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Fit to practice.  
Exploring the work experiences of registered nurses  
who are disabled during the course of their careers

A thesis presented in partial fulfilment of the requirements for the

Masters of Philosophy  
in  
Social Policy

Massey University, Manawatu,  
New Zealand.

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2012

## Dedication

To Patricia Wood - a nurse for 42 years.

And to the memory of

Tadeusz Edward Korzon

1934- 2001

a nurse for 20 years.

## Abstract

A potential for systemic discrimination against nurses with impairments has been identified within literature relating to the nursing profession. Workforce shortages combined with an ageing nursing population suggests that there will be an increase in the number of nurses with impairments and a need to recruit and retain these nurses. There is very little known about the experience of nurses who have acquired impairments during the course of their careers. The intention of this research is to explore the experience of nurses who have acquired impairments and the impact on their identity and their nursing practice.

The study draws on a range of theoretical works including those from disability studies and employs a qualitative approach that is influenced by Somers' (1994) narrative methodology. Inclusive to this methodology is an abductive strategy based on a constructivist view of social reality (Blaikie, 2000; 2007; 2010) which produces accounts of social life drawing on the concepts and meanings used by social actors and the activities in which they engage (Douglas, 1996). Seven nurses were interviewed and their narratives analysed to identify the social and cultural scripts which shape their experiences and the formation of identity within the nursing context.

The research findings indicate the participant's experience of negotiating a disabled identity takes place largely in isolation and is influenced by biomedical narratives of disability which provide the foundation of the continuity of a predominantly disabling nursing environment. The experience of impairment is viewed as problematic and as an individual responsibility whilst the practices of organisations which perpetuate disabling environments were largely unquestioned. Issues of disclosure and non-disclosure have created tension for most of the participants within workplace environments that operate on an assumption of non-disability. The participants contribute to the practice of the nursing profession in a variety of roles which they have sought out as a means of managing within the nursing context.

This research challenges the perspective of an individual pathologised view of disability and promotes a perspective which embraces a rights based understanding. The research suggests that a willingness to promote equity of access and freedom from discrimination needs to be reflected in policy and standards of both the Nursing Council of New Zealand as nursing's regulatory body and within employing organisations.

### With gratitude

This study has been the work of a community. My first appreciations must go to the seven nurses who took part in the research and generously shared their stories. Without them this work would not have taken place.

I have had expert and kind supervision from Dr. Suzanne Phibbs from the inception of this study. She has skilfully extended my thinking and understanding of both theoretical viewpoints and the research process through her ability to provide succinct and insightful feedback. Dr. Tula Brannelly has provided supervision for the last year and has been a welcome addition to the team, able to offer timely nursing wisdom and engage fully in supporting my writing.

I would like to acknowledge the support of my work colleagues some of whom 'doubled up' as critical friends and mentors through the process. Thank you to Dr. Fran Richardson, Dr. Debra Wilson, Joanna Davison and Wendy Trimmer. Thank you to the librarians at both Massey University and Whitireia Polytechnic for their skill and support and to Theresa Nimorata for her advanced formatting skills.

There are friends I call family and family I call friends who have all been instrumental in contributing in important ways to my ability to complete this work. Thank you to Dr. Lisa Dorn, Chris Hill, Anja Van-Holten and Jayde Kawana. Finally, thank you to my partner Carol Shand who literally left the house when I needed her to, and who supported me foremost by engaging with my process and willingly providing whatever support was requested of her.

