stated that she had "gone through the whole grief cycle" because she was unable to experience "normal" health. In her account of what it had been like for her in the "early days" of having RA, Fay highlighted how RA had changed the sense of control that she could have over her body. She said: "my body performs in certain ways that sometimes I have no control over [and] sometimes I think this body has a mind of its own". Fay had been unable to reproduce the norms of medical, body-aesthetic, sport and physical work discourses, as in "produc[ing] a body which is 'docile', that is one which can be subjected, used, transformed and improved (Foucault, 1977, p.136)" (Tremain, 2002, p.36).

In asking Fay what it was like for her to have a body that “sometimes she had no control over” and “sometimes...has a mind of its own”, Fay replied:

I don't fight it [now] like I may have in the beginning... you can't defy it [the impact of RA on her body] for too long. I've tried doing that, I've been there. I've tried pushing myself regardless, thinking that you can do it, do something that I want to do. I didn't want to be told what to do by this body of mine. I wanted to be the one to make the decision to that, you know, either I can't do this or I can't do that. I've sort of been through a lot of that sort of stuff... if I'm having a bad [body] day, I manage my activity in such a way that I don't have to do so much that day so I actually listen to my body and the way that it operates now and I know what I can get away with and what I can't so if I'm having a bad [body] day I may choose to take it easy for that day or for that few days then I know I'm going to come out of that and therefore I may be able to pick up the activity a little bit more or I might take on a little bit more in the next few days. I tend to be sort of tuned in physically to my body and my body tells me when I need to have a rest, things like that, and I need to go and take it...

In this account, Fay has storied a shift that occurred in the way she thought about and responded to her body. She had tried taking up the subject position that constructed a “docile” body but she realised that she could not “fight” against or “defy” her body (that has RA). As an alternative to disciplining and using her body, Fay took up a different subject position and began to “listen” to her body and the “way it operates”. Collaborating with her body was more helpful for Fay than fighting her body. In being “tuned in physically to [her] body and what [her] body was tell[ing] [her]”, Fay became aware of when she needed to rest and how she could manage the activities

she had planned to undertake during the day, when she was “having a bad [body] day”.

By actively choosing not to accept the position call to discipline her body, instead taking up the invitation to listen to her body, Fay was acting with agency. She understood the benefit to herself of taking up the “listen[ing] to her body” subject position, which produced the outcome of her continuing to achieve her goals, although perhaps within an extended time-frame. Although not stated definitively by Fay, there appeared to be an unspoken assumption or understanding by her, that fighting her body only increased the extent to which her body was out of control, thereby creating even less control for her in how and when she could undertake activities. She said, “there’s an acceptance of my limitations but it doesn’t stop me from still pursuing in my mind or having the determination and the courage and the perseverance to do what I need to do”. Fay has re-positioned herself in regard to how she relates to her body but she has not re-positioned herself in respect of achieving what she understands that she needs to do. She said, “I put a long term goal in place, and smaller goals along the way. so that I can actually obtain the larger goal as well”. In taking up behavioural psychology goal-setting discourse, with the “limitations” of having “a body” that “sometimes has a mind of its own”, Fay strengthened her identity claim as being someone who has “determination”, “courage” and “perseverance”.

In telling her story, Fay recalled that people had said to her “I can’t believe you’re so happy or you feel so joyful when you know, you’re telling me that your tests indicate

this and you've got this much activity in your body and you're struggling with fatigue". When asked how she might account for people's description of her as "happy" and "joyful", when she was "struggling" with the effects of RA, Fay replied: "It's actually a state of mind; I have to wake up every morning and consciously make a choice to be a certain way... to live my life the best you can for that day". In discussing with Fay what she had found "a struggle", she referred to a period prior to having RA, before her "twenties" she had been "too afraid to have an opinion". Fay said that having RA had been a helpful for her in changing from a person who thought she had "no rights" to someone who was able to "challenge her doctor", should she feel it important to do so. When asked what might have supported such a shift occurring from "being afraid to have an opinion" to being able to "challenge her doctor", Fay said:

I honestly don't know, all I can think of that makes sense is that I can remember going to church once and there was 'a word' spoken over me and I've always been reasonably skeptical about that sort of thing, I've tended to just shelf it until something gives me an indication that is true but there was a particular word spoken, it was actually taped for me, and I remember playing the tape when I got home. It was quite a long word but there was one piece that I think must have spoken into my spirit and it spoke about "daughter" as in my being God's daughter "arise form the ashes", and I remember repeating that and just repeating it over and over and over. I'm not too sure if that was the point or if other things were influencing me that 'I have the right as an individual', I don't really know, but that still stands out to me this day

At the time of attending "church" and having "a word spoken over [her]", Fay had been diagnosed with RA. The statement, "daughter... arise from the ashes" was a position call constructed by Christian spiritual/faith discourse, which involved an

understanding that “the word” was about Fay being “God’s daughter”, which was “spoken *into* [her] spirit” (emphasis mine). It was an invitation that called Fay into action: “arise from the ashes”. The ashes, Fay said, represented her struggle with “having no rights” and having “a body” that she “sometimes had no control over”. It was a subject position that produced personal change for Fay in how she viewed herself. She said:

As I was saying before, I think I've spiritually developed as I've grown as a person as certain situations have come along. I don't think it has been predominately RA that is the sum total of who I am now but I think it has given me more strength, determination to focus on what I want... everything becomes that much harder, including emotionally at times and it's like you need to find that extra strength and determination if you like to pull yourself through the tougher times... because I don't feel it (RA) is a destructive force in my life, I feel it is something that has happened to enhance my life.

In this account, Fay positioned herself to refuse dominant medical discourse’s construction of RA as a “destructive force” in her life. Instead, she re-frames the meaning for her of having RA, which is that it “happened to enhance [her] life”.

A third discursive change Fay engaged in after having RA, was how she came to re-position herself and take up a more feminist, less patriarchal discursive practice in regard to how she related to her husband and daughter. In recalling an incident within her family some years earlier, when RA had “first happened”. Fay said;

All I'm asking is that you help me in certain areas so how is this so difficult for you?”. I just could not see what the problem was for them. And of course it wasn't until we discussed it reasonably recently that [my daughter] said, “you know, I didn't really see it from your point of

view all I thought was from my point of view”, that she was forced if you like, in one respect, to be like the mother sometimes. She felt, you know, “mothers are supposed to do this and mothers are supposed to do that because ‘this’ mother always had. Now ‘this mother’ needed help to do the things she could do before so that meant [my daughter’s] role changed a little bit... so there were some changes there for her and for [my husband]... I think I had a problem in the beginning of being able to able to voice to him what was happening for me... it was the whole thing of having to come out and say (laughs).. “I can’t do this, I can’t do that” so it was this whole identity thing for me of having to say that I’m not the person that I was before.

Due to RA, Fay could no longer take up a presence within the discursive binary of what a mother and wife should be. Fay said this had been difficult “for a long time” but now the family “interact with each other; it’s more of an interdependence because I still like to feel that I’m independent as I can be but I don’t have much difficulty asking for assistance when I need it”. The construction of the idea and practice of “interdependence” enabled Fay to continue to be able to contribute to her family. She said, “[my husband] appreciates the support I do give him... I think he’s actually said to me, ‘You probably support me more than most wives would support their husbands.’”

Hence, even though Fay was initially positioned in deficit as a mother and wife because of the impact that RA was having on her physical capabilities, she did not continue to story herself in this way. She made an identity claim of having capability in offering “spiritual” and “emotional support” to her family.

John's multiple subjectivities

When first becoming blind, John continued to live in the town he had grown-up in, which John said he “found difficult because [he was] totally unusual and different: you were *the blind man*” (emphasis John’s). John said he then went on to become involved with the Royal New Zealand Foundation of the Blind (RNZFB), where he met other blind people and was no longer positioned as “unusual”, but was “just one of the crowd”. John said his experiences within the RNZFB enabled him to “walk alongside his blindness” and “accept” his blindness more than if he had continued to be “led by his blindness” as when he was the only blind person in the community. By participating in the blind community, John was much less positioned as “other.”

In describing what it meant for him to be blind, John used language that constructed blindness as an identity statement, which is consistent with how the social model positions people with impairments, as representative of and belonging to a minority group. For example, John talked about his blindness being “my lifestyle”; himself as “a professional blind man”; and undertaking his work as a blind consumer advocate in a way that “only another blind person would have been able to do”. However, John also described his blindness as “an impairment, yes, it’s a disability to some degree”; a definition which is similar to The World Health Organisation’s (WHO) construction of impairment as causing both a functional and sociological impact on the person. On these terms, blindness is not a cultural marker, but rather an aspect of one’s life. John captured this way of understanding his impairment, when he said “to a large extent blindness is just one of the currents that runs through my life.” At other times, John separated his identity from his blindness, saying “it’s the personality, it’s

not the blindness". For example, when snow skiing, John was functionally blind. He wore a bib that said "blind skier" but in comparison to when he took up the subject position of "the blind professional", when skiing John described himself not as "the blind skier" or even a skier who had a vision impairment, but as "just another skier". John told a story that illustrated how he was sometimes offered contrasting subject positions between being blind and sighted, depending on whether other people recognised him as being blind or not:

I've come off [ski-field] at the end of the day and we'd be standing in the public bar of the [name of town] Pub and somebody would be standing there and say 'oh did you see that blind skier up there today.' [I'd say] 'Oh yeah, I did actually!' ... They don't see me, they see the blind skier ... they don't realise I'm blind... I mean I'm just another skier as far as I'm concerned, just another skier up there. And I worked hard developing those skills as a skier because being blind is nothing. I mean being blind and been given all the assistance sure but at the end of the day it's me that's turning my feet... You know what I mean. It's me that's doing that and I enjoyed that, it's not being blind, that wasn't why I went skiing, 'cos I just loved it.

In giving this account, John is storying himself as someone for whom his blindness, while having a functional impact on the assistance he needed when skiing, was not a defining construction on how he viewed himself as a skier. As he said, he skied because he "just loved it".

Part of John's story was his passion for sport and outdoor activities, like snow skiing. In his account, John said he grew-up playing rugby, cricket and running marathons. John had a well-developed sportsman narrative before becoming blind. He continued

to claim this sports identity after becoming blind, by coaching basketball and playing goalball (a team sport designed for people with vision impairment). Blindness impacted what sports John could play, and how he accomplished an activity, such as having a guide when skiing, but it appeared that John's sense of identity as a sportsman was not contingent on him being blind, but constructed by his enjoyment of sport. John told stories that portrayed his love for sport. For example, he recalled an experience with a girls' basketball team that he was coaching:

I was coaching a girls' team... and we were one or two goals away from winning the national championships and I went out and said, there was a time-out or something, and I said "look girls, enjoy this now, enjoy it. This is the time now, this is where you really want to enjoy this, just get into it, live for the moment, this is the life, just really enjoy this next minute or two, this is the fun time, this is what we're here for". And I mean they just had a ball... Live the moment and remember it, savour it, but it's not the only moment.

In this account there is nothing to distinguish John as blind. In terms of John's identification of himself in his coaching role, he did not specifically position himself as a blind coach, as he did the "blind professional". He was perhaps drawing on his life experiences, some of which he might have gained as a blind person, as he encouraged the team to enjoy the chance of playing to win their championship.

In speaking about sport, John presented himself as someone who enjoyed competition. He said,

In sport, once I get the blood up... mate, the blood's up... the adrenalin's pumping mate, there's nothing, you know and I don't care, I just throw myself in front of a bus if I have to. That's the way it's always been. That's the gladiatorial sort of stuff, you know, the

old rugby player... always, always in sports, always been absolute death... I try to win. Yeah but I'm not a bad sportsman. You know I'm a, in terms of that ethical thing, I'm not a bad sports, I'm not, I mean I hate to lose, [I] refuse to give in but at the end of the day I'll be the first person who walks over and shakes somebody's hand and say "Well played," and have a beer. You know I'm the first one there at the end of it to say, "Look, let's give it death on the paddock," but at the end of it we're the ones who walk away and have a beer together... I've always been very sportsmanlike you know

The nouns, adjectives and metaphors that John used in describing himself as a sportsman, were replete with masculine constructs, such as “blood’s up”, “adrenalin’s pumping”, “gladiatorial.” On the sports field, John is constituted by sports competition discourse. He performs the uncompromising competitor who would also be a good sportsman should he lose. Arguably, these are iconic Kiwi images that all New Zealand children, especially boys, are subjected to and objectified by. John was successful in re-producing these New Zealand discursive ideals and so he took up the privileged subject position within the binary of competitive and good at sport/or not. Notably, John is a sportsman not a blind sportsman. He might be a blind man who plays sport but the way he engages in sport is not constituted by specific blind or disabled discursive practices but rather an acceptance and re-production of dominant masculinity as an identity claim (Pringle, 2003).

Often, such as when he was skiing or coaching basketball, John took up a subject position in which his ideals and values were broader than the story-lines that had developed since he became blind. For example, John identified himself as having a ‘hard work’ ethic. He said, “I’ve never been frightened of hard work... working hard

makes the day goes fast". In performing the subject who can work hard, John said he was "making a difference for others and that's the role I want to do":

At the same time in doing it [working hard], I'm actually earning money so that my kids can actually do things. I came from a home... when having single parent families was very, very unusual right, in the early 1960's it was a stigma, and I don't want my kids to go through that. And I also want to give them a chance. My son next year will be going to university and moving through. Now his generation would probably be the first part in my family that have achieved tertiary qualifications. And they've taken that for granted. There's never been a thought ever of their not going to university... [whereas] my Mum left school at 15 [and] my Aunty left school at 14.

In this story, John speaks of how he has created a different social experience for his children from what he or his family experienced. He portrays himself as a father who wants to give his children "a chance" to go to university. This claim contrasts with John's earlier derisive remarks about academia. These two story-lines sit alongside each other and John calls on them in relation to the discursive context he is speaking to. When speaking to me, a doctoral student, he positions himself as a subject who has been a disability activist for many years, the bloke-on-the-ground who doesn't waste his time "writing on bloody bits of paper." He positions himself as loyal to the activist cause. However, when he is speaking of his family, he positions himself as a responsible parent who has provided opportunities for his children. He said, "My children live a pretty privileged life. What I'm trying to do, is give them every advantage that they can possibly have. I provide to them the things that I never had: a settled home life".

John's subjectivities of "activist" and "parent" called him into taking up quite different subject positions. Both are constructed in co-existence with the discursive context he is both calling on and speaking to. Another identity claim, from activist and parent, that emerged in John's storytelling was that he could be "the bloke on the piss". For example:

I'm in a pub in [home-town] having a few beers at a bar, but I wasn't 'John, pillar of society', I was John back thirty years ago talking to people I'd known back then. It was interesting. I'm back home again. I can slip back into that, I was on the piss. I was very conscious of it, I was having a ball. It's like having a chance to step back and not be who I am you know... and you walk away and we had a great time. It was the night of the world cup final and we went from there to another pub, we thought this is a bit of us, there was some spunky bird singing good songs and playing, they had a guy playing, it was great, it was wonderful, we had a bloody good night and watched the World Cup final on the TV

In telling this story, John showed how in one social context, he can be "John, the pillar of society", that is, the blind professional who is actively making a difference, and in another discursive context, he can "slip back into" being the guy who is "on the piss". John said he was "very conscious" of the difference between the two ways he could be John. He accepted the discursive invitation to perform John who "is on the piss", having "a bloody good night out" with "some spunky bird singing good songs". John's language, in this story, embodies dominant masculinity and drinking culture discourses.

In comparison, John –the blind professional's language constitutes a different kind of

John:

Whenever we needed to really really do something, it was me who was wheeled out 'cos I can do it in a way that nobody else can... I'm the person that's the sharp end. I'm the one that can step up there and people will listen... and it's a positive approach. I mean I can be giving a negative message in a positive way, you're influencing people, you're guiding people and getting to where you want the thing to be

In this account, John is constituted as someone who is influential, unique, pioneering and responsible: He had multiple ways of understanding and living-out what it meant for him to be blind. The language he used in his account-making of his experiences would suggest that depending on the discursive context he was in, he would take up respectively the subject positions produced by the social model, medical and rehabilitation, SRV, parenting, dominant masculinity, and sports discourses.

John and Fay had both concluded that their impairment had provided them with opportunities and new directions in their personal and career lives. Their accounts illustrate how after having an impairment, they were able to take up new and preferred story-lines, concerning what they did and the kind of person they were.

Fay negotiates the power relation within medical discourse

Fay spoke at length about how she consciously and very actively positioned herself so as to have input into the discussions and decisions about her medical treatment.

She said:

When I'm sitting in front of my rheumatologist... I want to be the boss (laughs)... what I tend to do is take his power away from him by not going along with what he wants sometimes (laughs) or telling him

"What are WE going to do?" or "What I'm NOT going to do!" Yeah... and reminding him that it is a collaborative effort here and sometimes he likes to play the expert and I don't like that. I like us to be the expert together. It's taken ten years and we've built this relationship and we've come to this understanding (laughs). He calls me tongue in cheek, his *problem patient* but I think he really quite likes it (laughs) because I do put him in his place occasionally.

In the above example, Fay refused the traditional doctor-patient power relation in which the patient accepts the authority of the doctor to discuss and prescribe treatment for him or her. When Fay challenged her rheumatologist, he appeared not to position himself at fault but constructed Fay, perhaps fondly and/or paternally, as his "problem patient." Medical discourse legitimates and privileges the rheumatologist's understandings and actions and objectifies the patient. Within medical discourse, only two subject positions were available to Fay, either she was the good (complaint) patient or the problem (challenging) patient. When I asked Fay to account for why she felt so strongly about having her rheumatologist working collaboratively with her, she shared how being a patient had always been a struggle for her because of how she felt disempowered by medical practice when she was a child. She told a story of how, as a child, she had a blood transfusion in hospital, having had her tonsils removed. She said:

And I can remember being woken up in the middle of the night, not knowing what was going on, not being told anything and dragged into another room. And I remember there were a whole lot of nurses and doctors around and they were all poking, prodding and cutting me trying to find my veins... And I remember screaming the place down (laughs) and I remember asking for my mother because I was terrified

and I remember looking up and one point and there was blood everywhere and they were pretty much holding me down.

Fay said that because of the fear and confusion for her concerning this event, she now had “this really strong sense, not that I have to win but I have to change that balance of power a lot with medical professionals”.

John is offered inclusive and affirming subject positions

Over twenty years had passed since John became blind. He said:

I don't know how many years of my life being blind, where I became pseudo sighted, that's the only way I can phrase it, that I was so into looking "normal", and people often say to me you don't look blind, but the more relaxed I become about it [being blind] the more I assimilated.

John said he endeavoured to be “pseudo sighted” so he could pass for a “normal” sighted person. Although, he said, that as time passed he became “relaxed about himself” and he “assimilated”. When asked what he meant by the word “assimilated”, John said that regardless of the social context he was in, whether he was “one blind person in a crowd of blind people or the only blind person in a group, I am comfortable within myself”. When asked what might have attributed to the sense of feeling “relaxed” and being able to “assimilate”, John spoke of the opportunities that had occurred for him within his work. He said, he had been able to “rub shoulders with some of the... most amazing people from around the world who have spent fifty bloody years of their lives battling on behalf of other people to give them the opportunities that we now take for granted.” John positioned himself as privileged to spend time with seasoned campaigners within the blind rehabilitation industry. John spoke of how he was no longer “in isolation” but was “central”, with

others working in rehabilitation for persons with vision impairment in New Zealand. It was a subject position that offered John inclusion and purpose, which supported him to "relax" and be able to "assimilate".

Fay and John's positive identity claims

Fay was thirty years of age when she was diagnosed with RA. She described it as the "catalyst for change" for her overcoming being "dis-empowered in many areas of my life." She said, "I don't feel it (RA) is a destructive force in my life, I feel it is something that has happened to enhance my life". Hence, if David's story is distinctive for the number of years that he had no medical understanding about his impairment, John and Fay's accounts are illustrative of how the onset of illness and/or impairment in adult life does not necessarily produce an on-going loss narrative about that experience. John's account storied him as the blind professional who went from being "a hard nut" to becoming "the pillar of society" after he became blind. His story depicted him producing many achievements as a person who was blind, including raising blindness awareness in New Zealand, being a competitive blind sportsman and skier, and being a husband and father who supported his children to be the first generation in his family to attend university.

Both John and Fay made claims that impairment and/or illness had been an opportunity for them. Each had refused subject positions that positioned them in deficit and both had accounted for their impairment and/or illness in very appreciative terms. Fay stated: "I've come to believe that it [RA] was a gift given to me, so that I could be who I am now because without that, I don't know if I would have walked

the same road". John was equally positive about how his life had improved since becoming blind. He said :"it ain't been better... It's never been better for me as a human being than it is right now. I'm talking about me as a person, ain't never been better".

7

STORIES OF DEFICIT AND LOSS: CAROLE, JAN AND RON'S JOURNEYS TO RECOGNISE AND CONTEST POSITION CALLS

Deficit and loss descriptions prevail in Carole, Jan and Ron's account making. The overriding story for Carole was how difficult both physically and socially she had found the experience of having an illness. She described the onset of her illness as "exhausting", "distressing", "just terrible", "an intense grief". Furthermore, Carole noted that due to having an illness, she often felt socially positioned as "less than" other people. In remembering his childhood, Ron said "I don't have any positive memories, it's all pretty bad, the bad always was, I don't recall a time when the bad was never there". He retold incidents that showed why he would describe his life as having always been bad. His illustrations often related to how he had been treated in discriminatory ways by doctors, school teachers, and peers within tertiary education. Jan's story was also one of how arduous it had been for her since becoming ill and having an impairment. She shared how she had felt "a complete failure" because she could no longer do her own housework, be practically available for her children, or work so as to contribute earnings to the household income.

The construction of impairment and/or illness as an absence within health, gender, education, faith, work and sport discourses meant that Carole, Jan and Ron's account-making prominently storied impairment and/or illness as a problematic experience. However, within this overall negative picture of impairment and/or illness, they each relayed times in which they were able to recognise and contest position calls that disadvantageously position people who have an impairment and/or illness. These

actions of agency by Carole, Jan and Ron indicate how the impairment and illness experience can be a production of multiple, competing and contradictory discursive realities, rather than the reproduction of only singular pejorative constructions about impairment and/or illness.

In this chapter, the discussion primarily focuses on the co-existence between those position calls which construct the subject in deficit and how preferred subject positions are recognised and taken up. Carole, Jan and Ron's experiences within medicine, work and education are initially examined in regard to the operation and effects of such discursive practices when a person has an impairment and/or illness. Following this analysis, I then explore Carole, Jan and Ron's accounts in relation to the position calls that are produced by sports, gender and faith discourses for persons with impairment and/or illness. In the final section of the chapter, I consider the ways and extent to which Carole, Jan and Ron recognised and contested those position calls that produced them as feeling "less than" in some way.

Medical discourse constructs impairment and illness as a problem

Jan, Ron and Carole told stories about the impact of their impairment and/or illness on their physical and/or sensory functioning. Their language was a reproduction of the terms of reference found in medical discourse. Jan talked about having coronary heart disease, a heart attack, angina and high cholesterol, which caused her to have a hearing impairment that in turn affected her speech. Ron stated he had "a substantial hearing loss" being "completely deaf in one ear" and having "only partial hearing in the other ear." He also had a speech impairment and was born with physical

deformities, for which he had re-constructive surgeries when he was a child. Carole did not describe the nature of her illness in great detail, other than stating that she had been diagnosed with systemic lupus erythematosus (SLE). However, she did discuss the effects of the illness on her. She described being overwhelmed by pain, feeling very fatigued and overcome by despair.

For Jan, Ron and Carole the impairment and/or illness was very impacting on their bodies, significantly affecting what they could do. Jan said:

When I first had my heart attack and chronic angina, I couldn't do anything. I couldn't walk to the letter box without having angina and I still can't vacuum my house without getting angina and things like that.

Jan's language constructs the impact of her heart attack and subsequent angina as being very encompassing of her life: "I couldn't do anything." Illness had changed Jan's life because activities that had been a normal part of her day, such as walking to her letter box or vacuuming her house, she could no longer do. The account she takes up is one that portrays how her life was worse for her once she had an impairment and illness. Ron's language was similar in the way he described the impact of his impairment on him. He said, "I don't have any positive memories". Carole also took up this language of loss when she described the "serious consequences" for her of having to stand for two hours when coaching a youth sports team." She said, "You know, I lost a great big chunk of the feeling in the front of my leg just from that night... and that doesn't come back." In this story, Carole is storying her experience according to the terms of a progressive illness.

The stories of loss for Jan, Ron and Carole were not confined to the effects of the impairment and/or illness on their bodies but also what their impairment and/or illness meant for how people responded to them. Each spoke of experiences when they felt they had been positioned depreciatively in their interactions with others because they had an impairment and/or illness.

Ron's story of experiencing discriminatory actions within education

Much of Ron's childhood involved him having medical treatment. He recalled a scene when he was in hospital as a child: "I entered the staff dining room and apparently the room went quiet, absolutely stony, stony quiet and [name of the surgeon] just said without looking up 'And whose is that?'" Such an experience positioned Ron as powerless, objectified by the power relation of medical practice. The experience of being objectified and powerless was common for Ron during his childhood, especially during his school years. For example, one of Ron's teachers did not believe he had a hearing problem and thought he was "just being naughty" and put his desk "at the rear of the class facing the back wall." Another teacher "renowned for picking on kids" sent Ron "downstairs to the new entrants' class... to sit on the mat for half an hour", a directive which Ron considered was connected to his speech impairment. During tertiary training, Ron found his classmates surprised when he scored top in a test. He said his peers assumed that "because I had a speech problem, I had to have an intellectual problem too."

The subject position that was most available for Ron during his school years and in tertiary education, was a deficit position. In this respect, Ron's story of education is very similar to David's experience of school. At school, David was positioned as the "handicapped", "spastic", "mental", "retard" and "crippled" boy. During school, Ron was positioned as the "naughty" boy, and then when studying after school, he was viewed as who had an "intellectual disability." The impact of this on Ron was that he expected to be excluded in education, which impacted his expectations of how he would be responded to when studying. He spoke about an education experience in recent years when he had been included, which was such an unusual subject position for him to be offered that he struggled to take it up. He said,

For that entire [enrolment] interview, I don't think I strung together a coherent sentence.. and I came out and I thought "Well, I've stuffed that up, what am I going to do now?"... it's quite strange, because I've spoken to [the interviewer] a couple of times since... and I actually said to him, "How the hell did I get through it?", so I still don't actually know. If I was in (the interviewer's) shoes, I probably would have said, "Where's the bin!?" At the end of the day, after the interview, I adopted the "Oh, well, that isn't going to work"[attitude] and started looking for something else... it's probably [something I have] learnt from past episodes of ridicule, past episodes of apprehension... but I've stepped into this [education] programme that will teach me, we hope, to make a living out of speaking to people – "I can't do that, you're mad!"

In this example, despite being positioned favourably, Ron was expecting to be positioned in deficit so his internal dialogue of "I can't do that, you're mad!", continued to construct him as a person with deficits.

Jan's account of storying herself as a “complete failure”

Jan also had experiences of being positioned disadvantageously on account of her having illnesses. She said:

I wasn't allowed to have any help in the home because I was too young, I was only 40 when I had the heart attack... I was devastated, I was really devastated, (if I had been older) I would have had everything I needed, I could have asked for anything and got it. In fact, it probably would have been automatic and I wouldn't had to even asked. (It was) more than unfair, what's the word, I felt I was discriminated against because of my age. It made me feel worthless.

In this story, Jan's account of not meeting the usual age criteria regarding qualifying for home help suggests that she was outside the medical norms for having the kinds of illnesses she had. Therefore, on the one hand, the terms of medical discourse were the constructions that provided the explanations for why Jan was unwell and impaired but then those same constructions disqualified her from meeting the criteria by which it was acceptable to have the illnesses she had. Consequently, the decision by health authorities to not fund domestic support for her, left her feeling “worthless” as a person. It would appear from Jan's account that the age-range symptom was not considered critical in determining if she had any of her illnesses, but it was essential for establishing if she was eligible for funding. The policy as legitimated by medical discourse, worked to exclude Jan, effectively disabling her further because not only was she impaired in having the illnesses she had but she was also discriminated against by a funding policy that disqualifies her from receiving support.

Jan's illnesses resulted in her being positioned in deficit in three ways. First, she was positioned in an absence of health discursive. She was medically fragile and physically sick, she had a hearing impairment, and her speech intonation was different on account of her deafness. Second, on the basis of how health policy drew on and interpreted medical discourse, Jan was ill before she should have been. Based on the terms of medical diagnosis, it was not usual for her to have the illnesses she had for the age that she was. Third, the messages of "being independent" and "working hard" were emphasised in Jan's family of origin. She said "In our family, it was don't expect help from anyone else unless you've tried yourself... there was no such thing as sitting at home, you got out and worked, you earned your way." However, as a consequence of her illnesses Jan could no longer do housework. She said "I couldn't keep my housework up to date because it was physically taxing. I used to do house-work for others and took pride in the fact that I cleaned and worked really hard to make people's homes nice". Furthermore, not only could Jan not keep her house or earn by cleaning other people's houses, she was unable to undertake other mothering activities that she deemed were important for her to do. For example, she said "I couldn't go on school outings as it was too much for me." By not being able to reproduce traditional gender expectations, Jan storied herself as "a complete failure."

Carole's protest against disempowering practices of "kindness"

Much of Carole's struggle was about finding ways to challenge others' interaction with her when she felt she had been positioned disadvantageously on account of her illness. For example, she said,

One of the things I notice is that people that know I'm living with an illness, out of kindness and to save me, people make judgements about what I can do and can't do but it positions me as being globally disadvantaged rather than having a difficulty in a particular area. An example of that is at work...you know, I'm having struggles in my body but there is absolutely nothing wrong with my mind... out of kindness, people have thought to protect me and have given other things to other people so I've actually been made less than an experienced [health professional⁴] based on the assumption that I can't take on extra stress or challenging work.

Carole was not claiming that her illness does not affect her but that people's "judgements and what she "can do and can't do" disadvantaged her. The difficulty for Carole was that such "judgements" were not "malicious" but motivated by kindness, endeavouring to "save" and "protect" her. She said, "I got tripped up by what the motivation was for it... I felt that I lost my voice, I was silenced... if it had been malicious, I would easily have had plenty to say about it but because it was out of kindness I didn't know how to respond." Since having an illness, Carole had lost her sense of agency at work because without "access to a subject position in which [she had] the right to speak and be heard" (Davies, 1991, p. 51). She described how she would try to resist when "challenging work" that she would normally be given was allocated to other people to do. She came to realise that "kindness" prohibited people from hearing her when she said she "liked" and "was fine" to still do "challenging work". She said people responded by thinking she was "protesting but not really meaning it". "Kindness" was a position call that was hard to refuse because it appeared benign. The paradox of "kindness" producing effects that were

not experienced as kind arose because “kindness”, on these occasions, embodied more than one discursive practice. In one sense, being kind to one another is an idea held strongly within the Judeo-Christian ethic (Gal. 5:22). It resonates with the ethos and Biblical principle of love one another as you love yourself (John 13:34) and do unto others as you would have them do unto you (Matt. 7:12). However, if actions of “kindness” are also constructed by medical discourse, then the “kindness” practice may not produce effects consistent with the intention of the original discursive practice. A contradiction occurs between the idea of an experience and the actual practice of the experience. This was Carole’s experience, that “out of kindness and to save me, people make judgements about what I can do and can’t do”, a practice which she experienced as un-kind and dis-empowering.

The construction of illness as “less than” produces Carole’s “secret world”

Carole did not like being positioned as being “less capable” than she considered she was. Bird (2004) has argued that the experience of being “subjected to the measure ‘you don’t measure up’ [occurs because of] internal dialogue, anticipated external dialogue and received information from others (including the media)” (p.228).

Relative to this point, Carole said her internal dialogue about her illness became much more and proportionately larger in comparison to her external dialogue with others because she typically found other people’s responses to her were not helpful.

She said:

I think initially, I was quite open with a number of people and I notice now, I call it my secret world. I have a whole secret world and it's got more secretive as I've had more experiences where it's gone wrong. I think it's to do with chronicity when something goes on and on, how

many times you're allowed to say it. I feel more and more uncertain about how people are going to respond and I find their responses very unhelpful. I find there are very few people who I might get a response from that might be useful to me.

Carole was suggesting that the “chronicity” of her illness impacted how people responded to her. Medical discourse is orientated toward helping people recover but if impairment and/or illness continue then the person has not met the ideal of medical discourse and consequently is positioned pejoratively. Carole said, “I haven’t yet worked out a way of telling them [about my illness] without denigrating myself, describing myself as a ‘less-than’ person.”

Referring to experiences from coaching youth sports teams, Carole gave several illustrations of how people responded when she disclosed her illness. Sometimes during a Sports Meet or event, Carole disclosed to others how fatigued she felt, to which she found people replied with how they were even “more tired” than she was. When this occurred, she “just dropped it but I knew that they just couldn’t know when I said tired, I’m not talking about ordinary tiredness”. Carole said that in order to dispute this understanding that her fatigue was different from the kind of tiredness they were referring to, she would need to “do a great big thing about how bad it was” but she did not want to give a “detailed explanation.” When this happened, Carole said she was “positioned” to either disclose her illness and be positioned in deficit or not disclose her illness and be positioned problematically on account of her fatigue. She said, “How do I describe myself in a way that they believe me, that I can’t do it and I’m not shirking?”

In addition to Carole having to manage disclosure dilemmas about her illness, she also found herself positioned by the unpredictable nature of her illness in regard to not knowing in advance what she could commit to. She said,

[name] [My daughter's] got a trip for class for Friday this week, you know, and I can't tell whether I'm going to be able to walk on that day or not, so she says to me, 'Can you come and do mother help?' and I say 'I don't know yet' (small laugh). I can't say "why not?", you know, in the long term I probably feel quite guilty. I feel I'm not always the parent I would like to be. I'm probably a lot more tired and irritable than I would have otherwise been.

The physical effects of Carole's illness meant it was not easy for her to take up the subject position of mother and wife on the terms that she wished to or on the terms that a family member might expect. She talked about not discussing her fatigue and pain when family needs "coincided with her being really unwell", describing this as "an inevitable part of living with other people that you consider them and I think that's hard actually and it's hard with children." Hence, Carole did not have access to a subject position in which she could care for her own health needs and her family's needs at the same time. She discussed a situation that demonstrated how her illness prevented her from going shopping with her son so he could purchase "a cap" before "a social" he was going to attend. When Carole said, "We will get it by the social but I can't get it today, I'm not feeling well," her son replied, "But you're always sick Mum, you're just slacking, you're always sick, what's the difference today from any other day?" Carole described her son's response as "being blasted by him" when she said "I just can't do it." In making sense of this incident to me, Carole said her son "couldn't possibly understand" how it was not "reasonable to take him to [the

shopping mall] in this tiny gap of time". This effect of this incident on Carole was that she was "really upset" and "felt really guilty". Furthermore, she "resolved to say nothing," not wanting her illness "to negatively impact on her as a parent". In this example, Carole is again caught between disclosing the effects of her illness on her and being pejoratively positioned or not disclosing and managing the experience of her illness on her own. When Carole responding to this dilemma by "pulling right back" and not disclosing, then she said her "secret world got bigger." In explaining the phrase "my secret world", Carole said:

It is how it really is, how I feel... people walk in and out of bits of it [the secret world], no one would have all of it but me and [husband] would probably have the most of it [but] there would be parts only I have because that's the thing with chronicity. I don't enjoy it [the secret world] (said quietly). I feel quite depressed by it.

While the phrase 'secret world' was Carole's own term, Jan and Ron shared experiences that indicated that the subject positions that were available for them to take up were not common or universally known. In a very real sense they also had impairment and/or illness constructed experiences which were secret to them. For example, Ron said "I still deal with the issue that every time I speak... I still have this hesitation, is this going to sound understandable?" And Jan shared how her illness positioned her to fear losing her husband.

Male sex drive, gender and Christian discourses position Jan to fail

In respect of lovemaking with her husband, Jan recounted a time in which she felt split between the fear of losing her husband if she did not make love to him and the fear that she would have another heart attack if she did have sex.

Dominant masculinity discourse and Christian marriage discourse together position men as entitled to and needing to have regular sex and wives as needing to meet their husband's sexual needs. However, medical practice had constructed physical exercise, such as lovemaking, as medically dangerous for Jan to engage in. She said,

It was frightening because I have an incredibly supportive husband, he has always been there no matter what but there was always a fear that if I couldn't give him what he needed [sex] and he would be tempted in some way.. I was caught between a rock and a hard place. If I did make love with him, I would end up with angina all night and end up having to sit up all night or even end up in hospital. If I didn't, I felt like I was rejecting him and I was having to help him understand that I wasn't rejecting him.

Jan was storied as responsible for her husband's sexual needs and his protection from the temptation of being unfaithful to her. The assumptions, in this idea, positioned her, not her and her husband, as having the problem, when illness impacted on their lovemaking. It became her responsibility to help her husband understand this dilemma for her.

Jan's illnesses prohibited her from fulfilling the expectations she had learned from her family of origin, in regard to how she should be as a mother and wife. She said,

"I was brought up with "you look after your family, your children, your husband, your house, you made sure your house was clean... [if you did those things] you were a good mother and a good wife." These messages are informed by gender and working class discourses, which positioned Jan as failing if she could not be a mother and wife on those terms. As women, Carole and Fay were also positioned very similarly. For example, Fay had, until her impairment, also taken up the idea that women were to serve and put the needs of their husband and children first. Once she became ill, Fay said she had "to come out and say (laughs) 'I can't do this, I can't do that'". The person that Fay was before she experienced RA was someone who in her own words was continuing the beliefs she had learned from her family and church while growing up. She said,

The type of family I was brought up in and the sort of church belief we had, a lot of it was from a patriarchal, dictatorial, authoritarian place. It was certainly serving a purpose for someone greater than myself at the time, it was serving the greater whole.

Fay called such beliefs "social stories," which "definitely came from my parents". However, having RA meant Fay was much less able to serve her family. As a result she reviewed the "social stories", and decided her "contribution" could at times be "for Fay."

Jan, like Fay, through the experience of becoming ill, also reflected on how her family training constituted her to meet her family's needs at the cost of caring for herself. She said:

Yep, I had done something really wrong because I followed my mother in that I worked hard and put myself last, the family, the

children and the husband all came first, well before. And in looking back, I think I have put myself last to the detriment of myself. I had neglected myself in some respects by putting others first.

Jan concluded that she had taken up so fully the idea that she must put her family first and herself last, that she had actually neglected her wellbeing, thereby becoming vulnerable to being ill. As a woman, the subject position that had most been available to her during her growing-up years had also included neglect and being physically and emotionally abused. Referring to her growing up years living with her mother and stepfather, Jan said, “The violence entailed [me having] increasing fear. It started with violence on Mum but turned to me so I was fearful of confrontation ‘cos it’ll always lead to a beating which happened most days.”

Experiencing a power relation in which men were privileged and women were subordinate and abused continued for Jan outside the home in the context of church.

She said:

In the first churches that I attended it [the violence] wasn't so much physical but there was fear there because there was an intimidation and very strong control. And so if you did something wrong I guess it was done as far as humiliation, humiliating you in front of others... they said that women were equal... [and] weren't downtrodden but there was an awful lot of emotional manipulation and undercurrents that kept you treated like a second class citizen.

Hence, Jan’s experience of church during her childhood and early adult years, perhaps stands alongside Fay’s childhood experiences of church as a “patriarchal, dictatorial, [and] authoritarian place.” Jan spoke about the pressure within one

church she attended to ask for faith healing but being positioned as being at fault, when after being prayed for, she was not healed. She was accused of “lacking faith”, of having “strong sin in [her] life”, of “needing to repent for past issues” and she was questioned whether she “liked being sick”: did she “get more attention from being sick and therefore didn’t want a healing.” The church in which Jan experienced such interactions believed that God healed people. This meant Jan, as a person with impairment and illness, was a target for prayer but then when healing did not occur, she was blamed for not being healed. Such a practice positioned God, the prayers, and the people praying as not at fault. The pressure within the church to be prayed for and healed implied that it was unacceptable for Christians to be sick or disabled, meaning that anybody who was not healed after being prayed for was positioned as spiritually unwell, as well as being physically impaired and sick. Such deficit positioning only added to Jan’s sense of failure having already failed her family of origin training that women were to cook, clean and look after their family, otherwise they were lazy. Clearly, within the contexts of her extended family, health services, and the church she attended, Jan did not have access to a subject position where she might feel well supported or understood in her experience of having impairment and illness. Gender, working class, medical, masculinity, male sex drive, Christian faith, and Christian healing discourses, all positioned Jan poorly.

Carole, Jan and Ron contest deficit and loss position calls

Carole, Jan and Ron's stories illustrate how medical discourse with allied reproductions occurring in education, work, class, gender, sports, healing and faith discourses, construct impairment and/or illness in deficit terms. However, despite the prevalence of this construction, Carole, Jan and Ron each gave examples of how they had consciously taken up ideas and practices that positioned them less disadvantageously. These actions of agency bear evidence of Foucault's (1980, p.82) thesis regarding "subjugated and disqualified knowledges appearing and performing critique on dominant discourse". In accordance with Davies and Harré's conceptualization of multiple subject positions, Carole, Jan and Ron were able to:

[bring] to a particular situation their history as a subjective being, that is the history of one who has been in multiple positions and engaged in different forms of discourse [so that each respectively was] not inevitably caught in the subject position that the particular narrative and the related discursive practices might seem to dictate. (Davies and Harré, 1990, p.48)

One discourse that had shaped Carole's life prior to her illness was competitive sport. Her illness meant she was no longer able to take up the sportswoman subject in ways that she was used to. She described the "athletic part" of her as "an intrinsic part of her identity." However, despite the presence of illness prohibiting her from continuing her narrative as a sportswoman in the way she had known, she found ways for her knowledge and practice as an athlete to continue in her life. She said, "it [the athletic part] does inform my life and what I've done is try to funnel it into helping other people by coaching". Carole's account about her coaching did not, however, construct it as an activity that was necessarily a "loss" for her. She said,:

I need it because I can't run around and do all those things which have been a big part of my identity and it's my way of actively seeking good things in my life, and I love it. I love children, I love helping people and teaching them skills. For me, the standing is very difficult but it's wonderful, I love it, it's rewarding, I've made a choice to do it.

In this example, Carole has intentionally re-positioned herself to “seek good things in my life.” Carole’s practice of “seeking good things” was not something that occurred by chance or unconsciously but developed as a result of a very specific experience.

She said,

I was walking around the stadium and you know being very low indeed and having all these negative thoughts going round in my mind about loss and I decided that I was just noticing them and I was feeling sad and I was noticing that and I was thinking how unhelpful they were and somewhere in that reflection there came the idea that maybe I could change it by doing something differently.