## Contents

Chapter One: Introduction .....	1
Situating the research .....	1
Methodology/method .....	3
Research aims and objectives .....	3
Defining disability .....	4
Findings.....	5
Overview of thesis chapters .....	5
Chapter One .....	5
Chapter Two.....	6
Chapter Three.....	6
Chapter Four .....	6
Chapter Five.....	6
Chapter Six.....	6
Chapter Seven: .....	7
Chapter Two: Literature Review.....	8
Introduction.....	8
Construction of disablement .....	8
Models of disability .....	10
Medical sociology and the study of disability.....	14
Disability and identity.....	15
Narrative approaches to identity .....	17
Portrayal of disability in the context of nursing.....	19
Student nurses with impairments .....	20
Research about disabled nurses.....	21
Summary .....	24
Chapter Three: Methodology .....	26
Narrative methodology .....	26
Narratives and disability .....	28
Method and design.....	30
Recruitment.....	30
Participant characteristics .....	31
Data collection .....	32

Ethical considerations: .....	33
Analysis of interview materials.....	35
Consistency and credibility issues .....	37
Summary .....	38
Chapter Four: Disabled identity, life circumstances and the workplace.....	39
Negotiations of identity.....	39
Discursive positioning .....	42
Tessa's Story: I wish nobody knew I had MS.....	44
Finding out and getting support .....	44
Disabled identity and impact on working life .....	45
Disability and social identity.....	46
Disabled identity and normalisation .....	49
Repositioning the disabled identity.....	51
Constructing the 'other' .....	54
Vicky's Story: I'm alive, I can get through this.....	56
Labelling disability .....	57
Being supported .....	58
Chapter Five: Corporeality and identity development.....	64
Impairment, corporeality and disability theory .....	64
Corporeality and the self .....	66
Corporeality and space.....	67
Mary's Story: Over the years most of my colleagues wouldn't have had any idea of what my pain levels were. ....	68
The temporal context .....	69
Managing corporeality by being strategic.....	70
Corporeality and the nursing context.....	71
Lonnie's Story; I guess for me then this doesn't look like a real disability, you know, I'm managing it better because I'm not having to burden my work with it. ....	75
Managing conditions by allowing time.....	76
Corporeality and managing day to day practicalities .....	78
Managing conditions by allowing space .....	80
Corporeality, identity and thinking of the future .....	81
The nursing space and the lived experience.....	82
Chapter Six: Invisible impairment and identity .....	85
Identity projects and stigma .....	85



Jo's Story: I don't want to be 'that'. I don't want to be sick. I don't want people to know about that because it changes how they think. ....	88
Setting the scene .....	88
Disability, being silenced and silencing.....	90
The public and private face of disability.....	92
Riro's story: I try to look on the bright side of it all rather than the 'this is what I've got' because I don't believe that at all.....	95
Disability, knowledge and control .....	96
Coping strategies: The avoidance of stigma .....	98
Concerns about stigma.....	99
Bella's Story: fit and proper doesn't include being mentally ill. ....	101
Being 'outed' .....	101
Impairment and disclosure decisions .....	103
Becoming an advocate and enabling others.....	104
Fit and proper: Power agencies and discrimination .....	105
Summary .....	107
Chapter Seven: Telling stories of disability .....	109
Introduction.....	109
Review of the findings .....	109
Disabled identity negotiations.....	110
Language and identity.....	111
The influence of medical discourses.....	112
Barriers and opportunities.....	112
Combined methodology .....	115
Recommendations for practice.....	115
Limitations of the study .....	117
Further research .....	117
Conclusion .....	118
Appendices.....	119
Appendix 1 – Email Advertisement .....	120
Appendix 2 – Participant Information Sheet .....	121
Appendix 3 – Participant Consent Form .....	123
Appendix 4 – Interview Guide .....	124
Appendix 5 – Ethics Approval .....	126
References:.....	128

# Chapter One: Introduction

Literature pertaining to the employment of registered nurses within the nursing profession identifies potential for systemic discrimination against those nurses with impairments (Kidd, 2008; Morrow, Wasik, Cohen & Elah Perry, 2009; Storr, Wray & Draper, 2010). Potential sites of discrimination are related to the regulatory fitness requirements and the interpretation and implementation of these in practice (Sin & Fong, 2008). This is further exacerbated by negative attitudes of nursing professionals toward colleagues with impairments (Boyles, Bailey & Mossey, 2008; Matt, 2008; Northway, 1997). These concerns have been articulated by nursing professionals in both the United States of America (USA) (Maheady 1999, 2004, 2006; Marks 2000), and Britain (Schick Makaroff, 2006). This chapter situates the research within the context of nursing and describes my own journey in the study. The research question and aims are presented. An over view of the key findings and the content of each of the chapters is also described.