Carole “notices” her “noticing” about “being very low indeed” and “having all these negative thoughts going round in my mind”. The experience of “noticing” her “noticing” provides Carole with some space from feeling “very low” and “sad” and thinking “negative thoughts.” In narrative therapy terms, this would be called externalising, when a linguistic space is created between the person and the problems she is experiencing (Bird, 2004; White, 2006). In “noticing” the negative thoughts and feelings, Carole concluded “how unhelpful they were” and had an “idea that maybe I could change it by doing something differently”. Carole said she had already “reflected extensively on what connected me with loss and what connected me with good feelings” but in addition, she then began “thinking of the concept of bad news and the effect of collecting bad news rather than good news”. At this point, Carole

asks a very agentic question of herself. She said, "How can I collect some good news?" In responding to this question, she said, "It occurred to me that I'm very goal orientated as a person and I've always had a lot of joy about working towards a goal". Carole then described how these understandings created some new actions for her. She began to set physical goals for herself, knowing that "doing my best was enough". She said "I have had to literally walk lamp posts [taking] ten months to walk three kilometers and I've been cycling and I've been doing all sorts of things to try and add to it very slowly; it's been a very patient process". The effect for Carole on deciding to set physical goals for herself and "adding to it slowly" was that this goal orientation was a practice she was familiar with. It connected her to the stories she had of herself as someone who has "a lot of determination or drive to keep on, I don't give up. I'm a real not-giver-upper."

As a result of this reflection, Carole began to refuse medical discourse's position call to collect bad news about her health and began to look for ways that she could collect good news about her body. The refusal was critical because medical discourse constructs progressive illness as an experience that measures and focuses on the extent of deterioration that has occurred. In contrast, Carole began orientating herself toward noticing when small steps of progress had been achieved. Carole enjoyed the re-orientation from collecting bad news about her body to collecting good news about her body. She said,

I'm measuring my fitness and so I'm getting lots of good news about my body.... Well [it] has been absolutely exhilarating. It's really really changed my thinking, from loss thinking to how am I going to work at this, what am I going to do kind of thinking. Very positive

thinking from the area that was the biggest sadness for me. It's been enormously significant in terms of how my future will be."

Carole's actions of agency in relation to filing good news about her body demonstrate Davies' concept of "mo(ve)ment", signify[ing] the simultaneity of specific embodied *moments* and the *movement* toward the subject as a process that can come about through the mode of telling" (italics in text) (Davies, 2006, p.92). Carole's process was to experience herself as having an illness but not have it constructed as only an experience of loss and deficit. To use Davies' phrase, she was "unmooring" herself from an aspect of medical discourse. She had recognised how she had been subjected by medical discourse, namely noticing the effects of collecting bad news about her body on her, and had taken up a position which made that practice unacceptable or "unthinkable" to her (Davies, 2006, p.99). In this regard, she was no longer the subjected subject (Drewery, Winslade & Monk, 2000) of medical discourse. Carole was able to do this because she was used to "notic[ing] what it is that connects me with feelings of grief or different power hierarchies, and I would review that and... talk to myself kindly about that or do something differently about that or change that." In regard to her work situation where she felt 'challenging work' was being given to other people on account of her being too ill and tired to do such work, Carole took up a subject position that enabled her to share her understanding of her experience, thereby challenging the positioning effects of other people's judgments on her. She said: "I've got stronger and stronger at trying to create a space of understanding. I've been very direct. I've said a repeated statement now when I'm doing work – "my body might be sore but there's nothing wrong with my mind" or "my mind is perfectly capable"". Through these claims,

Carole is actively refusing the construction of her illness impacting both her body and her mind. She distinguishes the difference, with the result that “kindness has to get in behind me at that point because I’ve actually given instruction about where it can go, where it can be useful.” In other words, actions of “kindness” can be directed toward supporting her body that has been impacted by illness but she does not need any support or help with her mind.

Carole was very active in constructing meaning and undertaking actions so as to take up a subject position that worked for her. She refused those ideas that positioned her in ways that she did not like and accepted different ideas that she evaluated as preferable for her. Another illustration of how Carole took up a practice that cared for herself when she was being invited into a deficit or loss construction of herself, was how she watched two comedy movies a day for four months when she first became ill. She said,

It was the only way that I could think of intentionally [doing something]. I couldn’t drive and things, so I sat and I watched comedies. I knew that that would fill in the time, that it would be uplifting, that it would help me cope, it was a planned strategy, laughing is good therapy, isn’t it?

I was interested in what ideas informed Carole’s responses to position calls that invited her into an experience of loss and being in deficit, for example, creating good news for herself when feeling overwhelmed with bad news, creating a space of shared understanding when she felt misunderstood, and creating an experience of laughter when life felt desperate and unbearable. In response to this question, Carole spoke

about three social contexts: her family of origin, her work as a health professional and her family. She said she grew up in a family where people with disability were viewed as capable and never seen as “other” to her. In her work she spoke of seeing how difficulty in one’s life produced a person who would “have more understanding and might have a big opportunity in their life to grow enormously.” She also said that the “framework” she used in her work was very helpful for her in being able to analyse the “construction of language, power structures and the forces that come on to a person”. She described it as an “on-the-spot analysis that allows me to work things out, it’s a huge resource [that] also provides a way of understanding kindly why people might do what they do”. Carole’s process of analysis appeared to enable her to re-position herself when she felt dis-empowered by others’ actions but at the same time tend not to blame or position negatively people whose actions had positioned her problematically. She sought a socio-cultural-political understanding for people’s actions. In Carole’s analysis she de-constructed discourse and the impact of discourse on her. Consistent with this approach, was how Carole made sense of her body and her illness. She said,

I just always felt it [my body] was doing its best for me. I think that again that I had a good relationship with it [my body] in the past, I think that makes a difference perhaps... I seem to talk about how my body is but when I'm actually thinking about the illness I think about it separately... the actual way that I think about it is that they're separate in a way... [the body is having to] deal with it [the illness]... it deserves to be looked after... and cared for.

In this story, Carole has not conflated her body with her illness but separated them, constructing the illness as a problem for her body, thereby positioning herself to feel

compassion for her body, rather than feeling depressed or despairing about her ill body. Finally, Carole said that she felt her social circumstances provided a context of support and enabling for her. She referred to having a loving husband, living in a home environment that she found replenishing and economically being comfortable. She spoke about how much harder it would be if she did not have those resources, referring to a friend with the same illness who was a solo mother living on a domestic purposes' benefit. Again, in this analysis, Carole is noticing how the social context produces realities, constructing the kinds of experiences a person has.

Carole drew on pre-illness narratives to resist position calls that disadvantaged her on account of her illness. However, Ron was born with a hearing impairment and physical deformities and can only ever remember speaking with a speech impairment. And like David's school experiences, Ron's growing up years were shaped by experiences of discrimination and marginalisation, especially during his schooling. Ron did however, emerge from his school experiences of being positioned as "other" to actively take a stand against practices that discriminated against him. For example, he told the story of how his tertiary class peers assumed he had an intellectual disability because of how he spoke. In response to their assumption about him having an intellectual impairment, Ron said to himself, "I don't think so. I thought , 'I'll show you buggers, I'm not stupid'. I understand at times and especially when I'm disfluent, I do appear to have an intellectual problem. Well, no, I can understand how they viewed it".

In this example, Ron has refused to be storied as someone who was stupid. In recounting this scene, Ron began to say when his speech was disfluent he did “appear to have” an intellectual problem but then he changed his language to state “I can understand how they viewed it.” In this wording change, Ron created more agency for himself. “How they viewed it” suggests his classmates had a perspective or interpretation about him having an intellectual disability, whereas the words ”I do appear” more constructs Ron as agreeing with his classmates or even believing that he looks as if he has an intellectual disability when his speech is disfluent.

When I asked Ron how he accounted for his determination to prove that people’s assumptions about him were incorrect, he surmised that it would be related to having read detective fiction since he was fourteen years of age. He said he was an avid fan of Agatha Christie crime fiction and he had identified with the detective hero in the stories. He said:

The hero is told they're wrong or the hero hits a dead-end or the hero goes off on a tangent to find it isn't the right one but our detectives often come up with a trump and it's their ability to keep going after being ridiculed, after getting to a dead-end, after seeing things that don't add up... that resilience... that keeps me going. It probably instilled in me that "I can do it". You have to go on despite the odds or regardless that you know that it's going to be a bad outcome.

The ideas of “resilience” and “you have to go on despite the odds”, became a theme in Ron’s life. On a number of occasions he talked about “forever pushing the boundaries”, which related to “the boundary that says ‘don’t speak up because you are going to be ridiculed’ not because of what I say, but because of the way I’m

saying it.” Ron told stories of specific times when he had pushed the boundaries, such as using radio telephones when driving a taxi or courier van, doing radio interviews and even counting down and starting ninety cars for a car race in which the timing of the countdown had to be precise. Ron said he was “forever looking for the next challenge,” the purpose of which was to try to be like non-impaired people. He said:

I'm only striving to be normal, so I don't see the things I've done with my speech as extra to what a lot of people have... I'm not normal . I still believe it's only me coming up to, coming up to “normal” because I'm in deficit mode [but] I think that is just the way it is and I don't think I'd actually like it any other way... I don't believe I'm ever going to be number one, number two is forever going to be the best place because you're forever working.

In this description, Ron takes up the deficit subject position available to him within medical discourse but he then reframes the position to be that which he prefers, a position that enables him to be like the detective hero in Agatha Christie’s novels, overcoming the odds and coming up with a trump card, the person who is not normal but is coming up to be normal.

Ron’s narrative of being in deficit mode but working to be normal, embodies a sense of struggle. He described his “speaking issue... as a twenty four hour challenge” in which there was always a fear of “not being understood”, “looking stupid” or “being ridiculed.” However, in more recent years Ron’s fear about his speaking became less and he attributed this to a smooth speaking programme he had undertaken, which he said improved his speaking fluency to the point where he “could actually talk to

people.” He said the impact of this on him was that he was “more comfortable talking to people, [he] could hide his problem [and] a personality was starting to emerge [and] that personality was saying ‘I’m here!'” Rehabilitation practice, as produced by medical discourse, enabled Ron to be less positioned in deficit. He responded by performing a subjectivity that previously had been impeded by the impact of his speech impairment on his relating to other people. In other words, he submitted to and achieved a degree of mastery on the terms of medical discourse and therefore was less positioned in the absence of normality as defined by medical discourse. Ron’s desire to overcome and not be limited by his speech impairment was in part also informed by how he had felt inspired by a prominent Christian educator and media personality who had had a speech impairment like his own. For over twenty years Ron said he had admired the man’s “nerve, knowing he had a speech problem, to do a show like that.” Ron said watching the TV show “re-started [his] faith journey.” It offered him a subject position that declared the possibility of working with people in a public role whilst having a speech impairment. It was a position call that invoked the idea of not being limited by speech impairment, to succeed on the grounds of medical discourse which was to become less disabled by overcoming and reducing the effects of the impairment on the person.

Interestingly, in regard to his hearing loss, Ron did not define his impairment on the terms of medical discourse. He said:

You see a lot of people say to me “Oh, you don’t hear normally”, which I reply, “Yes, I do hear normally for me.” That isn’t normal to the level that others hear, but I’ve always heard it... I was talking to a lady... who just got hearing aids... and she was having some trouble

adjusting to it, and we got talking and she said to me, "so how bad is your hearing?" and I said, "it's anything between 45 and 50 odd percent" and she just about fell over, she said, "Oh, but you don't hear normally" and I said "yes, I do!"

In defining his hearing as “normal for me”, Ron is taking up a subject position akin to the philosophy of the social model of disability and disability rights’ discourse. This is a different subject position to that which he takes up concerning his speech impairment. A discursive contradiction co-exists in which Ron reproduces the terms of the disability movement in regard to his hearing impairment, but takes up the counter to the social model of disability, medical discourse, in his thinking about his speech impairment. Many debates, theoretical exposition and research agendas have occurred in relation to the social model being advocated as opposite from and more advantageous for disabled people than the medical model and yet Ron reproduces both discourses simultaneously. One way of making sense of this contradiction is to consider the impact of visible versus invisible impairment. Carole’s disclosures related to her illness for the most part being invisible to people, while the effects of it on her body were very visible to and impacting on her. From Ron’s account, it was clear that the visibility of his speech impairment caused him to have experiences in which he felt ridiculed by people and considered stupid. On the other hand, while he did speak of how he had been discriminated against as a child because of his hearing impairment, he told of no adult incidents of being positioned as “other” on account of his having a hearing impairment. He did wear hearing aids but this is not uncommon and there was no evidence that he had difficulty hearing what was said to him.

However, it was very evident that Ron had a speech impairment, which did impact on his conversations and communication with other people.

Medical discourse constructed Ron in deficit for both his speech and hearing impairment but as an adult he was more able to refuse the position call of being in deficit in regard to his hearing impairment because it was more invisible to others. Nevertheless, Ron still contested the deficit position call of medical discourse in relation to his speech impairment but more within the terms of medical discourse. That is, Ron liked to challenge an idea that he would not be able do something on account of his speech impairment. For example, he got top marks in his class when he left school and later he trained and worked in an occupation that required him to be a proficient communicator. Ron took up the subject who worked at not being as disabled as medical discourse might position him to be. In regard to Ron understanding his hearing impairment as normal for him, the extent to which Ron was very consciously taking up the social model of disability was not clear, but he did reflect on how ideas and practices about disability had changed over the last twenty years. He said, "difference is now embraced rather than shunned... discourses around disabled people are definitely changing, society is becoming more accommodating". It may have been this knowledge that supported Ron to take a stand as an adult, against one of the teachers who he described as "picking on" him when he was at school. A number of years after leaving school, Ron recognised the teacher who had sent him to the new entrants' class to sit on the mat and had picked on him and a girl in his class "who also had disabilities." At the time he saw his ex-teacher, Ron was working in a restaurant. He spoke of how he very deliberately

chose to serve his ex-teacher the “the scungiest, horriblist meal I could lower my standards to”. In this moment, Ron refused the narrative of being a victim of discrimination. He re-positioned himself to “get even” with “the bully”.

Jan’s account shared some similarities with Carole’s and Ron’s, in that she called on ideas and practices which enabled her to contest position calls that constructed her as “less than.” When Jan first became ill, she was unable to meet the expectations she had grown up with concerning being a homemaker and so she storied herself as a complete failure. Further, the practices of the church she was attending at the time in which she became ill constructed her as being to blame and at fault for not receiving healing from God after she had been prayed for. In response to these deficit narratives, Jan began to review the assumptions that had guided her life. She said,

I don't have to do everything for everybody else. I don't have to fix everybody else's problems. Being a good mother constitutes more than just doing everything for your child and I wasn't allowing (name of husband) to be a good father cause I was so busy doing it all which was really not good.

Illness became the catalyst for Jan reviewing her family of origin beliefs. She said prior to her illness “I was too scared to say no if anyone asked me to do anything so I would do it. I was probably in some ways killing myself, you know, to serve everybody else”. In her illness forcing her to take up a different discursive practice in relation to how she performed as a woman, wife and mother, Jan came to the conclusion that it was sad that other women in her family had not had the chance to experience this also. Jan was of the view that her illness had contributed toward improving her marriage. She said, “I actually wonder where our marriage would be, I

think we would still be together but how strong would it be?" In inquiring what ideas might have supported the shift to no longer require that she serve others in the way she had been, Jan talked about a different church she began attending once she felt blamed by her old church for no longer receiving healing. In the new church, Jan said the husband and wife ministered equally and she thought that the combination of that faith environment, along with "a lot of prayer" gave her "the freedom to experiment a little bit more I guess with who [she] was." She came to the "realisation that it was God's prerogative whether or not [she] was healed." In the new church, Jan said, women were not treated as "second class citizens."

The dominant story for Carole, Jan and Ron was that illness and impairment meant they took up subject positions of disadvantage. However, within these stories of deficit and loss they called on known and helpful narrative story-lines and took up new subject positions so as to be able to recognise and contest those subject positions which disadvantaged them.

8

THE COMPLEXITY OF DISABLEMENT AND AGENTIC ACTION: A CONTRIBUTION OF LOCAL STORIES TO THEORY, RESEARCH AND PROFESSIONAL PRACTICE

This study began as a response to Corker and Shakespeare's (2002) contention that "disability is the ultimate postmodern concept... [because] it is too complex to be rendered within one unitary model or set of ideas" (p.15). Corker and Shakespeare argued that disabled people are not a minority like other minority groups because impairment and illness would still cause disablement even if discrimination on the basis of impairment and illness were to be completely erased. Moreover, they contended that the range of impairments and illnesses people can have is extremely diverse, creating a much greater degree of variance between disabled people's experiences than the diversity experienced within other minority groups. In making this statement about the complexity of disablement, Shakespeare and Corker are claiming that the disability experience can not be reduced to a single underlying and essential structure or model. Instead, they are taking a more postmodern stance in which experience is viewed as pluralist, multiple and fragmented (Burr, 2002). This postmodern position was one with which I was already familiar and committed to at the time of reading Corker and Shakespeare's thesis about the complexity of disablement. Indeed, an important aspect of discourse theory is that people's lives are constituted by multiple discourses. Hence, irrespective of whether disability is claimed to be too complex for one unitary model or set of ideas, discourse theory would suggest that all people's experiences are too complex to be completely understood or represented by any single theoretical reductionist analysis.

In relating discourse theory to disability, I held two assumptions prior to commencing this study; firstly, that (some) discourses were not beneficial but would work to the detriment of those persons who are viewed as having an illness or impairment, and secondly, that while the participants' lives would demonstrate disadvantage and discrimination because of the presence of illness and impairment, their lives would also demonstrate resistance to those position calls that produced such effects on them. Hence, one of my aims for this study was to explore how existing theories within Disability Studies relate to the lives of people with impairment and illness, with particular attention being paid to what various discourses meant for how the participants were able to live their lives. Critical to this inquiry was the extent to which the participants had access to and consciously took up preferred subject positions, as well as what processes occurred that enabled them to negotiate and experience moments of agency and what discourses they called on as they took up preferred narratives.

However, in addition to my purpose of relating the post-structural concepts of discourse, narrative and agency to the experience of disablement, a secondary interest arose for me in the course of this study, namely, how narrative therapy ideas and practices might relate to and inform narrative research methods and discourse analysis. These questions arose because my background as a narrative therapist influenced the way I undertook this research project. The details of how I combined aspects of narrative research and discourse analysis in this study have already been discussed in Chapter Four. In addition to theorising the particularity of the narrative-

discourse methodology undertaken in this study, several of the participants spoke directly about or alluded to how, through the process of being involved in the study, they had come to new understandings about their experiences which had been helpful for them. In many respects, this outcome is not very different from that which narrative therapists might seek to facilitate for their clients: people (clients) having an increased sense of agency as a result of participating in the process of narrative therapy. In light of this finding, narrative research with a discursive agenda does have much to offer disabled people (Smith & Sparkes, 2008) and certainly avoids Oliver's (1993, 1996) and others' (Bury, 1996; Scotch, 2002) concerns that researching disability only serves the purpose of the researcher(s) while further positioning disabled people to experience disadvantage and disempowerment.

Given these two foci (disabled people's experiences of discourse and their corresponding actions of agency, plus the advantages of combining narrative research with a discursive analysis), my focus in this final chapter is to explore the potential contribution of this study for Disability Studies. The chapter begins with a discussion of the dominance of medical discourse, and the advantages and limitations of disability rights' discourses. The chapter continues by highlighting aspects of the participants' processes of agency, noting the intersection between power relations, language, subject positions and agency in the accounts given by the participants. In this examination, suggestions are made concerning future directions and foci for disability research, theory and professional practice.

The dominance of medical discourse

The accounts given by the participants in this study support the Disability Studies literature in which it has been argued that disabled people are viewed negatively on account of their having an impairment and/or illness (Hunt, 1966; Morris, 1991; Shakespeare, 2006). David, John, Fay, Carole, Jan and Ron's stories were particular to each of their respective life experiences but taken as a group, their stories illustrate how people with impairment and/or illness have experiences in which they are told or feel that they are different from non-disabled people. Their stories, for the most part, suggest that when disabled people are constructed as being different from non-disabled people then, typically, they experience disadvantage and discrimination.

The ways in which the participants of this study took up deficit subject positions have been detailed earlier in Chapters Five, Six and Seven. David, John, Fay, Carole, Jan and Ron's accounts encompassed a number of contexts, including experiences at school, in the workforce, at church, in health settings, in sport and at home. David shared how when he was ten years of age, his peers at school said that he did not belong with them. When he was eleven years of age, another boy told him that he should have been aborted. John said when he initially became blind he was "known as the blind man" who stood out. He was not "one of the crowd" as when he subsequently became involved with other blind people at the Royal New Zealand Foundation of the Blind (RNZFB). As "the blind man" who was "unusual and different", John said he was "led by his blindness". His preference he said was to "assimilate" alongside others, which he described as "walk[ing] alongside his blindness". Fay said she was advised she was making it personal when she advocated

for her disabled clients in meetings at her work. Fay's colleagues considered her personal experience of impairment and illness was unduly biasing her professional opinion. It was not viewed as legitimate for Fay to have her experiences of disability inform her ideas about people in the realm of her profession. Personal knowledge about disability was not viewed as helpful for or equivalent to professional knowledge. Fay, Carole and Jan each spoke of how they were initially invited into ideas about failing and/or feeling guilty as a parent because of the limitations their impairment and/or illness placed on them for what they could no longer physically do in their role as a mother. Carole also said her illness meant she was given less challenging work to do in her job and that she had not found a way to disclose her illness without denigrating herself. Jan talked about her experiences within a church where it was expected that she ask for prayer to be healed of her illnesses but was then blamed by people in her church when she did not receive healing. Ron spoke of being picked on and treated unfairly by teachers when he was at school on account of his having hearing and speech impairments. Later, when he had left school and was undertaking tertiary study, Ron said his classmates assumed he had an intellectual disability because of how he spoke as a person with a speech impairment.

Medical discourse constructs impairment and illness as the absence of health. When people are classified as having an impairment or illness, then in effect they are subjected to the idea that they have something wrong with them. Medical discourse on these terms is broader and more encompassing than just medical practice. David's story illustrates this point. His first memory of being involved in any kind of medical practice, was physiotherapy at fifteen years of age. David's parents did not take up

medical discourse in how they related to David. He had no memory of them ever speaking about him having an impairment, being disabled or having any kind of disability. However, well before David remembered visiting the physiotherapist, he was subjected to discrimination at his school. His peers called him “spastic” and “retard”. At the time in which this occurred, David had not engaged with medical discourse but his friends and peers at school had and in his interaction with them he was objectified as being different from and not belonging with them.

The problem for disabled people concerning medical discourse is that any classification of impairment and illness is a construction that implies abnormality. This construction occurred when medicine shifted its focus “from ‘dis-ease’ [in the eighteenth century] to diseases” (Porter, 2006, p.83) in the nineteenth century. In “Birth of the Clinic” (1963), Foucault noted that in comparison to eighteenth century medicine, nineteenth century medical practice was “regulated more in accordance with normality than health; it formed its concepts and prescribed its interventions in relation to a standard of functioning and organic structure” (Foucault, 1963, p.35). Medicine focuses on the diagnosis and treatment of pathology for the purpose of curing and alleviating illness and impairment. It is an ambitious and somewhat never ending project. Despite the many technological advances in medicine over the years, recovery from all impairment and illness continues to elude medical science. The result therefore, at this point in time, is that medicine is not completely successful on the terms of its own agenda. Irrespective of a contradiction between the agenda of medicine and the degree of success achieved by medical practice relative to its agenda, health in the Western world has remained unchallenged as “the duty of each

and the objective of all” (Foucault, 1980, p. 170). This assumed legitimacy, within medical discourse, to prioritise health as an obvious objective for all people, has produced medicine to become “a world power [with] social privilege, economic power, and political influence” (Starr, 1982, p.4-5). Unfortunately, people with impairments and illness are not well-positioned within medical discourse to benefit from such privilege, power or influence. Instead, they encapsulate and depict abnormality, providing a contrast with which people can favourably compare themselves, thereby being able to take up the privileged subject position of normality or being normal.

However, to state that medical discourse only constructs deficit positions for people with impairments and/or illness does not present the entire story concerning how medical discourse constituted the lives of the participants. With the exception of David, all the participants gave accounts of how they had been subjected to medical discourse’s agenda of rehabilitation and/or medical recovery. In taking up the subject position of endeavouring to adapt well to an impairment or achieve increased levels of health, the participants did, at times, experience an increased sense of mastery on the terms of medical discourse. For example, Ron’s speech impairment lessened when he attended a speech therapy intensive, which proved to be very helpful by enabling him to communicate more freely. Ron said that as his speech improved, it “started to change the way I viewed myself. I was probably more comfortable in talking to people. I could hide my problem. There was quite a wacky personality starting to emerge.” By experiencing a reduction in his level of impairment, Ron was positioned less in deficit on the terms of medical discourse. He was able to take up a

subject position in which he had more agency because his impairment was less. Fay, also, very intentionally engaged with medical practice in regard to exploring medications that reduced the progression of her RA. She said, “long term if it’s (rheumatoid arthritis) not treated properly or quickly enough then you can get a reasonable amount of being out of control ’cause it’s an auto-immune disorder.” Hence, Fay participated in and experienced the medical progress that could be achieved through pharmacology.

John did not speak about his own journey of blindness rehabilitation but did speak as someone with knowledge and experience of blindness rehabilitation. For example, he made comments about how an orientation and mobility instructor should have responded in their role of supporting a blind person ride on a bus. Indeed, John’s life was a kind of demonstration that he had achieved the goals of blindness rehabilitaion. Much of John’s narrative storyline, of blindness being an opportunity for him, had been enabled by rehabilitation discourse. Like Ron, as John succeeded on the terms of rehabilitation and medical discourse, he became less constructed in deficit by those discourses. Jan’s story was that her illnesses had not progressed to the extent that medical specialists had predicted. As the subject who was doing better than expected, Jan was experiencing some improvement in relation to how she was able to measure herself against the expectations of medical discourse. Carole’s journey of success within the terms of medical discourse was different than Jan’s. Carole had not experienced any improvement through medical practice and was very much aware of how quickly her illness was progressing. However, through noticing that she did not like the effect on her of feeling sad and thinking negative thoughts, she had

decided to very intentionally position herself to collect good news about her body. As she began achieving some physical milestones she had set for herself, she was indeed generating good news about her body. This enabled her to engage with her familiar narrative storyline of “being determined” and “never being a giver-upperer”. As a former sportswoman, this was a subject position that Carole had always enjoyed and preferred.

In describing some of the participants’ accounts about the respective gains each had made in regard to reducing the disabling impact of their impairments and/or illnesses on their lives, it is worth noting that researching the process, effects and relative merits of medical and rehabilitation practice has always been the domain of medicine, rehabilitation and perhaps medical sociology. Academic scholars within Disability Studies have taken up a counter position to medical discourse. Advocates of the social model of disability have referred to the medical model as the individual tragedy theory of disability (Oliver, 1983, 1990, 1996). Their argument is that disability is a socially created phenomenon, produced by a society which does not accommodate the needs of people with impairment (Barnes, 1992; Oliver, 1990, 1996).

The advantages and limitations of disability rights’ discourses

Disability rights’ discourses have provided alternative subject positions for people with impairment and/or illness. Indeed, John and Fay’s accounts were conspicuous by the relative absence of deficit descriptions. John spoke positively about his life, claiming “it’s never been better for me... as a person, ain’t ever been better”. The life that John was referring to was his life after becoming blind: working as a blind

professional, representing his country in sport, becoming married, and enabling his children to have the option to attend university when no previous generations in his family had ever been given this opportunity. Fay's account of having an impairment and illness was similar to John's, in that she described her rheumatoid arthritis (RA), "as a gift given to me." She said RA was the catalyst for her living differently, including relating to her family differently, understanding her body differently, thinking about her faith and spirituality differently, and undertaking training and beginning a new career. David's account of his life was not like Fay and John's, in that, for many years the only subject position available to him was a deficit position. However, in telling his story, David was no longer caught in the subject position of his teenage years as the boy who felt "disdained". He was able to reflect on those years as having been defining experiences for him. He told his account from the position of someone who had traveled through the years of marginalisation and discrimination to become the subject who could identify and speak against disablism. He challenged the deficit subject position of medical discourse by becoming the "spastic with attitude" who "owned the [spastic] label now...it didn't own me, I owned it!" As the disabled but proud subject, David had committed himself to working with and improving life for other disabled people. By these actions, David refused the subject position of privilege and opportunity offered to him by his father in being mentored into the family business. Instead of continuing to take up this entrepreneurial agenda of striving for wealth and competing successfully in the market place, David shifted his orientation to prioritise an ethic of care and justice for other disabled people.

David and John's careers, in the field of disability rights and education, suggest that impairment was not necessarily a disability for them but most likely served them well. John described himself as someone who was "having a crack at changing society." He said only another blind person could "do the job the way I have done it." John's involvement with the RNZFB had not only assisted him to develop skills of orientation, independence and mobility as a blind person but had also provided the means by which he developed a career in blindness awareness and advocacy. This was a role that was not prohibited to him because he was blind but perhaps even the inverse, since being blind gave John a unique credibility when he was "on the soapbox" campaigning for the needs and rights of blind people. The same could be argued for David, as authenticity is invoked when a disabled person is advocating for and supporting other disabled people. In their jobs, David and John were the subjects who had 'insider' or 'local' knowledge (Foucault, 1980; Geertz, 1983) about the experience of disablement. In their careers, David and John took up and embodied the cause of the disability movement, which was to "mobilise for equal citizenship... [resisting] a demeaning reliance on charity, [and] demand[ing] their rights" (Shakespeare, 2006, p.30).

Disability rights' discourses have provided the cultural-political context whereby disabled people, like John and David, have become valued for the knowledge and understanding they have of the disability experience. John and David's experiences in the world of disability politics needs to be understood in terms of how they had been positioned within the history of the disability movement in New Zealand. Within recent years, due to the work of disability rights, a strategic shift has occurred

in the Western world, in which disabled people have become re-positioned from being recipients of help to becoming their own advocates of change. Here in New Zealand, the ‘New Zealand Council for the Disabled Incorporated’ changed its name in 1983 to the ‘Disabled Persons Assembly (New Zealand) Incorporated’. The organisation shifted from having an agenda of helping disabled people to being the vehicle by which disabled people campaigned for their own rights. Similarly, the Royal New Zealand Foundation of the Blind Act became law in 2002, which mandated that the governing board of RNZFB was voted in by the Foundation members, most of whom were legally blind. The RNZFB changed its name from the ‘Royal New Zealand Foundation *for* the Blind’ to the ‘Royal New Zealand Foundation *of* the Blind’ [*my italics*]. John’s involvement with blind awareness and advocacy occurred throughout this period. He well understood the intersection between his life as a blind person and the era of blindness and disability politics of which he was a part. He said, “It’s never been better for blind people than it is right now... it’s the blind man that gets the opportunity, it’s because I’m blind that I’ve had that opportunity.”

In contrast to David and John, the other participants were not directly involved in disability awareness, education and support of disabled people in such specific ways. Nonetheless, Fay, Carole, Jan and Ron’s accounts showed how they had, at different times, taken up ideas and practices that prioritised a disability rights’ perspective. Ron, for example, spoke about his hearing being fifty percent which was “normal” for him, indicating how he refused to story his hearing loss in deficit terms. Jan argued how it was unfair that she was denied home help because of being too young for the

illnesses she had. Carole had refused to be storied as someone who was less able to do challenging work on account of having an illness. She also resisted the invitation to only collect bad news about her body. Fay, when she first became ill, had difficulty understanding why her family was not helping her more with the work in the home, stating she expected her family to assist with the impact of her illness on her. Later, Fay had come to learn about the social model of disability and she said she had come to see how both the medical and social models informed how she made sense of, and responded to, experiences. Carole also discussed the medical model, and spoke respectfully and appreciatively of people who she described as having difficulties with their bodies. Ron spoke of how attitudes towards disabled people had changed, with society in recent years having become more accommodating of disabled people.

Given these examples of how the participants called on disability rights' ideas and practices to take up positions in which they were either advantaged or they refused positions of disadvantage, disability rights' discourses contributed to constructing opportunities and alternatives for the participants. However, there were other times when the participants resisted one subject position, preferring another and the process they called on to do this was not, for the most part, overtly informed by disability rights' discourses. Their actions of agency at the time of intersection between their narrative accounts of themselves and the social experiences they encountered, appeared to often be quite a new construction of meaning-making for them, one that was not necessarily identifiable to a disability rights' discourse. Hence, agency for the participants appeared to be less straightforward than conjecturing, for example,

that the ideas of normalisation and social role valorization helped David train, have a career and be financially independent just like non-disabled people. Another example would be assuming that Carole refused to be given less challenging work in her job because she knew she was being discriminated against on the basis of her illness, at which point she took a stand against the way societal attitudes, not her illness, was disabling her. This action would be an example of Carole accepting the position call of disability rights discourse. However, there was no indication from Carole's account that she had taken up disability rights ideas when she resisted against her workplace practice of no longer being given challenging work since having an illness. Instead, Carole named and critically questioned how people's actions of "kindness" meant she had been treated differently and disadvantaged on account of her having an illness.

Often, the negotiation of agency in the lives of the participants seemed more complex than my theoretical example of the disabled swimmer that I discussed earlier in Chapters Three and Four. In this illustration, the disabled swimmer either accepted the position call of medical discourse or refused it by calling on social model discourse, or even simultaneously accepted both position calls at the same time. However, in light of the participants' accounts, the subject positions they took up when acting with agency more reflected Davies et al.'s (2006, p. 93) view that a person is "constituted by multiple discourses, a subject who is in process, a verb rather than a noun." Potentially, the narrative and discursive resources available to people is multiple but at the same time very limited. They are multiple, because people would always have had experiences of and exposure to many discursive

resources by which to respond to a deficit position call in a way that might enable them to have agency, but limited because the power relation involved in the subject position produced by the dominant discourse is likely to colonise a person's meaning-making unless they have a well rehearsed counter discursive reply available to call on. An example of this was when Fay insisted that her rheumatologist work collaboratively with her and she actively resisted when he prescribed treatment without consulting her. She called on some negative experiences in hospital as a child to resist medical discourse's subject position of the patient who complies with the doctor. However, there were other times when the participants' expressions of agency represented them taking up a new subject position, such as when David decided he would like to make the world a better place for the person with an intellectual disability to whom he had just delivered a television. In that moment, he changed subject positions from being the young businessmen following in his father's footsteps to the disability advocate, and yet there is no evidence that he was consciously calling on disability rights' discourse when he did this. Indeed, it may have been his mother's ethic of compassion, care and solidarity in refusing to treat David as disabled, that David was taking up when he decided he wanted to help a man with an intellectual disability have "a better life."

What I have found interesting about the participants' actions of agency, therefore is that when they took up a new subject position, it often did not appear to represent an obvious reproduction of any disability rights' discourse. If this be so, then one implication for Disability Studies is that theorising of disablement has been useful for offering counter discourses to medical discourse and helpful for promoting the

disability rights' agenda in institutional matters, (such as the law, social policy, professional practice), but that the journey to equal rights and removal of social barriers for disabled people will not only be on the terms of the global political actions but will often be negotiated at a local level within the discursive complexity of individual's lives. In regard to the relevance of individual actions of resistance, Peters, Gabel and Symeonidou (2009) have noted that:

The disabled people's movement has frequently relied on tactics of contestation or 'single issue pressure group activity targeted at political decisionmakers' (Oliver 1990, p. 113), rather than on strategies of resistance that educate, 'conscientization' and take political action aimed at underlying sources of discrimination in the broader society... Understanding resistance globally at both the individual and collective level, and using it strategically, opens up a space for improved opportunities to create societies that are more just and equitable and freer from oppression. (p.546)

Researching people's processes of negotiating agency does, in my opinion, acknowledge and seek to learn how resistance to the subjugation of people with impairment and/or illness is both a local practice, as well as a global action. Moreover, it is through local actions of agency that new and alternative discourses emerge. For example, Paul Hunt met with other disabled people in the UK, which led to the formation of UPIAS, which in turn re-defined disability that then became the cornerstone of the disability movement and Disability Studies. Hence, it is important to research what Foucault (1980) referred to as "popular knowledges" from across the spectrum of those who have been disadvantaged on account of having an impairment and illness so as to discover the kinds of discursive and narrative resources that

people call on when they refuse those position calls that have been problematic for them. It is for this very reason that I have viewed the different illness and impairment experiences of the participants of this study as a strength of the research. For example, David and Ron were born with impairments. David has a clearly visible physical and speech impairment and Ron experiences speech and hearing impairments. Carole and Fay have progressive illnesses that impact their health and body abilities. John is blind. Jan has different illnesses, is hearing impaired and experiences medical fragility as a daily aspect of her life.

In theorising aspects of David, John, Fay, Carole, Jan and Ron's accounts in earlier chapters, three distinct narrative themes emerged: David's 'into, through and beyond deficit discourse', John and Fay's 'politics of difference and non-deficit identity claims', and Carole, Jan and Ron's 'actions of agency within deficit discourse'. The differences between the thematic narratives I have constructed in my telling of the participants' stories are quite considerable, which I would argue relates in part to the dissimilarity between the kinds of impairments and illnesses the participants had. That is, the kind of impairment and/or illness a person has is likely to impact what subject positions are available to them. For example, I would argue that Jan and Carole, with their chronic but largely invisible illnesses, were probably less able to take up the social model of disability discourse than David and John, both of whom had very visible impairments. Interestingly, the social model of disability makes no allowance for levels or types of disablement varying depending on the nature of a person's impairment and/or illness. Disability rights' discourses would typically be attributed to constructing John and Fay's narratives of 'politics of difference and non-

deficit identity claims' and yet as discussed, all the participants had at different times taken up disability rights' discourses. Carole, Jan and Ron tended to take up different discursive constructions than disability rights in their actions of agency. David and John were involved in public relations and disability rights and education roles and therefore it might be anticipated that disability rights' discourses would be constructing their actions of agency. However, in contrast to this expectation, their actions of agency and indeed all the participants' processes of agency, were unique to each person's respective narrative and discursive journey, which inevitably involved engagement with more social contexts than just medical and disability rights' discourses.

Hence, I would argue that disability rights' discourses are not the unequivocal and only answer for disabled people. As Shakespeare (2006, p.198) has claimed, "disability studies should be pluralist, valuing analytical rigour and debate. Disability researchers should look outwards and engage with medical sociology, bioethics and other areas of academia." In this study, with its emphasis on discourse and narrative, with a particular focus on agency, I have sought to take up this invitation.

Processes of agency

Ron's narrative storyline of being "a fighter" who overcame the odds as a person with hearing and speech problems, arose through his identification with the detective hero in Agatha Christie novels. During his teenage years, Ron said he indulged in these novels as an excursion into "a world that seemed simple and easier". He liked the way the novels invariably had a twist in the end, where the "detective surprised

everyone and cracked the case.” This idea became so much a metaphor for Ron’s life that he stated he preferred being second to first because in second place you “could always come from behind.” Ron’s life was a testimony to him engaging in this underdog subjectivity. For example, he surprised his classmates with how well he did in his studies after school. He counted down a stock car race, which was a very significant achievement given his speech impairment. He drove taxis which involved him having to communicate frequently and fluently using a two-way radio, and he trained in a profession that required him to be an excellent communicator. It would appear that Ron’s story of himself was how he succeeded in doing those activities which were difficult for him to do on account of his impairment. This story could be viewed as an account that had been solely constituted by rehabilitation and medical discourse, where Ron adapted to and reduced the degree by which his impairments disabled him. At the same time, it could be argued that Ron’s determination to not have his impairments prevent him from engaging in activities suggests he had taken up the ‘disabled and proud’ mantra of disability rights discourse. However, according to Ron’s account, what produced him to take up a subject position that provided him with a sense of success was his identification with the detective in crime fiction, a discourse that is beyond the terms of reference discussed in Disability Studies.

Fay and Jan’s accounts could be referred to as stories that are unique to the subject positions into which women are called. Their experience of impairment or illness meant they could no longer sustain the narratives they had been engaged in as women prior to having an impairment or illness, especially in relation to how they practised

being wives and mothers. Impairment and illness became the experience which enabled them to review the subject positions they had taken up as women. Fay came to realize she could pursue a different career and she could still support her husband by what she could offer emotionally and spiritually. Feminist discourses, more than disability rights' discourses, informed Fay when she shifted her position in relation to what she could commit to as a woman. Similarly, Jan gave up the practice learned within her family of origin of "having to do everything for everybody else [and] fix everybody else's problems." She came to realise that "being a good mother constitutes more than just doing everything for your child [and] because of the illness I've listened to people, especially to my daughter." Jan credited her illness with enabling her to have made this change and for having an improved relationship with her husband and daughter. She said, "I think we, [my husband and I], have a stronger friendship because we have taken the time to sit down and talk, we enjoy each other's company more and we appreciate the time we spend together." In this example, Jan has privileged relationship and communication discourse over working class women and puritan work ethic discourses.

Jan said she had been examining her family of origin as part of the study she had been doing and had come to realise she had "grown up in an abusive family [in which] I could find no strengths". In contrast to relationships based on abuse, Jan said she was seeing examples of "good relationships in the [new] church" she was attending, in which the "pastor and his wife ministered equally together, his wife was respected as a pastor... [and] he publicly claimed her to be equal with him and it was... teaching that women weren't second class citizens." Jan also credited her relationship with

God as helping her “change and grow”. She viewed her illness as “God’s way of slowing me down” and that without her illness, her marriage “would not be as strong as it is now... [and she] wouldn’t trade the world for that”. Hence, in response to the experience of illness, Jan’s narratives changed as she experimented and engaged with different subject positions. These changes were informed by communication and relationship discourses, feminist discourses, and faith discourses.

In contrast to Jan’s experiences of taking up new narratives in adulthood, Carole’s pre-illness narratives sustained and enabled her to take up agency through the difficult experience of having an illness. She drew on her sense of identity as a sportswoman and her analysis of power learned through her profession, to re-position herself when she felt positioned in deficit and not heard. She said “I would notice what it is that connects me with feelings of grief or different power hierarchies. I would review that and think about what I might need to do to talk to myself kindly about that or do something differently about that.” Carole also had an historical story of herself as “quite a happy sort of a person. I’m not an anxious person so it’s not natural for me to have worries” [and she was used to] “consciously connecting myself to different sorts of feelings. I would be an agent in that, rather than just thinking negative thoughts. I feel I have control and I act on it.” Hence, Carole brought considerable awareness and skills to her experience of having an illness. These narratives had been constituted prior to Carole becoming ill, informed by a range of discursive experiences, including but perhaps not restricted to feminist ideas and sport discourses. Carole’s experience of illness was relatively new for her, several years at the time I interviewed her. Her understanding of how her illness had

impacted her life was different from some of the other participants, in that she considered “it [the illness] has not added to my life in any way.”