## Situating the research

There is a scarcity of recorded literature in regard to disabled nurses<sup>1</sup>. This can be explained, to a degree, by disability not featuring as a subject for deliberation until recently in the nursing curriculum (Sin & Fong, 2008). Scullion (2000, p. 9) argues that disability is still perceived within the nursing profession as a medical event “*synonymous with illness, deviation or dependence,*” rather than being determined as being an equality and rights issue. Representation of impairment and disability within nursing literature and practice is problematic, as it supports oppression and minimal emancipation of disabled people (Boyles et al. 2008). People with impairments may be seen as ‘unfit’ for entry into the nursing profession or may be viewed as a risk (Wright & Eathorne, 2003). Much of the literature concerning disabled nurses focuses on nursing students’ experiences (Blankfield, 2001; Dale & Aiken, 2007; Griffiths, Worth, Scullard & Gilbert, 2010; Kane & Gooding, 2009; Kolanko, 2003; Maheady, 1999; Storr, Wray & Draper, 2010). Whilst there are some studies that consider disabled nurses (Grainger, 2008;

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<sup>1</sup> The use of the term ‘disabled nurses and/or people’ is deliberate and aims to represent a materialist or structural analysis which locates disability within social structures. The term ‘disabled people’ fits with the politics of the disabled people’s rights movement in New Zealand and with the philosophical underpinnings of the New Zealand Disability Strategy. This viewpoint, consummate with the social model of disability, identifies disability as imposed on people with impairments by society and in that process creates disabled people. Disability is a social phenomenon and a form of social oppression; it is socially created and does not reside in individuals (Sullivan, 1999). Not all authors, however, write from this position and hence there will be an inconsistency at times within this thesis due to differing terminology used.

Matt, 2008; Wood & Marshall, 2010), little is known about nurses experiences in practice and less is known about nurses' experiences who acquire impairments whilst in practice.

Currently, nurses in New Zealand are part of an ageing workforce. As a result, there is increasing discussion regarding nurse retention and recruitment (Ferguson et al. 2009). There are expectations of widespread retirement resulting in significant loss of specialist nurses across each sector (Eley et al. 2007). Therefore, it is pertinent to identify how both applicants and nurses with impairments can be recruited and retained within the profession (Wood & Marshall, 2010).

There have been a number of pathways in my professional nursing career that have converged to the point of undertaking this research. The majority of my nursing career was within forensic mental health environments. Several years ago, I began working for Disability Support Services within the Needs Assessment and Service Coordination area. It was here that I commenced postgraduate papers in disability studies and became aware of the theoretical underpinnings of disability scholarship. My nursing education had not previously exposed me to this ideology. I worked with individuals and their families experiencing a variety of impairments including mental illness and noticed two salient points. Firstly, people were often very surprised that my education was in the field of nursing. Some family members acknowledged their surprise as they felt that my understanding appeared to not correlate with their usual experience of nurses. A colleague mentioned that she had noticed my inclusive approach to disabled people. She had not expected this of me as I was a nurse and therefore 'bio-medically influenced'. Secondly, I noticed that disabled people were very political; many were engaged in supportive communities be it with other families or groups that were actively engaged in anti-discrimination work. In effect, this raised my own consciousness in regards to disability rights and the social model of disability (Finkelstein, 2001; Oliver, 1983; 1990).