John’s experiences, of course, were very different from Carole’s in that he viewed his blindness as having created an opportunity for him to have a better life. John’s subject positions changed after he became blind as he learned additional skills and took up a career in promoting blindness awareness and advocacy. However, John’s life as a blind person was still very much informed by his working class, poor, single parent family narrative in which he had storied himself as a “hard nut.” As John told his story, he took pride in the way he could challenge people, refusing to do what was asked of him if he so chose, commanding attention, and making an impact on a crowd of people. The “hard nut” subjectivity had not been passed over for other ways of being a man. He knew himself as the man who on the sports field, whether boyhood rugby or goal ball for blind people, would be extremely competitive. He said, when playing sport, “I don’t give an inch, not one bloody inch”. Even though John, by his very actions, was at the forefront of human rights and minority group politics, his childhood and youth narrative storylines continued to constitute how he performed as the blind professional. Hence, while John embodied the subject position of disability rights’ ideas and practices, he was also simultaneously taking up working class, dominant masculine, and sport competition discourses.

Ron and David were the two participants who had no pre-impairment narratives for they had always known life as people who had impairments. Much of their narratives were shaped by the discriminatory subject positions they experienced at school.

David found subject positions that afforded him a greater sense of belonging within marginalised groups, such as the rebel group at school and later visiting sex workers. The combination of mastering the terms of these particular discursive practices, along with some key moments in which he was able to take up agency, enabled David over time to re-write his narratives from deficit descriptions to narratives where he was the advocate of change for other disabled people. Such subject positions, while being representative of disability rights discourse, were not, according to David's account, entirely the production of disability rights' ideas and practices. A key aspect of David's journey to agency was the re-description of what the word "spastic" meant for him, from a label that denigrated him to a word that he owned and wore with pride. The shift for David in his relationship with the word "spastic" did not occur at a disability rights' meeting or rally or through reading Disability Studies literature but through love-making when his partner called him a "spastic" as a positive term when they were having sex. In being called the very word that had claimed his entry into ableism but during the time that he was taking up and enjoying sex discourse, David was able to reconstruct what the word meant for him. It was an experience generated through the conflation of discourses, when a possibility arises for the meanings held within one discourse to be exchanged for preferred meanings within another discourse. Indeed, this is the process of agency as defined by Davies, "when a person... having a sense of oneself that can go beyond the meanings in any one discourse... [can] forge something new... through imagining not what is but what might be" (Davies, 1991, p. 51). By re-describing the meaning of the word "spastic" to himself, David had been able to refuse the deficit subject position of being a spastic in a pejorative sense. And while David's account showed that he had taken up

disability rights' discourse in his journey of endeavoring to find belonging and acceptance again, his commentary indicated that it was sex and relationship discourses that provided him with access to a new subject position where he re-described what "spastic" meant for him.

In very different circumstances, Ron also found he was able to take up agency in respect of re-writing the subject position he had been subjected to at school, as a boy who had been discriminated against by some of his teachers. Ron told how he had "got even" when as an adult he had the opportunity to serve a meal to a former teacher of his whom he remembered had bullied him when he was at school. Ron no longer took up the subject position of the picked on and bullied child but took up a subject position that constructed his former teacher as the victim by serving him "the scungiest meal I could lower my standards to." In this moment of "revenge", Ron called on the autonomy and seniority of his role within his place of employment. His old teacher was on his discursive domain where Ron was no longer a pupil but a person with authority. The context provided the opportunity for Ron to take up agency and re-author an old and problematic narrative for himself as someone who had struggled to believe that he could succeed:

One's being shifts with the various discourses through which one is spoken into existence. The individual or heroic "I" is understood as a discursive construction, not stemming from the particular characteristics of that person but from the subject position made available to him/her. (Davies, 1991, p.43).

Whilst the discursive context that enabled Ron to take up agency could have been disability rights' discourse, on this occasion it appeared to be more the opportunity

presented through employment discourse. Of course, ideas of disability rights may well have been informing Ron at the time he took up the moment of “revenge” but even so, his account indicated that this was only one of several discursive ideas that prompted him to challenge the deficit subject position from his school years.

Secret, subjugated and contradictory subject positions

Carole referred to her daily experience of having an illness as her “secret world.” Carole’s illness was not easily noticeable or visible, which produced a disclosure dilemma for her. If she wanted to be heard and understood in her experience of illness then she needed to tell people what she was experiencing. However, the problem for her was that she had not found people’s responses to her disclosure about her illness as helpful for her, thereby creating a bigger “secret world.” Carole said she did not like the “secret world” and found it “quite depressing.” Part of Carole’s “secret world” involved her deciding how to act on contradictory subject positions. For example, Carole intentionally told people in her place of employment that “it is actually good for me to come to work because it forces me to sit down for a few hours every day and that is really good for me.” In saying this, Carole was taking up a position as a subject who enjoys her work and sees it as an important part of coping with her illness.

Carole was aware that her work was “difficult” for her and that “a lot of people don’t do paid work with this [illness].” However, she chose to “present a different idea” about how she experienced work because she had “genuinely realised over the holidays that this was part of the active things that I needed to do”. Clearly, Carole

was concerned that if she had presented both experiences, that work was good for her and it was difficult for her, then people would have responded more to the construction that work is difficult for her. She had previously experienced people not hearing her and “thinking I don’t mean it” when she had said “I am fine to do that work”. As a result, Carole shared only how work was good for her and the other aspect of her experience, that work was difficult for her, became storied in her “secret world”. Although Carole was the only participant who talked of having a “secret world”, the other participants discussed times when their experiences were specific to their impairment and/or illness, and therefore were beyond other people’s understanding.

Jan struggled with the dilemma of whether to have sex with her husband and “risk having an angina attack”, or not have sex with her husband thereby not risking angina but running the risk of “him getting his sexual needs met elsewhere.” Jan said she “struggled” with this problem but eventually talked about it with her husband. In this example, Jan was caught between different subject positions. Dominant male sex drive and Christian marriage discourses positioned Jan to want to make love to her husband but medical discourse positioned her to care for her health by not having sex. The risk for disabled people is that when they speak from the subject experience of their impairment and/or illness, it challenges dominant discourses. For example, Fay’s experiences of what it had been like for her having an impairment, informed how she spoke from “a consumer’s perspective” when advocating for a client. She was told by a non-disabled colleague, “that is personal for you, isn’t it.” The dilemma for Fay was that if she spoke from her impairment experience then she

served the needs of her clients but jeopardised her standing and conduct as a professional.

Ron said “every time I speak I fear that I will be ridiculed.” Ron said he did not discuss this fear very often, indicating by implication that he must have lived with this fear on his own as a daily part of his life. John also had experiences of being caught between subject positions. He said he could be “in the pub… after a hard day’s skiing” and people would say “did you see that blind skier up there today?” At this moment John is not being constructed as the blind skier because he “is passing as a sighted person”. However, he is not able to simultaneously take up the subject who is a non-blind skier and the subject who is the blind skier. The dominance of medical discourse means he either kept silent about his blindness or is constructed in the deficit subject position of being blind.

David’s impairment was too visible for him to be viewed as not disabled, which meant he was often constructed as being different, even if he was not taking up this construction for himself. David spoke of how a teacher had tried to educate the class about David’s impairment, introducing him as being “a spastic.” The subject position of being a “normal” student is taken from David at this point and he is publicly subjugated as the “spastic” student. Later, David redefined what the word “spastic” meant for him. He “owned the word” as an identity descriptor that could be positive for him when he referred to himself as “a big bad spastic mother fucker” when doing weights in the gym. In regards to being categorised as a “spastic”, David took up a preferred subject position about what it meant to him to be a spastic but what was not

available to him was a subject position of not being a “spastic”. Medical discourse was too dominant for David to escape being positioned as a “spastic”. David’s challenge had been how could he find a desirable subject position within the stigmatising label of “spastic”, given his preferred subject position of not being a spastic was unavailable to him.

Negotiating the power relation and agency

Secret, silenced and subjugated subject positions occur for people with impairments and/or illness because they are disadvantaged in power relations with others. Often the participants were able to re-position themselves when they were invited into a subject position that was problematic for them. These were the times in which they had access to subject positions that afforded them agency. John was positioned as a valued staff member because of his blindness. Carole took up coaching children so as to continue her legacy as a sportswoman. Jan negotiated an improved relationship with her husband and daughter. Fay took up a new career, which she preferred. David came to understand his negative teenage years were not because he had a flawed character but were people’s interpretations about him on the basis of his impairment. Ron took up a position as a subject who overcame experiences that he found challenging because of his impairments.

In agreeing to participate in this study, the participants were also positioned in a power relation with me as the researcher. A reflexive approach to my conversations with the participants about their lives recognises how “the qualitative research interview entails a hierarchical relationship with an asymmetrical power distribution

of interviewer and interviewee" (Kvale, 2006, p.484). The relationships I had with the participants prior to the study was varied. Three of the participants were studying in my place of work, a small educational institution, where I lecture and they had, previous to this study, attended one of the papers that I had taught. Of the other three participants, one person I knew quite well and two of the participants I had met once or twice before. Hence, in my relationship with all the participants I was taking up a dual role. This dual role was discussed at the start of my conversations with the participants, considering how being involved in this research project may alter my relationship with them or create vulnerability for them. With the three people studying at the institution where I worked, I took particular care to explore some of the potential problems that may arise for them because of participating in the study. Not all the participants approached the interviews with me in the same way. Jan, for example, said "I trust you to be professional and I trust you as a person". It was important for Jan to feel she could trust me and the process and she said that if she thought that she couldn't trust me then she would not have participated in the study. Whereas John said it was "no problem" to have the interviews and he was "fine with it". John took up a position of being happy to participate. Carole, on the other hand, positioned herself to gain something from participating in the study. She said, "I think there's quite a bit of potential to hold onto something I've lost and that's why I've decided to do it and while it might rub my nose in it a little bit, I think that will pass". Fay at the end of the first interview said to me "I think you've done very well" and at the conclusion of the second interview commented "Done pretty well, haven't we." In making these comments, Fay positioned herself more as an equal to me by first encouraging me and then defining the process as a shared task. David

made no comments that indicated how he was approaching the interviews or what they might mean for him. Ron said he was “used to being in a dual role” and he was known for being “open.”

During the second interviews, three of the participants reported that they had found the interviews helpful for them. Ron said:

Something that stood out to me is I get this feeling you were quite surprised by the journey that I had been on and upon reflection, although I see it as just the way things are, it actually is quite a journey and I probably don't honour it enough... It has probably helped me to find a little bit of strength... I think it helps me to go reminding me how far the journey has come I think.

Jan said:

Something that I did find interesting was that how strong the family was. In fact, a lot of the stuff we talked about I hadn't ever really sat down and thought about and even talked about the sickness and how I changed so much. It was really good to be able, for the first time probably to speak out and identify it. It was quite amazing, a lot of my past I haven't really thought about in terms of where things come from... It was interesting to see how many strengths my family did have. It was reassuring, and comforting I guess. I think it actually did give me a sense of peace within myself.

Carole said talking about her secret world had been “helpful” and led to her thinking more about “setting some goals for myself.” For Ron, Jan and Carole, it appeared they had access to a more agentic subject position as result of participating in the research.

Constructing narrative and discursive change

A key aspect of this study was exploring how power worked in the lives of the participants. The power relation within medical discourse constructs a deficit subject position for disabled people, where impairment and/or illness are viewed as a problem. In their accounts of resistance to being positioned in deficit, the participants while benefiting from the subject positions constructed by disability rights' discourses, also clearly called on a broader range of narrative and discursive resources than just disability rights ideas and practices. One implication from this finding, for future research about disability, is the relevance of researching further what narrative and discursive resources, people with impairments and illnesses call on when they resist those subject positions that situate them to experience disadvantage, marginalisation and discrimination.

This study's approach, of inviting the participants to give an account of their lives as people who live with impairments and/or illnesses, was effective for understanding how discourse, narrative and agency worked in the participants' lives. Within the interview process, a primary aim was to listen carefully for and inquire about how the participants refused or resisted those position calls that disadvantaged them. In seeking to understand the complex processes of how the participants called on and negotiated agency, it proved very important to explore how the language, especially the metaphors, evocative phrases and positioning statements, used by the participants, embodied and were a vehicle of discourse. For example, Fay said she preferred the mechanical metaphor of "not firing on all four or six cylinders" in comparison to the medical term of being "sick". This metaphor of an engine temporarily not working as

well as it might, needing a mechanical service, positioned Fay as a person who has rheumatoid arthritis (RA), to have increased agency at her work, in her relationship with her medical specialist and within her family. It was a metaphor that contributed to her being able to describe RA as a “gift given to me” which is a very different position call than the deficit descriptions of “sickness” and “illness” constructed by medical discourse. The metaphor allowed for Fay to have the symptoms of illness without having to take up the subject position of being an ill or sick person.

The participants’ use of metaphors and respective narrative storylines were not identical and the differences, at least in part, were related to the kinds of impairments and/or illness each person had. The social model of disability has not explored what subject positions are available to people on the basis of the nature of their impairment and/or illness. This would appear problematic because a key factor is being missed concerning what contributes to disablement. Any research of the relationship between impairment/illness and disablement would need to be considered carefully though because potentially impairments and illnesses could be compared one against another. However, understanding how discursive contexts support or disadvantage people with impairments and/or illness could be very useful. Research of this kind could lead to the development of ideas and practices in specific social contexts that seek to make alternative subject positions available for people with impairments and/or illness.

The complexity of the participants’ narratives and the existence of secret, subjugated and contradictory subject positions, is a relevant finding for professional practice. Medical discourse positioned the participants to manage aspects of their impairment

and/or illness experiences on their own. If education and health professionals focused on recognising and sensitively attending to the possibility of disabled people having a “secret world”, then it may become safer for people with impairments and illness to share their experience without the risk of being constructed in negative terms. On this note, Carole’s point was that “kindness” had not been helpful for her and David was very upset as a child when his teacher, “a magnanimous and kindly man”, introduced him to the class as “a spastic”. In these examples, the intentions of people toward Carole and David would appear to be well-meaning but the effects of their actions were not helpful. Given this, it might be useful for health professionals and those working in the disability field to undertake training in which they explore the language they use in their work and how this language, such as well-meaning “kindness” positions people with impairments and/or illness.

This research has highlighted that negotiating and understanding the subject positions a disabled person is taking up in engaging with a professional service is critical. Just as the participants positioned themselves in relation to me differently from each other, so too will disabled people approach professional practice on different terms from one another. If professionals in the health and disability field had the time and skills to explore what subject positions their client/patient is taking up, then that is likely to be helpful for establishing positive outcomes for the person with impairment and/or illness. If professionals impose their discipline’s discourse on clients/patients rather than endeavoring to negotiate some shared meanings about their work together, then commitment to and effectiveness of the process is likely to be negatively impacted.

The participants' actions of agency were all part of a journey. In this journey, key incidents happened when it became possible for them to take up preferred subject positions. Helping professionals could accordingly focus their practice on noticing, exploring and supporting these alternative storylines in the lives of people with impairments and/or illness. Given the power of medical discourse to subjugate disabled people, the need to develop and make available support that enables disabled people to recognise and take up preferred storylines in their lives is, I would argue, a political imperative. In other words, although it is critical to develop strategic and structural interventions that change the law, social policy and professional practice on the terms of disability rights, the participants' discussions about their lives demonstrated how they each engaged with a range of discursive and narrative ideas in taking up preferred subject positions.

Reducing disablement for people with impairments and/or illnesses can be an individual as well as a collective process. As disabled people take up agency in their lives, then the discursive understandings that have enabled such actions are being reproduced, thereby contributing to such discursive subject positions becoming more accessible to other disabled people. Inevitably, there is a reciprocal relationship between individual and collective action.

Finally, this study has left me very appreciative of the six people who were willing to engage in this study. Their actions of agency have illustrated how diverse the process is, and how powerful the positioning by medical discourse is in the lives of people with impairment and illness. Moreover, they have illustrated how attention and

support at the local level are as relevant as global actions for enabling people with impairments and/or illnesses to experience opportunities for agency in their lives.

BIBLIOGRAPHY

- Albrecht, G. (1992). *The disability business: Rehabilitation in America*. London: Sage.
- Andrews, M., Squire, C., & Tamboukou, M. (2008). (Eds.), *Doing narrative research*. London: Sage.
- Appleton, P., & Minchom, P. (1990). Models of parent partnership and child development centres. *Child: Care, Health & Development*, 17, 27-38.
- Arkwright, J. (2005). Disability: Theorising experiences in the critical analysis of discourse. *New Zealand Journal of Disability Studies*, 10, 33-56.
- Arkwright, J. (2008). Thinking beyond deficit positioning of self: Relevance for faith and practice. In R. Cook & I. Alexander (Eds.), *Interweavings: Conversations between narrative therapy and Christian faith*. (pp.126-142). North Charleston, S.C.: CreateSpace Books.
- Bakhtin, M. (1984). *Problems of Dostoevsky's poetics* (C. Emerson, Ed. & trans.). Minneapolis: University of Minnesota Press.
- Banister, P., Burman, E., Parker, I., Taylor, M., & Tindall, C. (1994). *Qualitative methods in psychology – a research guide*. Buckingham: Open University Press.
- Barnes, C. (1990). *The cabbage syndrome: The social construction of dependence*. Lewes: Falmer Press.
- Barnes, C. (1991). *Disabled people in Britain and discrimination*. London: Hurst & Co.
- Barnes, C. (1992). Institutional discrimination against disabled people and the campaign for anti- discrimination legislation. *Critical Social Policy*, 12, 5–22.
- Barnes, C. (1995). [Review of the book *Disability is not measles – new research paradigms in disability*, by M. Rioux & M. Bach (1994) (Eds.)] *Disability & Society*, 10(3), 378-381.

- Barnes, C. (1996). Theories of disability and the origins of oppression of disabled people in western society. In L. Barton (Ed.), *Disability and society: Emerging issues and insights*. London: Longman.
- Barnes, C. (1998). The social model of disability: A sociological phenomenon ignored by sociologists? In T. Shakespeare (Ed.), *The disability reader*. London: Continuum.
- Barnes, C., & Mercer, G. (1996b). (Eds.), *Exploring the divide: Illness and disability*. Leeds: The Disability Press.
- Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability, a sociological introduction*. Cambridge: Polity.
- Barnes, C. (1998). [Review of the book *The rejected body*, by S. Wendell, (1996)]. *Disability & Society*, 13(1), 145-147.
- Barnes, C. (1999). Disability studies: new or not so new directions, *Disability & Society*, 14(4), 577-580.
- Barnes, C. (2000). A working social model? Disability, work and disability politics in the 21st century. *Critical Social Policy*, 20, 441 - 457.
- Barton, L. (1993). The struggle for citizenship: The case of disabled people. *Disability, Society & Handicap*, 8(3), 235-248.
- Barton, L. (1998). Sociology, disability studies and education: Some observations. In T. Shakespeare (Ed.), *The Disability Reader*. London: Continuum.
- Barton, L., & Oliver, M. (1997). *Disability studies: Past, present and future*. Leeds: Disability Press.
- Beauchamp, T., & Childress, J. (2009). *Principles of biomedical ethics*. (6th Edn.). Oxford: Oxford University Press.
- Bateson, G. (1979). *Mind and nature: A necessary unity*. New York: Dutton.

- Best, S. (2007). The social construction of pain: An evaluation. *Disability & Society*, 22(2), 161–171.
- Berger, R. (2004). Pushing forward: Disability, basketball and me. *Qualitative Inquiry* 10, 794-810.
- Bird, J. (2004). *Talk that sings, therapy in a new linguistic key*. Auckland: Edge Press.
- Boazman, S. (1999). Inside aphasia. In M. Corker & S. French (Eds.), *Disability discourse* (pp.13-14). Buckingham: Open University Press.
- Booth, T. & Booth, W. (1996). Sounds of silence: Narrative research with inarticulate subjects. *Disability & Society*, 11(1), 55-69.
- Bowkin, N., & Tuffer, K. (2002). Disability discourses for online identities. *Disability & Society*, 17(30), 327–344.
- Brechin, A., & Walmsley, J. (1989). *Making connections: Reflecting on the lives and experiences of people with learning difficulties*. London: Hodder & Stoughton.
- Briggs, L. (1993). Striving for independence. In J. Swain, V. Finklestein, S. French & M. Oliver (Eds.), *Disabling barriers – enabling environments* (pp. 129-135). London: Sage.
- Brisenden, S. (1986). Independent living and the medical model of disability. *Disability, Handicap & Society*, 1(2), 173-178.
- Brown, H. (1994). A normal sexual life?: A review of the principle of normalization as it applies to the sexual options of people with learning disabilities. *Disability & Society*, 9(2), 123-144.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge: Harvard University Press.
- Bruner, J. (1990). *Acts of meaning*. Cambridge: Harvard University Press.
- Bruner, J. (1991). Self-making and world-making. *Journal of Aesthetic Education*, 1, 67-78.

- Burr, V. (2003). *Social constructionism* (2nd Ed.). London: Routledge.
- Bury, M. (1996a). Defining and researching disability: challenges and responses. In C. Barnes & G. Mercer (Eds.), *Exploring the divide: chronic illness and disability*. Leeds: The Disability Press.
- Bury, M. (1996b). Disability and the myth and the independent researcher: A reply. *Disability & Society*, 11(1), 111-113.
- Bury, M. (2005). *Health and illness*. Cambridge: Polity Press.
- Butler, J. (1997). *The psychic life of power*. Stanford, CA: Stanford University Press.
- Cameron, C. (2007). Whose problem? Disability narratives and available identities. *Community Development Journal*, 42(4), 501–511.
- Campbell, J., & Oliver, M. (1996). *Disability politics: understanding our past, changing our future*. London: Routledge.
- Carr, M. (1997). Technological practice in early childhood as a dispositional milieu, pp. 84 – 110. PhD thesis. Hamilton: University of Waikato.
- Chase, S. (2003). Learning to listen: Narrative principles in qualitative research methods course. In R. Josselson, A. Lieblich & D. McAdams. (Eds.), *Up close and personal, the teaching and learning of narrative research*. (pp. 79-99). Washington: American Psychological Association.
- Cixous, H. & Derrida, J. (2001). *Veils: Cultural memory in the present* (trans. Geoffrey Bennington). Stanford, CA: Stanford University Press.
- Clarke, A. (2003). Biomedicalization: Technoscientific transformations of health, illness, and US biomedicine. *American Sociological Review*, 68(2), 161-194.
- Cohen, L., Manion, L., & Morrison, K. (2001). *Research methods in education* (5th Ed.), New York: RoutledgeFalmer.
- Corker, M. (1999). Differences, conflations and foundations: the limits to the ‘accurate’ theoretical representation of disabled people’s experience. *Disability & Society*, 14(4), 627-642.

- Corker, M., & French, S. (1999). (Eds.), *Disability discourse*. Philadelphia: Open University Press.
- Corker, M., & Shakespeare, T. (2002). (Eds.), *disability / postmodernity*. London: Continuum.
- Crocket, K. (2002). Introducing counsellors to collaborative supervision. *The International Journal of Narrative Therapy and Community work*, (4), 19-24.
- Crow, L. (1996). Including all of our lives: Renewing the social model of disability. In J. Morris (Ed.), *Encounters with strangers, feminism and disability* (pp. 206-226). London: The Women's Press.
- Danermark, B., & Gellerstedt, L. (2004). Social justice: redistribution and recognition—a non-reductionist perspective on disability. *Disability & Society*, 19(4), 339 – 353.
- Danforth, S., & Rhodes, C. (1997). Deconstructing disability. *Remedial & Special Education*, 18(6), Nov/Dec, 357-367.
- Davidson, I. (1994). Images of disability in 19th Century British children's literature. *Disability & Society*, 9(1), 33-46.
- Davies, B. (1991). The concept of agency: A feminist poststructuralist analysis. *Postmodern Critical Theorising*, 30, 42-53.
- Davies, B. (1998). Psychology's subject: A commentary on the relativism/realism debate. In I. Parker (Ed.), *Social constructionism, discourse and realism* (pp. 133-145). London: Sage.
- Davies, B. (2000). *Inscribing body/landscape relations*. Oxford: AltaMira Press.
- Davies, B., & Laws, C. (2000). Poststructuralist theory in practice: working with "behaviourally disturbed" children. *Qualitative Studies in Education*, 13(3), 205-221.
- Davies, B., Browne, J., Gannon, S., Hopkins, L., McCann, H., & Wihlborg, M. (2006). Constituting the feminist subject in poststructuralist discourse. *Feminism Psychology*, 16(1), 87-103.

- Davies, B., & Davies, C. (2007). Having, and being had by, “experience”: or “experience” in the social sciences after the discursive/poststructuralist turn. *Qualitative Inquiry*, 13, 1139-1159.
- Davies, B., & Harré, R. (1990). Positioning: The discursive production of selves. *Journal for the Theory of Social Behaviour*, 20(1), 43-63.
- Davies, B., & Harré, R. (1999). Positioning and personhood. In R. Harré & L. Van Langengrove (Eds.), *Positioning theory*. (pp.32-53). Oxford: Blackwell.
- Davis, S., & Buskt, W. (2008). (Eds.), *21st century psychology: A reference handbook*. Los Angeles: Sage.
- Davis, K., & Watson, N. (2002). Disabled children’s resistance to societal stigma. In T. Shakespeare & M. Corker (Eds.), *disability/postmodernity* (pp. 159-74.). London: Continuum.
- DeJong, G. (1983). Defining and implementing the independent living concept. In N. Crew, N. & I. Zola (Eds.), *Independent living for physically disabled people* (pp.4-27). San Francisco: Jossey-Bass Publishers.
- Derrida, J. (1977). *Signature: Event contest*. Evanston: NorthWestern University Press.
- Derrida, J. (2000). Différance. In P. du Gay., J. Evans & P. Edmonds. (Eds.), *Identity: A reader*. (pp.87-93). London, Sage.
- Drake, R. (1994). The exclusion of disabled people from positions of power in British voluntary organisations. *Disability & Society*, 9(4), 461-480.
- Drake, R. (2000). Disabled people, New Labour, benefits and work. *Critical Social Policy*, 20, 421 – 439.
- Driedger, S., Crooks, V., & Bennett, D. (2004). Engaging in the disablement process over space and time: Narratives of persons with multiple sclerosis in Ottawa, Canada. *Canadian Geographer*, 48(2), 119-136.

- Drewery, W. (2005). Why we should watch what we say – position calls, everyday speech and the production of relational subjectivity. *Theory & Psychology*, 15(3), 305-324.
- Drewery, W., Winslade, J. & Monk, G. (2000). Resisting the dominating story: toward a deeper understanding of narrative therapy. In R. Neimeyer & J. Raskin (Eds.), *Constructions of disorder* (pp. 243-263). Washington DC: American Psychological Association.
- Earl, S. (1999). Facilitated sex and the concept of sexual need: disabled students and their personal assistants. *Disability & Society*, 14(3), 309-323.
- Engel, G. L. (1977). *The need for a new medical model: A challenge for biomedicine*. Science, 196(4286), 129-196.
- Epston, D. (1989). *Collected papers*. Adelaide: Dulwich Centre Publications.
- Epston, D. (1996). *Catching up with David Epston: A collection of narrative practice-based papers, published between 1991 and 1996*. Adelaide: Dulwich Centre Publications.
- Epston, D., & White, M. (1990). A storied therapy. In D. Epston., & M. White (Eds.), *Literary means to therapeutic ends*. (pp.77-187). New York: W.W. Norton & Co, Inc.
- Epston, D., & White, M. (1992). *Experience, contradiction & imagination*. Adelaide: Dulwich Centre Publications.
- Fabian, H., & Dunlop, A. (2005). The importance of play in the transition to school. In J. Moyles (Ed.), *The excellence of play*. (pp.228-241). Maidenhead, England: McGraw Hill.
- Ferguson, M. (1992). The puzzle of inclusion: A case study of autistic students in the life of one high school. In P. Ferguson, D. Ferguson & S. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 145-174). New York: Teachers College Press.
- Ferguson, P., Ferguson. D., & Taylor, S. (1992) (Eds.), *Interpreting disability: A qualitative reader* (pp. 145-174). New York: Teachers College Press.

- Fine, M. (1985). Unearthing contradictions: An essay inspired by "Women and Male Violence". *Feminist Studies*, 11(2), 391-407.
- Fine, M., & Asch, A. (1993). Disability beyond stigma: social interaction, discrimination and activism. In M. Nagler (Ed.), *Perspectives on disability*. (2nd ed). Palo Alto: Health Markets Research.
- Finklestein, V. (1980). *Attitudes and disabled people: Issues for discussion*. New York: World Rehabilitation Fund.
- Finklestein, V. (1996). Outside, "inside out". *Coalition*, April, 30-36.
- Finkelstein, V. (2001). *A personal journey into disability politics*. Leeds: University of Leeds, Centre for Disability Studies.
- Foucault, M. (1963). *The birth of the clinic. An archaeology of medical perception*. (A. M. Sheridan, Trans.) 1997. New York: Vintage Books.
- Foucault, M. (1972). *The archeology of knowledge*. London: Tavistock.
- Foucault, M. (1980). *Power/Knowledge: selected interviews & other writings*. (C. Gordon, Trans.). New York: Pantheon.
- Frank, A.W. (1991) For a sociology of the body: An analytical review. In M. Featherstone., M. Hepworth & B. Turner, B. (Eds.), *The body: Social process and cultural theory*. London: Sage.
- Frank, A. (1995). *The wounded storyteller*. Chicago: University of Chicago Press.
- Frank, A. (2000). The standpoint of the storyteller. *Qualitative Health Research*, 10(3), 354-365.
- Frank, A. (2002). How can they act like that? Clinicians and patients as characters in each other's stories. *The Hastings Centre Report*, 32(6), 14-22
- Frank, A. (2004a). After methods, the story: From incongruity to truth in qualitative research. *Qualitative Health Research*, 14(3), 430-440.
- Frank, A. (2004b). Asking the right question about pain: narrative and phronesis. *Literature & Medicine*, 23(2), 209-225.

- Frank, A. (2004c) *The renewal of generosity*. Chicago, IL: The University of Chicago Press.
- Frank, A. (2005a). *Narrative selves in a world of stories* [Public Lecture]. University of Technology, Auckland.
- Frank, A. (2005b). What is dialogical research, and why should we do it? *Qualitative Health Research*, 15, 964-974.
- Frank, A. (2007). The five dramas of illness. *Perspectives in Biology & Medicine*, 50(3), 379-394.
- Frank, A. (2008). Generous medicine: Complexity, responsibility, and the simplest questions. *Families, Systems & Health*, 26(3), 317-327.
- French, S. (1993). Disability, impairment or something in between? In J. Swain., V. Finklestein., S. French & M. Oliver (Eds.), *Disabling Barriers – Enabling Environments*. London: Sage.
- French, S. (1995). Visually impaired physiotherapists: their struggle for acceptance and survival. *Disability & Society*, 10(1), 3-20.
- French, S. (1999). The wind gets in my way. In M. Corker & S. French (Eds.), *Disability discourse* (pp.15-20). Buckingham: Open University Press.
- French, S. & Swain., J. (2006). Telling stories for a politics of hope. *Disability & Society*, 21(5), 383-396.
- Frye, N. (1990). *Anatomy of criticism: Four essays*. Princeton: Princeton University Press.
- Fulcher, G. (1992). *Disabling policies? A comparative approach to education policy and disability*. London: Falmer.
- Gabel, S. & Peters, S. (2004). Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disability & Society*, 19(6), 585-600.
- Galvin, R. (2003a). The making of the disabled identity: A linguistic analysis of marginalisation. *Disability Studies Quarterly*, 23(2), 149-178.

- Galvin, R. (2003b). The function of language in the creation and liberation of disabled identities: From Saussure to contemporary strategies of government. *Australian Communications Journal*, 30(3), 83-100.
- Galvin, R. (2003). The paradox of the disability culture: The need to combine versus the need to let go. *Disability & Society*, 18(5), 675-690.
- Galvin, R. (2005). Researching the disabled identity: Contextualising the identity transformations which accompany the onset of impairment. *Sociology of Health & Illness*, 27(3), 393-413.
- Galvin, R. (2006). A genealogy of the disabled identity in relation to work and sexuality. *Disability & Society*, 21(5), 499-512.
- Garro, L. & Mattingly, C. (1998). Narrative as construct and construction. In C. Mattingly & L. Garro. (Eds.), *Narrative and the cultural construction of illness and healing* (pp.1-49). London: University of California Press.
- Geertz C. (1985). *Local knowledge: Further essays in interpretative psychology*. New York: Basic Books.
- Gergen, K. (1991). *The saturated self: Dilemmas of identity in contemporary life*. New York: Basic Books.
- Gergen, K. (1994). The cultural consequence of deficit discourse. In K. Gergen. *Realities and relationships: Soundings in social constructionism*. (pp. 143-164). Massachusetts: Harvard University Press.
- Goodley, D. & Rapley, M. (2002). Changing the subject: Postmodernity and people with learning disabilities. In M. Corker & T. Shakespeare (Eds.), *disability / postmodernity* (pp. 127-142). London: Continuum.
- Goodley, D., Lawthom, R., Clough, P., & Moore, M. (2004). *Researching life stories*. London: Routledge-Falmer.
- Graham, L. & Slee, R. (2008). An illusory interiority: Interrogating the discourse/s of inclusion. *Educational Philosophy & Theory*, 40(2), 277-293.
- Greene, M. (1995). *Releasing the imagination: Essays on education, the arts, and social change*. San Francisco: Jossey-Bass.

- Gustavsson, A. (2004). The role of theory in disability research: springboard or strait-jacket? *Scandinavian Journal of Disability Research*, 6(1), 55-70.
- Hahn, H. (1988). The politics of physical differences: disability and discrimination. *Journal of Social Issues*, 44(1), 39-47.
- Hahn, H. (1989). Disability and the reproduction of bodily images: The dynamics of human appearances. In J. Wolch. & M. Dear (Eds.), *The power of geography*. (pp.370-389). Boston: Urwin Hyman.
- Hahn, H. (1993). Can disability be beautiful? In M. Nagler (Ed.), *Perspectives on disability* (2nd ed.) (pp.217-227). Palo Alto: Health Markets Research.
- Harris, J. (2003). 'All doors are closed to us': a social model analysis of the experiences of disabled refugees and asylum seekers in Britain. *Disability & Society*, 18(4): 395-410.
- Heaton, J. (1999). The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. *Sociology of Health & Illness*, 21(6), 759–777.
- Higgins, P. (1992). Working at mainstreaming. In P. Ferguson, D. Ferguson & S. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 103-123). New York: Teachers College Press.
- Hughes, B. (1999). The constitution of impairment: modernity and the aesthetic of oppression. *Disability & Society*, 14(2): 155-72.
- Hughes, B. (2007). Being disabled: Towards a critical social ontology for disability studies. *Disability & Society*, 22(7), 673-684.
- Hughes, B. & Paterson, K. (1997). The social model of disability and the disappearing body: towards a sociology of impairment. *Disability & Society*, 13(3), 325-340.
- Hughes, B., Patterson, R. Russell, E., Tulle-Winton, M., & Tyler, M. *The body, culture, and society, An introduction*. Buckingham: Open University.
- Humphrey, J. (2000). Researching disability politics, or, some problems with the social model in practice. *Disability & Society*, 15(1): 63-85.

- Hunt, P. (1966). The critical condition, chapter one of *Stigma: The experience of disability*. London: Geoffrey Chapman. In T. Shakespeare (Ed.), (1998). *The Disability Reader*. London: Continuum.
- Illich, I., Zola, I., McKnight, J., Caplan, J., & Sharden, H. (1977). *Disabling professions*. London: Marion Boyars.
- Islam, Z. (2008). Negotiating identities: the lives of Pakistani and Bangladeshi young disabled people. *Disability & Society*, 23(1), 41–52.
- Josselson, R., Lieblich, A. & McAdams D. (Eds.) (2003). *Up close and personal, the teaching and learning of narrative research*. Washington, DC: American Psychological Association.
- Kaluanes, V., & Rubenfeld, P. (1997). Disabled women and reproductive rights. *Disability & Society*, 12(2), 203-221.
- Keith, L. & Morris, J. (1995). Easy targets: a disability rights perspective on the 'children as carers' debate. *Critical Social Policy*, 15, 36 – 57.
- Kinavey, C. (2006). Explanatory models of self-understanding in adolescents born with spina bifida. *Qualitative Health Research*, 16(8), 1091-1107.
- Kvale, S. (2006). Dominance through interviews and dialogues. *Qualitative Inquiry*, 12(3), 480-500.
- Kvale, S. & Brinkmann, S. (2009). *InterViews: Learning the craft of qualitative research interviewing* (2nd ed.). London: Sage.
- Laws, C. & Davies, B. (2000). Poststructuralist theory in practice: Working with behaviourally disturbed children. *Qualitative Studies in Education*, 13(3), 205-221.
- Llewellyn, A., & Hogan, K. (2000). The use and abuse of models of disability. *Disability & Society*, 15(1): 157-65.
- Locke, T. (2004). *Critical discourse analysis*. London: Continuum.
- Lyotard, J. (1984). *The postmodern condition: A report on knowledge*. Minneapolis: University of Minnesota Press.

- Mattingly, C. (1998). *Healing dramas and clinical plot – the narrative structure of experience*. Cambridge: Cambridge University Press.
- Mattingly, C., & Lawlor, M. (2000). Learning from stories: narrative interviewing in cross cultural research. *Scandinavian Journal of Occupational Therapy*, 7, 4-14.
- Mcdonald, K., Keys, C., & Balcazar, F. (2007). Disability, race/ethnicity and gender: themes of cultural oppression, acts of individual resistance. *American Journal of Psychology*, 39, 145-161.
- Ministry of Health. (2001). *The New Zealand Disability Strategy: Making a world of difference – whakanui oranga*. Wellington: Author.
- Moore, M., Beazley, S. & Maelzer, J. (1998). *Researching disability issues*. Buckingham: Open University Press.
- Morgan, A. (2000). *What is narrative therapy? An easy to read introduction*. Adelaide: Dulwich Centre Publications.
- Morris, D. (2000). How to speak postmodern: Medicine, illness & cultural change. *The Hastings Centre Report*, 30(6), 7-16.
- Morris, J. (1991). *Pride against prejudice: transforming attitudes to disability*. London: The Women's Press.
- Morris, J. (1993). *Independent lives? Community care and disabled people*. London: McMillan.
- Morris, J. (1996). (Ed.), *Encounters with strangers: Feminism and disability*. London: The Women's Press.
- Morris, J. (2004). Independent living and community care: A disempowering framework. *Disability & Society*, 19(5), 427-442.
- Neimeyer, R. (1998). *Lessons of loss: A guide to coping*. New York: McGraw-Hill.
- Nelson, H. (2001). *Damaged identities, narrative repair*. Ithaca, New York: Cornell University Press.

- Nelson, G., Clarke, J., Febbraro, A., & Hatzipantelis, M. (2005). A narrative approach to the evaluation of supportive housing: stories of home. *Psychiatric Rehabilitation Journal*, 29(2), 98-104.
- Nettleton, S. (1998). *The sociology of health and illness*. Malden: Blackwell Publishers.
- Newell, (1996). The disability rights movement in Australia: A note from the trenches. *Disability & Society*, 11(3), 429-432.
- Nirje, B. (1969). The normalization principle and its human management implications. In R.Kugel & W. Wolfensberger (Eds.), *Changing patterns in residential services for the mentally retarded*. (pp. 179-195). Washington DC: President's Committee on Mental Retardation.
- Norrick, N. (2005). The dark side of tellability. *Narrative Inquiry*, 15(2), 323-343.
- Ohman, M., Soderberg, S., & Lundman, B. (2003). Hovering between suffering and enduring: the meaning of living with serious chronic illness. *Qualitative Health Research*, 13(4), 528-542.
- Oliver, M. (1983). *Social work with disabled people*. Basingstoke: Macmillan.
- Oliver, M. (1990). *The politics of disablement*. London: MacMillan Education.
- Oliver, M. (1992). Changing the social relations of research production? *Disability, Handicap & Society*, 7(2), 101-114.
- Oliver, M. (1993). *Disability, citizenship and empowerment*. Milton Keynes: Open University Press.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. Basingstoke: MacMillan.
- Oliver, M. (1999). Final accounts and the parasite people. In M. Corker, & S. French. *Disability Discourse*. (pp.183-191). Buckingham: Open University Press.
- Packer, M., & Greco-Brooks, D. (1999). School as a site for the production of persons. *Journal of Constructivist Psychology*, 12(2), 131-151.

- Parker, J. (1975). To understand. In L. Buscaglia (Ed.), *Counseling the disabled and their parents*. Thorofare, NJ: Charles. B. Slack.
- Parker, I. (1992). *Discourse dynamics: Critical analysis for social and individual psychology*. London: Routledge.
- Parker, I. (1999). Introduction: Varieties of discourse and analysis. In. I. Parker, *Critical textwork: An introduction to varieties of discourse and analysis* (pp. 1-12). Buckingham: Open University Press.
- Paterson, K. & Hughes, B. (1999). Disability studies and phenomenology: the carnal politics of everyday life. *Disability & Society*, 14(5), 597-610.
- Paterson, K., & Hughes, B. (2000). Disabled Bodies. In P. Hancock, B. Hughes, E. Jagger, K. Paterson, R. Russell, E. Tulle-Winton & M. Tyler (Eds.), *The body, culture, and society, an introduction*. Buckingham: Open University.
- Perrin, B., & Nirje, B. (1989). Setting the record straight: a critique of some frequent misconceptions of the normalisation principle. In A. Brechin & J. Walmsley (Eds.), *Making connections: Reflecting on the lives and experiences of people with learning difficulties* (pp. 220-246). London: Hodder & Stoughton.
- Peters, S. (2009). Responsive, reciprocal relationships: The heart of the Te Whaariki curriculum. In J. Papatheodorou., & J. Moyles. (Eds.), *Learning together in the early years: Exploring relational pedagogy*. (pp.24-35). London: Routledge.
- Peters, S., Gabel, S., & Symeonidou, S. (2009). Resistance, transformation and the politics of hope: imagining a way forward for the disabled people's movement. *Disability & Society*, 24(5), 543-556.
- Pfeiffer, D. (1992). A comment on the social model(s). *Disability Studies Quarterly*, 22(4), 234-235.
- Pfeiffer, D. (1994). The Americans with Disabilities Act: Costly mandates or civil rights? *Disability & Society*, 9(4), 533-542.

- Phillips, D. (2007). Embodied narratives: Control, regulation and bodily resistance in the life course of older women with learning difficulties. *European Review of History—Revue européenne d'Histoire*, 14(4), 503-524.
- Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. Albany: State University of New York Press.
- Porter, R. (1999). *The greatest benefit to mankind: A medical history of humanity*. New York: WW. Norton & Co.
- Porter, R. (2004). *Blood & guts: A short history of medicine*. New York: WW. Norton & Co.
- Priestly, M. (1998). Childhood Disability and Disabled Childhoods – Agendas for Research. *Childhood*, 5(2), 207-23.
- Priestly, M. (1999). Discourse and identity: disabled children in mainstream high schools. In M. Corker & S. French (Eds.), *Disability Discourse* (pp.92-102). Buckingham: Open University Press
- Priestly, M. (2001). (Ed.), *Disability and the life course: Global perspectives*. Cambridge: Cambridge University Press.
- Pringle, R. (2003). Doing the damage? An examination of masculinities and men's rugby experiences of pain, fear and pleasure. PhD thesis. Hamilton: University of Waikato.
- Reinelt, C., & Fried, M. (1993). "I am this child's mother": A feminist perspective on mothering with a disability. In M. Nagler (Ed.), *Perspectives on disability* (2nd ed.) (pp.195-202). Palo Alto: Health Markets Research.
- Reynolds, J., & Walmsley, J. (1998). Care, support or something else. In A. Brechin, J. Walmsley, J. Katz & S. Peace (Eds.), *Care matters: concepts, practice and research in health and social care*. (pp. 66-78). London: Sage.
- Rich, L., Simmons, J., Adams, D., Thorp, S., & Mink, M. (2008). The afterbirth of the clinic: a Foucauldian perspective on "House M.d." and American medicine in the 21st century. *Perspectives in Biology and Medicine*, 51(2), 220-237.

- Riessman, C. (1993). *Narrative analysis*. London: Sage.
- Riessman, C. (2003). Performing identities in illness narrative: Masculinity and multiple sclerosis. *Qualitative Research* (3), 5-33.
- Riessman, C. (2008). *Narrative methods for the human sciences*. (2nd edn.). London: Sage Publications.
- Rioux, M. & Bach., M. (Eds.) (1994). *Disability is not measles: New research paradigms in disability*. New York: L'Institut Roeher Institute.
- Rock, P. (1996). Eugenics and euthanasia: A cause for concern for disabled people, particularly disabled women. *Disability & Society*, 11(1), 121-128.
- Roesta G., Kristiansenb, K., Van Hovea, G., & Vanderplasschena, W. (2007). Living through exposure to toxic psychiatric orthodoxies: exploring narratives of people with 'mental health problems' who are looking for employment on the open labour market. *Disability & Society*, 22(3), 267-281.
- Rose, N. (2007). *The politics of life itself: Biomedicine, subjectivity and power in the twenty first century*. Princeton: Princeton University Press.
- Samuels, E. (2002). Critical divides: Judith Butler's body theory and the question of disability. *NWSA Journal*, 14(3), 58-76.
- Sampson, E. (1993). Identity politics. Challenges to psychology's understanding. *American Psychologist*, 48(12), 1219 –1230.
- Scotch, R. (2002). Paradigms of American social research on disability: What's new? *Disability Studies Quarterly*, 22(2): 23-34.
- Shakespeare, T. (1993). Disabled people's self-organization: a new social movement? *Disability, Handicap & Society*, 8(3), 249-264.
- Shakespeare, T. (1994). Cultural representations of disabled people: dustbins for disavowal? *Disability & Society*, 9(3), 283-299.
- Shakespeare, T. (1995). Back to the future? New genetics and disabled people. *Critical Social Policy*, 15, 22-35.

- Shakespeare, T. (2006). *Disability rights and wrongs*. New York: Routledge.
- Shakespeare, T., Gilleppe-Sells, K. & Davies, D. (1996). *The sexual politics of disability*. London: Cassell.
- Shakespeare, T. & Watson, N. (2002). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, (2), 9-28.
- Shuttleworth, R. (2002). Defusing the adverse context of disability and desirability as a practice of the self for men with cerebral palsy. In M. Corker & T. Shakespeare (Eds.), *disability / postmodernity* (pp.112-126). London: Continuum.
- Silburn, L. (1993). A social model in a medical world: the development of the integrated living team as part of a strategy for younger disabled people in North Derbyshire. In J. Swain, V. Finklestein, S. French & M. Oliver (Eds.), *Disabling barriers – enabling environments* (pp. 218-232). London: Sage.
- Slack, S. (1999). I am more than my wheels. In M. Corker & S. French (Eds.), *Disability discourse* (pp.21-27). Buckingham: Open University Press.
- Smith, B., & Sparkes, A. (2005). Men, sport, spinal cord injury and narratives of hope. *Social Science & Medicine*, 61(5), 1095-1105
- Smith, B., & Sparkes, A. (2006). Narrative inquiry in psychology: Exploring the tensions within. *Qualitative Research in Psychology*, 3(3), 169-192.
- Smith, B., & Sparkes, A. (2008a). Changing bodies, changing narratives and the consequences of tellability: a case study of becoming disabled through sport. *Sociology of Health & Illness*, 30(2), 217-236.
- Smith, B., & Sparkes, A. (2008b). Contrasting perspectives on narrating selves and identities: an invitation to dialogue. *Qualitative Research*, 8(1), 5-35.
- Smith, B., & Sparkes, A. (2008c). Narrative and its potential contribution to disability studies. *Disability & Society*, 23(1), 17-28.
- Sontag, S. (1991). *Illness as metaphor: Aids and its metaphors*: Hammondsworth: Penguin.

- Sparkes, A., & Smith, B. (2005). When narratives matter. *Medical Humanities*, 31, 81-88.
- Speed, E. (2006). Patients, consumers and survivors: A case study of mental health service user discourses. *Social Science & Medicine*, 62(1), 28-38.
- Squire, C., Andrews, M., & Tamboukou, M. (2008). Introduction: What is narrative research? In M. Andrews., C. Squire., & M. Tamboukou (Eds.), *Doing narrative research*. (pp.1-22). London: Sage.
- Stalker, K., Baron, S., Ridell, S. & Wilkenson, H. (1999). Models of disability: The relationship between theory and practice in non-statutory organisations. *Critical Social Policy*, 19(1), 5-29.
- Starr, P. (1982). *The social transformation of medicine*. New York: Basic Books.
- Sullivan, M. (2006). Changing the relations of research production? The emancipatory research paradigm: towards resolution of some contradictions. *New Zealand Journal of Disability Studies*, 12, 178-195.
- Sullivan, M. & Munford R. (1998). The articulation of theory and practice: Critique and resistance in Aotearoa New Zealand. *Disability & Society*, 12(2), 183-198.
- Swain, J. (1993). Taught helplessness? Or a say for disabled students in schools. In J. Swain, V. Finklestein, S. French & M. Oliver (Eds.), *Disabling barriers – enabling environments* (pp. 155-162). London: Sage.
- Sween, E. (1998). The one minute question: What is Narrative Therapy? Some working answers. *Gecko*, (2), p.3-6.
- Taylor, S., & Bogdan, R. (1998). *Introduction to qualitative methods* (3rd ed.). New York: John Wiley & Sons.
- Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Buckingham: Open University Press.
- Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society*, 19(6), 569-583.

- Thomas, D. (1978). *The social psychology of childhood disability*. London: Methuen.
- Thomas, P., & Hall, C. (2008). Opportunities missed and/or thwarted? Funds of knowledge meet the English national curriculum. *The Curriculum Journal*, 19(2), 87-103.
- Todis, B. (1992). "Nobody helps!": Lack of perceived support in the lives of elderly people with developmental disabilities. In P. Ferguson, D. Ferguson & S. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 61-77). New York: Teachers College Press.
- Tremain, S. (2002). On the subject of impairment. In M. Corker & T. Shakespeare (Eds.), *Disability/Postmodernity – Embodying disability theory* (pp. 32-47). New York: Continuum.
- Turner, B. (2003). Biology, vulnerability and politics. In S. Willianms., L. Birke. & G. Bendelow. (Eds.), *Debating biology: Sociological reflections on health medicine and society*. (pp.271-282). London: Routledge.
- Ven den Ven, L., Post, M., de Witte, L. & Van den Heuvel, W. (2005). It takes two to tango: The integration of people with disabilities into society. *Disability & Society*, 20(3), 311-329.
- Vernon, A. (1999). The dialectics of multiple disabilities and the disabled people's movement. *Disability & Society*, 14(3), 385-398.
- Walmsey, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, 16(2), 187-205.
- Watson, N. (2002). Well I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and disability. *Disability & Society*, 17(5), 509-527.
- Weingarten, K. (1991). The discourses of intimacy: Adding a social constructionist and feminist view. *Family Process*, 30, 285-305.
- Weingarten, K. (2000). Witnessing, wonder, and hope. *Family Process*, 39(4), 389-402.
- Weingarten, K. (2003). *Common shock*. New York: Dutton.

- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. London: Routledge.
- Wetherall, M., & Potter, J. (1992). *Mapping the language of racism: Discourse and the legitimisation of exploitation*. Hemel Hempstead: Harvester Wheatsheaf.
- White, M. (1995). *Reauthoring lives: Interviews & essays*. Adelaide: Dulwich Centre Publications.
- White, M. (1997). *Narratives of therapists' lives*. Adelaide: Dulwich Centre Publications.
- White, M. (2000). *Reflections on narrative practice: Essays & interviews*. Adelaide: Dulwich Centre Publications.
- White, M. (2001). Folk psychology and narrative practice. *The International Journal of Narrative Therapy & Community Work*, 2, 18-21.
- White, M. (2004). *Narrative practice and exotic lives: Resurrecting diversity in everyday life*. Adelaide: Dulwich Centre Publications.
- White, M. (2006). *Narrative practice and exotic lives: resurrecting diversity in everyday life*. Adelaide: Dulwich Centre.
- White , M. (2007). *Narrative maps of practice*. Adelaide: Dulwich Centre.
- White, M., & Epston, D. (1991). *Narrative means to therapeutic ends*. Adelaide: Dulwich Centre Publications.
- White, M., & Epston, D. (1992). *Experience, contradiction, narrative & imagination: selected papers of David Epston & Michael White, 1989-1991*. Adelaide: Dulwich Centre Publications.
- Whitehead, L. (2006). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science & Medicine*, 62(9), 2236-2245.
- Williams, M., & Nind, L. (1999). Insiders or outsiders: Normalisation and women with learning disabilities. *Disability & Society*, 14(5), 659-672.

- Williams, S. (1999). Is anybody there? Critical realism, chronic illness and the disability debate. *Sociology of Health & Illness*, 21(6), 797–819.
- Willig, C. (1999). Introduction: Making a difference. In C. Willig (Ed.), *Applied discourse analysis – applied psychological and social interventions* (pp.1-21). Buckingham: Open University Press.
- Wilson, C. & Bartak, L. (1997). Self understanding of normalisation and social role valorisation: Anstey and Gaskin (1985) revisited. *Journal of Intellectual & Developmental Disabilities*, 22(3), 213-219.
- Wilson, A. & Beresford, P. (2002). Madness, distress and postmodernity: Putting the record straight. In M. Corker & T. Shakespeare (Eds.), *disability / postmodernity* (pp.143-158). London: Continuum.
- Winslade, J. (1994). The social construction of disability – some implications for counselling. *Journal of the New Zealand Association of Counsellors*, XVI(2), 44 – 54.
- Winslade, J. & Monk. G. (2000). *Narrative mediation: A new approach to conflict resolution*. San Francisco: Jossey Bass Publishers.
- Wolfensberger, W. (1985). Social role valorization: A new insight, and a new term, for normalization. *Australian Association for the Mentally Retarded Journal*, 9(1): 4-11.
- Wolfensberger, W. & Tullman, S. (1989). A brief outline of the principle of normalisation. In A. Brechin & J. Walmsley (Eds.), *Making connections: Reflecting on the lives and experiences of people with learning difficulties* (pp. 211-219). London: Hodder & Stoughton.
- Zarb, G. (1993). The dual experience of aging with a disability. In J. Swain, V. Finklestein, S. French & M. Oliver (Eds.), *Disabling barriers – enabling environments* (pp. 186-196). London: Sage.
- Zola, I. K. (1977). Healthism and disabling medicalization. In I. Illich, I. Zola, J. McKnight, J. Caplan & H. Shranken (Eds.), *Disabling professions*, (pp.41-68). London: Marion Buyars.

Zola, I. (1992). Any distinguishing features?": The portrayal of disability in the crime-mystery genre. In P. Ferguson, D. Ferguson & S. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 233-250). New York: Teachers College Press.

Zola, I. (1994). Towards inclusion: the role of people with disabilities in policy and research issues in the United States – a historical and political analysis. In M. Rioux & M. Bach (Eds.), *Disability is not measles: new research paradigms in disability*. (pp. 49-66). New York: L'Institut Roehrer Institute.

APPENDICES

Appendix 1: Consent Form

I have read a letter introducing James Arkwright's research study and have had opportunity to discuss his research with either himself, his research supervisor or the chair of [name of education institute] research committee.

I agree to participate in this study on the basis that:

- As a student at Bethlehem Institute, I will not participate in any data gathering exercise, such as being interviewed, whilst James Arkwright is the lecturer for one of my classes or a supervisor for my practicum work, unless all evaluations for those papers are undertaken by another lecturer.
- As a student at Bethlehem Institute, I understand that my course grades will not in any way be affected by my participation in this research project.
- If I wish to withdraw from this study I am free to do so up until 30 January 2005.
- I have sighted a timetable for the research project and agree to participate in the study on the basis of the time-frame outlined.
- If I have questions or complaints about this research project, I can contact either James Arkwright or his research supervisor: Professor Margaret Carr, University of Waikato, Ph (07) 838 4500 extn 7854
- Initial discussions held prior to the interviews will discuss and negotiate the parameters of the research project. The study will not continue until there is agreement between James Arkwright and all the participants about the design of the study.
- I agree to my interviews being taped by James Arkwright and transcribed by a person other than James Arkwright, on the basis that the transcriber has signed a confidentiality agreement. The confidentiality agreement prohibits the transcriber from discussing my interviews with anyone other than James Arkwright, and then only for the purposes of providing accurate transcription.
- I will sight written transcripts of my interviews before data analysis begins and I will be able to have changed or deleted anything that I have previously said.
- I will receive a copy of the data analysis and will be given an opportunity to comment on it, and any comments I make will be acknowledged within James Arkwright's final thesis report.
- I am aware that the research report will become either an unpublished thesis held in the University of Waikato library or be published in complete or part form of the doctoral thesis report

- Up to two years after the completion of the research, I will be contacted if the study is going to be developed for a paper or presentation, and I will have an opportunity to be involved in such processes should I wish to be.
- I understand that in James Arkwright's thesis report and in any subsequent papers or presentations that I will not be able to be identified in any way, thereby remaining anonymous.

Name

Signed

Witnessed

Date .. / .. / 2004

Appendix 2: First letter to participants

Dear.....

As part of my doctorate in education at the University Waikato, I am undertaking a research project that considers how people with impairments/illness/long-term health problem make sense of and live their lives. It is my hope that this research project will ultimately contribute to disability theory and be in the best interest of people with impairments/illness/long-term health problem.

The study will involve two or three separate one to one interviews and one written reflection about the experience of being a participant in the study.

The time frame for the study is:

1 August 2004	Research project begins
15 February 2005	Interviews completed
15 March 2005	Participants have submitted written reflection on their experience of the research process
1 August 2005	Data analysis completed
30 February 2006	Final thesis report completed

For the study to be an ethical and a safe project for all concerned, a number of issues have been considered:

1. Participants are able to withdraw from the study up until 30 January 2005, should they wish to.
2. If you are a student at Bethlehem Institute and have me either as a lecturer for one (or more) of your papers or I am your practicum co-ordinator, then you will not be interviewed until either those learning processes have been completed.
Alternatively, ALL marking and grading related to the respective papers that I am either a lecturer or a practicum co-ordinator for, is undertaken by another lecturer who is not involved in this research project.
3. Any reports/papers/presentations produced from the research will not identify the participants of the study in any way.
4. Each participant will sight, sign and retain a copy of the research's consent form before participating in the study.
5. Each participant will have access to her/his verbatim transcripts and will have an opportunity to change or have deleted anything that they said during an interview.

6. All participants of the study will have an opportunity to read the final data analysis and have an opportunity to comment on it, which will be acknowledged within my final thesis report.
7. Following the thesis report, opportunities may exist for the research to be developed further in terms of writing papers or giving presentations. In this eventuality, within a time frame of two years post completion of the research, all participants will be consulted and given an opportunity to be involved in such enterprises should they wish to be.

If you would like to participate in this research project and are in agreement with the terms of the study stated in the consent form, then please sign the consent form and return to me by 1 September 2004..

If you are not sure about this study and would like to know more, please contact either myself ((07) 579-1747), my principal research supervisor, Professor Margaret Carr (University of Waikato, School of Education: (07) 838.4500, extn 7854) or Bevs Norsworthy (Chair of the Research Committee, Bethlehem Institute: (07) 579-1712.

Thank you for your consideration of this research project.

Yours sincerely,

James Arkwright.

Letter of introduction for participants NOT from Education institute

Dear.....

As part of my doctorate in education at the University Waikato, I am undertaking a research project that considers how people with impairments/illness/long-term health problem make sense of and live their lives. It is my hope that this research project will ultimately contribute to disability theory and be in the best interest of people with impairments/illness/long-term health problem.

The study will involve two or three separate one to one interviews and one written reflection about the experience of being a participant in the study.

The time frame for the study is:

1 August 2004	Research project begins
15 February 2005	Interviews completed
15 March 2005	Participants have submitted written reflection on their experience of the research process
1 August 2005	Data analysis completed
30 February 2006	Final thesis report completed

For the study to be an ethical and a safe project for all concerned, a number of issues have been considered:

1. Participants are able to withdraw from the study up until 30 January 2005, should they wish to.
2. If you are a student at [name of education institute] and have me either as a lecturer for one (or more) of your papers or I am your practicum co-ordinator, then you will not be interviewed until either those learning processes have been completed. Alternatively, ALL marking and grading related to the respective papers that I am either a lecturer or a practicum co-ordinator for, is undertaken by another lecturer who is not involved in this research project.
3. Any reports/papers/presentations produced from the research will not identify the participants of the study in any way.
4. Each participant will sight, sign and retain a copy of the research's consent form before participating in the study.
5. Each participant will have access to her/his verbatim transcripts and will have an opportunity to change or have deleted anything that they said during an interview.

6. All participants of the study will have an opportunity to read the final data analysis and have an opportunity to comment on it, which will be acknowledged within my final thesis report.
7. Following the thesis report, opportunities may exist for the research to be developed further in terms of writing papers or giving presentations. In this eventuality, within a time frame of two years post completion of the research, all participants will be consulted and given an opportunity to be involved in such enterprises should they wish to be.

If you would like to participate in this research project and are in agreement with the terms of the study stated in the consent form, then please sign the consent form and return to me by 1 September 2004. .

If you are not sure about this study and would like to know more, please contact either myself ((07) 579-1747), my principal research supervisor, Margaret Carr (University of Waikato, School of Education: (07) 838.4500, extn 7854) or Bevs Norsworthy (Chair of the Research Committee, [name of education institute]: (07) 579-1712.

Thank you for your consideration of this research project.

Yours sincerely,
James Arkwright.

APPENDIX 3: Practice questions before first interview

Questions which may inform the interview enquiry

- Have you ever been a participant in a research study before?
- If so, what was that experience like?
- If it was good, what happened that made it a good experience for you?
- If it was not good, what do you think contributed to it being a not so good experience? What would we need to avoid in this research project so the same problems did not occur again?
- What might be some of the things which are behind you deciding to participate in this research project?
- What might be some of the things that you would want to have happen for this research project to be judged as useful and relevant for you?
- Would you be interested in being a researcher for this research project as well as being a research participant for this project?
- If you are interested in being a researcher for this project, what do you think is contributing to your interest in being a researcher as well as a participant in this research project?
- If so, what are your thoughts about being involved as a participant as well as a researcher in this project?
- It is my idea, to research the concept of agency as it relates to disabled people's lives. What do you know about the concept of agency? What would you like to know about the concept of agency?
- If you were to be asked about times when you may negotiate agency in your life, what kinds of times come to mind?
- If you were to be asked about times when you may find it hard to negotiate agency in your life, what kinds of times come to mind?
- How will you know if this research project about agency in the lives of disabled people will be worthwhile for you or not?
- What do you think would have to happen during and/or after this research project in order for it to be worthwhile for disabled people?
- How might you be able to contribute to this research project for it to become more worthwhile either for yourself or for disabled people in a general sense?
- What you think might be the advantages and/or the disadvantages in choosing participants for the study from Bethlehem Institute [name of education institute], either as current or past students, or current staff members?
- What do you think it will be like for you to be involved in this research project with me while I am concurrently working as a lecturer at [name of education institute].?
- What do you think might be some of the good things about my having the dual role of lecturer and researcher?
- What do you think might be some of the not so good things about my having the dual role of lecturer and researcher?
- If my being both a lecturer and researcher at [name of education institute] became problematic for you in some way, how do you think you and I would know?
- If my dual role were to become problematic in some way, what steps do you think we should take in order to address the difficulties that had arisen?
- In terms of accountability for this research project, what do you think I should be responsible for and what do you think you should be responsible for?
- In being part of this research project, what are you looking forward to?
- Overall, what are your hopes for this research project?
- Is there anything else that you would like to say?

- What is it like being here now about to have this interview?
- Since our meetings as a group, has anything come to mind for you about this research project? If so, what?
- Have you thought at all about the concept of agency and how it might relate to your life?
- If so, what?
- I wondered if I shared a story of agency operating in my life if that would be helpful in terms of orientating us in this discussion?
- As you have heard that story, has it connected to any stories of your own for you?
- If so, can you share those stories with me?
- As you tell me those stories, what stands out as significant or interesting to you?
- Why do you think these stories in particular have been chosen by you as the ones to mention today? What might they represent about your life, which seems worth noting?
- Since our last meeting has anything been happening for you in relation to what you shared and we discussed last time? If so, what?
- In the telling and being listened to about the stories you told, has anything else happened for you? If so, what?
- If these reflections you are sharing now, were to represent anything new in your life what might that be?
- Given the reflections you have been having, how important do you think it is to recall and discuss experiences of 'agency' and restraints around 'agency'?
- In our original meetings we discussed how individual experiences of agency are in fact resistances and/or modifications or changes from how a discourse or social story has been positioning us. Could we discuss now about some of the ways you have been positioned because of your disability?
- If you are OK to do that, what are some of the many ways you have been positioned?
- What was the effect of that positioning on you?
- How did the positioning influence what you felt, thought or did?
- What assumptions or taken for granted facts about life do you think created this positioning?
- What kind of actions or practices have been required to support this type of positioning?
- Have you ever felt yourself be invited or drawn into reproducing the actions or practices which support this kind of positioning?
- What was it like to contribute to a positioning, especially if it was a positioning that you didn't like?
- What does this tell you about discursive positioning or the power of cultural and social stories?
- In regard to positioning which you don't like but may have unconsciously or consciously had a hand in keeping alive, what do you think it would take for you to not reproduce the practices that support a positioning you don't like?
- What might support you or has supported you in the past to resist that positioning which you don't like?
- As you think about either the possibility of resisting positioning you don't like or having resisted such positioning in the past, what is that like for you?
- If you were able to do this more often, what difference, if any, do you think it would make for how you experience life?
- Do you think you would see yourself differently in anyway if you consistently practiced resisting, changing or modifying positioning that you did not like?
- What has stood out as of most value to you today in this interview?
- What is it about that holds special significance for you?
- In what way might that relate to the theme of this research project, considering agency in

<p>disabled people's lives?</p> <ul style="list-style-type: none"> • This is our last individual interview for you today. What is that like? • What kind of things do you want to discuss today? • I am interested in what is different for you now, if anything, as a result of having the last two interviews? • What have the interviews affirmed for you? • What have they highlighted for you? • What have they raised which is interesting or new for you? • What impact have they had on you regarding the way you relate to yourself, other people, other disabled people? • Who else has been affected because you have taken part in this research project? • How have they been impacted by your participation in this study? • In these other people being influenced by a study that they were not directly involved in, What do you think that might suggest? • Is there anything else you want to say before we finish this interview? • What has been your experience of participating in this study? • Is there anything else you would like to say that you feel you have not said during the discussions you have had with James or you would like to repeat or emphasise again?
--

APPENDIX 4: Letter to participants after first interview

Dear

I very much enjoyed our last conversations together.

Please find enclosed a copy of the transcripts of our conversation. When you have time please read the transcripts, checking that they are an accurate record of our conversations together, as you remember it. Also, if you wish to change or have anything you said deleted, then please let me know and I will amend the original transcript.

It is my belief that conversations are never neutral or remain in a vacuum but they continue to act in our lives both during and after a conversation has occurred. Therefore, I would like to suggest that we begin our next conversation by reflecting on any thoughts you have had since our last conversations together. For example, perhaps you have considered some aspect of our conversation further or maybe some part of the transcript has stood out as interesting or significant to you.

I have also been reflecting about our conversations, especially some of the things that you said and in response to my interest and curiosity of wanting to know more, I have composed a few questions, which perhaps we can discuss when we next meet as well:

APPENDIX 5: Letter to Carole after first interview

Dear Carole

I really enjoyed our last conversation together. It was so nice to catch-up again. And from a research point of view, what you had to say was very relevant and invaluable for my research study. My supervisors felt there was a whole paper in the way you conceptualised kindness and its consequential positioning effects. They found this particularly revealing about how disability is storied in well meaning but problematic ways for people living with impairment/illness. The dilemma around disclosure and ways of disclosing impairment/illness we have discussed before but it was no less interesting for that and certainly is a pervasive part of the territory of disability, especially when the impairment is invisible. The secret world you discussed was something I very much identify with and one that I am keen to ask the other participants in the study about as well.

I am now hoping we can meet again for the follow-up and concluding conversation. If you can find time before we next meet, would you please check that the transcript of our first conversation is an accurate record of our conversation together, as you remember it. Also, if you wish to change or have anything you said deleted, then please let me know and I will amend the original transcript.

It is my belief that conversations are never neutral or remain in a vacuum but they continue to act in our lives both during and after a conversation has occurred. Therefore, I would like to suggest that we begin our next conversation by reflecting on any thoughts you have had since our last conversation together. I know we've already talked a little about how you found it helpful to talk about the 'secret world', which you likened to 'lancing a boil'. Perhaps you have been reflecting on this further or maybe some other part(s) of the transcript has stood out as interesting or significant to you.

I have also been reflecting about our conversation, especially some of things you said and in response to my interest and curiosity of wanting to know more, I have written a few thoughts and questions, which I'm hoping we might also discuss when we next meet.

1. I felt that we could have spoken more about how you've "been shocked about the amount of grief and it's so intense". You also described the grief as "sobering... exhausting.... staggered by it.... distressing... just terrible." These are descriptively strong words and I am interested in knowing more about them, regarding the window they might provide for understanding more about some of the experiences you have had.
2. On a number of occasions you said you "were working on it" or "it's a work in progress" in relation to finding ways of disclosing the effects of illness in your life without being positioned as 'less than'. The word 'work' indicates intentionality to me as in being

proactive rather than reactive and I'm wondering if the word 'work/working' has the same meaning for you? I am interested in uncovering the thinking and activities that go along with the word 'work' for you, such as the history and effects of 'working at things' or things being 'a work in progress' in your life. And of course, I'm interested in what the thinking and activities of 'work' have meant for how you have responded to the effects of illness in your life.

3. You described 'sports' as "a big part of my identity" and that you "loved it" and "loved the feeling", all of which you said has now "gone completely" (although you do draw on that knowledge and experience for the coaching that you do). Clearly, you have resisted other aspects of your identity disappearing from you as well due to the effects of illness, such as your identities as a counsellor and mother, although you have spoken about both of those areas not being easy for you either. I am interested in your thoughts about the impact of illness on a person's identity and in particular what illness has meant for your sense of self/selves. In what ways do you think you might you be similar and/or different from the person you were before illness entered your life?
4. Finally, Carole, what probably most stood out for me was your ability to take-up a position of authority or agency in your life and in so doing cope with and minimise the effects of physical difficulties (as in "my body feels so bad nearly all the time") and socio-cultural losses (such as being positioned "less than"). In this vein, you said "I need to be very active in making sure my life is good" and "feeling good is something I have to work at." Often this meant that you are able to help/benefit others as well, and you gave examples of using your abilities to contribute to the lives of others within your work, community and home environments. This deliberate position-taking and ability of making sure your life is good (which includes helping/benefiting others) seems to have been informed by your counselling training/experiences, your nursing experiences, your family of origin beliefs/values, your commitment to and receiving from your own family, and your love of sport/athletics. Is there anything else that you would like to say about how these dimensions of experience (and any others not yet mentioned) stand behind your daily practices of being "very active in making sure my life is good"?

Thank you Carole for taking the time to read and reflect on the transcript and consider the above thoughts and questions. I look forward to our next conversation together. .

Warmest regards,

James.

APPENDIX 6: Letter to Ron, after first interview

Dear Ron

I very much enjoyed and am appreciative of our last conversation together, which has been very relevant for my research study.

I am hoping you can find time to read the transcript of our first conversation together. Please check that the transcript is an accurate record of our conversation together, as you remember it. Also, if you wish to change or have anything you said deleted, then please let me know and I will amend the original transcript.

It is my belief that conversations are never neutral or remain in a vacuum but they continue to act in our lives both during and after a conversation has occurred. Therefore, I would like to suggest that we begin our next conversation by reflecting on any thoughts you have had since our last conversations together. For example, perhaps you have considered some aspect of our conversation further or maybe some part of the transcript has stood out as interesting or significant to you.

I have also been reflecting about our conversation. I have written a brief summary of the conversation and included some questions for us to discuss when we next meet.

Summary

In reflecting on the transcript, medical treatment was clearly a significant feature of your childhood years. The memories that you relayed to me of these times did not seem to evoke any emotional difficulties for you today; indeed you described the experiences as simply ‘how it is’. A number of stigmatising and disabling experiences did happen to you though on account of you having a speech impairment, especially during school and at catering school. Fighting, rather than taking flight, appears to have generally been your response, aided very interestingly by your ability to absorb and identify with the detective hero in Agatha Christie’s crime fiction. And a number of incidents stand out, in which you have had to either overcome barriers or the fear of barriers. For example, being cast as having an intellectual disability by your fellow students at catering school and the issue of losing your hair in your early twenties, meaning your re-constructed ear became visible. Further, you state that even now, every time you speak ‘there is a hesitation’, wondering ‘is this going to sound understandable?’

Two areas which we did not discuss were the place that your current family (wife and children) and spirituality / faith has played in your journey of living with the affects of hearing loss, ear reconstruction and speech impairment. If these areas interest you, then perhaps we could discuss them in our upcoming conversation together.

Questions

1. *What do you think Dr. [name of Dr] words 'whose is that?' might indicate about how children were positioned within pediatric hospital wards prior to 1969?*
2. *Would you refer to a child as 'whose is that?' now that you are an adult? If so, why? If not, why not?*
3. *What do you think might have been some of the experiences and spoken or unspoken messages that led you to having 'an issue' because at 20 years of age (due to losing your hair) you were no longer able to hide your ear with your hair?*
4. You say it took you 'some time to come to terms' with not being able to hide your ear with your hair. *What do you think were some of 'the terms' you came to in response to no longer being able to hide your ear?*
5. You said you got 'even' with the teacher who was 'a bully'. *What did it mean for you that many years later you were able to 'get even' with a teacher who ridiculed and picked-on you when you were at school?*
6. At catering college it was assumed by some of your peers that you had an intellectual disability because of your speech impairment. You recalled saying to a class-mate at the time 'I don't think so!' and you spoke of another experience when you said, 'I'll show you buggers, I'm not stupid.' *How do you account for how you knew you weren't stupid and refused to be seen in such a light?*
7. In referring to people's prejudices, you have stated that you are 'a lot happier where I am now' and 'I get to the stage where I can't be blimmin bothered'. *What has changed for you so that you are happier now and are no longer so bothered by other people's prejudices?*
8. The hero in Agatha Christie's novels has been a point of identification for you, in particular 'their ability to keep going after being ridiculed, after getting to a dead-end, after seeing things that don't add up.' *Can you say a bit more about how the hero in Christie's novels might have informed the expectations and hopes you have held for your own life?*
9. You have also said that 'you have to.. you have to.. you have to go on despite the odds or.. regardless that you know it's going to be a bad outcome'. *I was wondering if there was anything other than the Agatha Christie stories that might have contributed to this stance of 'having to go on?' If so, could you say a bit more about this please.*
10. The difficulty of living with a speech impairment is evident when you say 'I still deal with the issue that every time I speak, even at 40, I still have this hesitation: is this going to sound understandable?' *Can you say more about what this is like? And how you manage to move past the 'hesitation' into speaking despite the question in your mind of 'is this going to sound understandable?'*

11. You have described yourself as tending ‘to be a fighter’ as opposed to taking the flight stance. *How significant do you think this image of seeing yourself as ‘a fighter’ has been for you? What do you think has contributed towards you having this image of yourself? And what impact do you think this image of being ‘a fighter’ has had on the decisions and choices you have made?*
12. *Can you explain how ‘Ian Grant’ has made a difference to how you have viewed and lived your life?*

Thank you Ron for taking the time to read and reflect on the transcript and consider the above questions. I look forward to our next conversation together.

Kind regards,

James.

APPENDIX 7: First coding analysis guide

NARRATIVE CODES

KEY:

Numbers	= Narrative practices of participants / <i>Discursive influences</i>
Letters	= Narrative experiences

- 1 = Receiving medical treatment/expertise / *Medical Model*
 - a) medical treatment taken for granted as 'right / normal / necessary'
 - b) grateful / fortunate for medical treatment
 - c) experienced discrimination / de-personalisation through medical treatment
 - d) medical treatment makes life busy / challenging

- 2 = Rehabilitation (physical and/or mental) helps / *Medical Model; Rehab Models; Social Role Valorisation; Psychology / psychotherapy*
 - a) impairments effects are reduced
 - b) reduction of impairment effects improves quality of life

- 3 = Are 'less than' / *Medical Model; Psychology; Charity Model*
 - a) assumed to have other impairments as well
 - b) impairment equates with being not normal
 - c) grief due to impairment effects and disabling experiences
 - d) fear about being stigmatised
 - e) pathologised / discriminated against due to, or in relation to, impairment
 - f) fear in relation to social contexts where discrimination occurred
 - g) discrimination not attributed to ableism
 - h) lifestyle / choices constrained due to impairment / disabling experiences

- 4 = Society is more accommodating of people with impairments / *Human Rights / Social Model*
 - a) difference due to impairment is accepted / proud of
 - b) impairment produces a new 'norm' – what's the norm for me
 - c) disability is caused by society, not impairment
 - d) identity is relative to and influenced by impairment and disabling experiences

- 5 = I am not 'less than' and I stand/fight against that / *Human Rights; Social Model; Professional (helping) practices; other discursive ideas / practices*
 - a) identifies / names and takes action against discrimination
 - b) challenges self to overcome disabling experiences
 - c) makes new (less pathologising) meaning around impairment
 - d) resistance to discrimination attributed to characteristics of self

- e) resistances to discrimination attributed to beliefs / practices learnt in social contexts
- 6 = I want to be normal or what was normal for me / *Medical Model***
- a) self as failure
 - b) doubts about self
 - c) desire to be normal
 - d) achievements minimised
- 7 = I am pleased / comfortable with who I am / have become / *Human Rights; Social Model; Social Role Valorisation; Spirituality frameworks; Professional (helping) practices; Family practices; other discursive ideas / practices***
- a) has faced implications of impairment effects / disabling experiences
 - b) less bothered by discrimination
 - c) has found ways of enabling self
 - d) has taken actions to produce changes for self / others
 - e) has an appreciation of self
 - f) recognises personal strengths
 - g) has a sense of understanding and negotiating between subjectivities
 - h) recognition of competencies
- 8 = Relationships are important / *Family ideas/practices***
- a) family supports person with impairment
 - b) person with impairment supports family
 - c) impairment influences family / other relationships
- 9 = My job / vocation is very important / how I do it is unique to me in some way / *Social Role Valorisation; Social Model; Employment ideas/practices***
- a) career/work is very important
 - b) impairment & disabling experiences improve competency in job
 - c) impairment & disabling experiences challenge competency in job
- 10 = I want to or am making a difference / *Social Model; Feminist ideas/practices; Human Rights; Spirituality frameworks***
- a) making it easier/better for others with impairment
 - b) educating non-disabled
- 11 = Faith/spirituality is relevant / *Christian ideas/practices; Buddhist ideas/practices; other spiritual ideas/practices***
- a) interested in faith/spirituality
 - b) faith/spirituality has impacted the effects of impairment & disabling experiences

APPENDIX 8: Second analysis guide

PARTICIPANT INTERVIEWS: DATA AND ANALYSIS

1. DISCURSIVE POSITIONING

What are the position calls that the participants are invited into? How are they called into existence for the different participants? What are the effects of these position calls on participants in terms of the participant's (and their friends / family) concrete actions and meaning making? To what extent do discourses / discursive practices position participants in contradictory ways? To what extent do participants experience conflict as alternative discourses vie for attention and ascendancy?

2. RESPONSES TO DISCURSIVE POSITIONING

What are the participants' responses to these position calls? How do the participants' manage/cope with contradictory discursive positionings? To what extent are the participants' responses to position calls, examples of acting agentically? What supports these actions of agency?

3. PARTICIPANTS' SUBJECTIVITIES

What were critical moments or sites of resistance to discursive position calls: examples of refusing to take them up as a singular disabled identity? To what extent are the refusals to take-up a singular disabled identity incorporated/orchestrated as part of multiple subjectivities, as in having multiple positions as a discourse user? What narrative / discursive practices have enabled these subjectivities to be reified, supported and held on to?

4. EFFECTS OF THE RESEARCH PROCESS

What are the effects of the research process on making visible the practices of agency? To what extent is the research process, itself a discursive practice, acting as an agent of change for participants thereby enabling them to move into practices of agency? What are the participants' experiences of the research process? If participants have experienced more agency as a result of the research process, then what is this experience and what is it effects on each respective participant?

5. NARRATIVE THERAPY – NARRATIVE RESEARCH

What have been the similarities and differences between the respective positioning of being a counsellor and being a researcher? What have been the discoveries in developing a narrative research praxis regarding interview process and data analysis?

APPENDIX 9: Third analysis guide

DECONSTRUCTING THE PARTICIPANT INTERVIEWS

1. DISCURSIVE POSITIONING

- What might the participants' stories/responses say/indicate about the discursive position calls they have been historically invited into?
- What might the participants' stories/responses say/indicate about the particular ways in which they have experienced how the position calls are called into existence, operate and engage them?
- What might the participants' stories/responses say/indicate about the effects of these position calls on their (and their friends / family) concrete actions and meaning making?
- What might the participants' stories/responses say/indicate about the position calls they are experiencing within the current research interview/relationship? What discourses/discursive practices have created the position calls operating within the research interview/relationship and what particular participant stories/responses might be generated/invited in response to those position calls?
- What might the participants' stories/responses say/indicate about the extent to which discourses / discursive practices position participants in contradictory ways? What might the participants' stories/responses say/indicate about the extent to which participants experience conflict as alternative discourses vie for attention and ascendancy?

2. RESPONSES TO DISCURSIVE POSITIONING

- What might the participants stories/responses say/indicate about what they are selecting and evaluating as worth telling? What might be some of the purposes behind those selections and evaluations?
- What might the participants' selections and evaluations, as indicated through their stories/responses, indicate about the particular arrangement/combinations of discourses/discursive practices that have been taken up by the participants? In terms of the particular arrangement/combination of discourses/discursive practices that have contributed to the participants selections and evaluations, what might be the background context or web of meanings which enable the participants statements to be meaningful? And what might be the opposite or antithesis (discursive practice) which enables the participants' distinctive meanings to be called into existence? And what might the participants' selections and evaluations suggest about the constitutions/influences on the participants lives that are typically hidden or invisible?
- What might the participants' selections and evaluations say/indicate about the kind of relationships they are creating with themselves and with others? In terms of the kind of relationships - with self and others, which are generated through the participants' selections and evaluations, how might the participants' language position them in relation to themselves and others? What actions and who is being privileged through the participants' language? And what background contexts or web of meanings might call into existence such position calls/privileging?

- To what extent have the participants' stories/responses been unanticipated by myself as researcher? What in particular has been unanticipated or unexpected by me in the participants stories/responses? What might my unexpected responses as researcher say/indicate about the participants' narratives? What might my unexpected responses say/indicate about the discourses and associated position calls embedded within the research praxis and my own narratives as researcher?
- What might the participants' stories/responses say/indicate about the changes that have taken place over time regarding their narratives and associated discursive responses to position calls? What might the participants' stories/responses say/indicate about what has contributed to the changes which have occurred in the participants' narratives and associated discursive responses to position calls?
- What might the participants' stories/responses say/indicate about the extent to which they have experienced contradictory and/or different discursive positionings? What might the participants' stories/responses say/indicate about how they relate to contradictory and/or different discursive positionings?
- What might the participants' stories/responses say/indicate about the extent to which their responses to position calls are examples of re-positioning themselves so as to take up a position of agency in their own lives? What might the participants stories/responses say/indicate about what narratives have supported these actions of agency? What might the participants' stories/responses say/indicate about what background contexts/web of meanings such narratives are embedded in?
- What might the participants' stories/responses say/indicate about what were the critical moments or sites of resistance to discursive position calls: examples of refusing to take them up as a singular disabled identity? And what background contexts/web of meanings might sit behind these critical moments and sites of resistance?
- What might the participants' stories/responses say/indicate about the extent to which the refusals to take-up a singular disabled identity are incorporated / orchestrated as part of multiple subjectivities, as in having multiple positions as a discourse user? What might the participants' stories/responses say/indicate about what background contexts/web of meanings have perhaps enabled these subjectivities to be reified, supported and held on to?

3. EFFECTS OF THE RESEARCH PROCESS

- What might the participants' stories/responses after beginning their participation in the research study say/indicate about what the effects are of the research process on making visible the practices of agency? What might the participants' stories/responses after beginning their participation in the research study say/indicate about the extent to which the research process, itself a discursive practice, has acted as an agent of change for participants thereby further supporting practices of agency?
- What might the participants' stories/responses, after beginning their participation in the research study, say/indicate about what their experiences are of the research process?

- If the participants' stories/responses, after beginning their participation in the research study, suggests/indicates that they have experienced more agency as a result of the research process, then what is this experience and what is its effects on each respective participant?

4. NARRATIVE THERAPY – NARRATIVE RESEARCH

- From the researcher's experience, what have been the similarities and differences between the respective positioning of being a counsellor and being a researcher? What might these similarities and differences suggest about the position calls the researcher has taken up, respectively as researcher and counsellor? From the researcher's experience, what might have contributed to the researcher taking up such counsellor and researcher position calls?
- From the researcher's experience, what have been the discoveries in undertaking research interviewing aimed at discovering 'what agency means for disabled people and what enables disabled people to negotiate agency in their lives' (and associated questions)? From the researcher's experience, what have been the discoveries in deconstructing the research interview transcripts, when such deconstruction was aimed at 'what agency means for disabled people and what enables disabled people to negotiate agency in their lives' (and associated questions)?
- From the researcher's experience, what might be some of the possible implications for narrative research and discourse analysis methodologies?

APPENDIX 10: 2 examples of a discursive map

(?) = not sure if belongs in this discourse