Presently, I work as a postgraduate educator of nurses and other health professionals in the mental health field. This work includes conducting workshops to raise awareness of issues of discrimination and inclusion. Whilst reviewing the workshop questionnaire recently, I was struck by the first question: Do you think that a person who has a mental illness can do your job? (Mental Health Commission, 2001). The apparent assumption in this question is that nurses do not have mental illnesses. This was incongruent with my experience, whereby many of the nursing students and staff I have worked with do experience mental illness and other impairments. Furthermore, discussion with colleagues also alerted me to the representation of disability within nursing. Nursing colleagues revealed awkwardness around interviewing both

nursing staff and potential nursing students when they perceived the candidates impairment as being inconsistent with the nursing role. In marked contrast, those who had experience of nurses with impairments perceived the applicants or nurses as being competent.

### **Methodology/method**

The study employs a qualitative approach that is influenced by Somers' (1994) four interrelated dimensions of narrative methodology comprising ontological, public, conceptual and meta-narratives. Inclusive to this methodology is an abductive strategy based on a constructivist view of social reality (Blaikie, 2000; 2007; 2010). This view produces accounts of social life drawing on the concepts and meanings used by social actors and the activities in which they engage (Douglas, 1996). The Central Regional Ethics Committee approved this study. Seven participants participated in one-on-one semi-structured interviews.

### **Research aims and objectives**

The central research question is as follows:

What are the work experiences of registered nurses who are disabled?

Aims:

The aim of this research is to explore the experience of registered nurses who have impairments/conditions and who may have experienced disability, during the course of their careers.

Objectives:

Specific objectives of this research are to:

- understand how research participants experience disability
- identify how the identity of the research participants changes once he/she has an acquired impairment
- determine what the participants have experienced as both barriers to their practice and what they have experienced as facilitators of their practice
- explore how the participants view the impact of their impairment/condition in relation to their nursing practice; does their perception of nursing change?
- identify what recommendations could be made to enhance the ability of the nursing profession to provide a nondisabling environment.

## **Defining disability**

The definition of disability is complex. The document entitled *Fundamental Principles of Disability*, produced by the Union of the Physically Impaired Against Segregation (UPIAS, 1975) separated disability from impairment and consequently revolutionised thinking about disability at that time (Sullivan, 1999). Disability was now located outside of the body and consisted of the actions, or inactions of people and organisations which work to exclude disabled people from full participation in society. Oliver (1990) drew on this thinking to create the social model of disability. The social model provides a tool for the critical analysis and explanation of the disadvantage people with impairments experience in a disabling society (Cameron, 2007; Oliver, 2010).

The New Zealand Disability Strategy (NZDS) describes disability as a process that occurs 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’* (Minister for Disability Issues, 2001, p.7). The term ‘impairments’ was broadly defined to include physical, sensory, neurological, psychiatric, intellectual and any other impairment, and to take into account those with permanent, intermittent, temporary and perceived impairments. This definition reflects the social model of disability which emphasises social barriers as the most significant problem experienced by disabled people. This definition is used in this thesis.

Ethically it is reprehensible to use any descriptive label that is offensive to members of a particular group, irrespective of whether or not they are participants in a research study (American Sociological Association, 1997; British Sociological Association, 2002). For these reasons, I also use the term ‘non-disabled’ rather than ‘able-bodied’. The term ‘able-bodied’ has a clear descriptive association with ‘do-ability’. As a result, people outside of this grouping can be viewed as deviant in relation to the perceived norm.

In this study, the participants explain how they view themselves in relation to being disabled. They did not commonly use the language of disability or impairment. Some participants referred to the term ‘limited’ or having ‘a limitation’ or ‘a condition’ or ‘an illness’. As such, the terms ‘disabled’ and ‘impairment’ are used as well as the terms used by participants within their stories. The participants did not identify as ‘disabled’ and demonstrated that they reflect the medical model of disability as being a physiological pathology that is located in an individual (Oliver, 1990; 2010). No participant used the terminology of disability that is

consistent with the social model of disability. Although participants talked about disabling practices, they did not use the language of disability or oppression to identify them.

## **Findings**

The research findings indicate that the participants do not consider that they are disabled and reject a disabled identity that is based in deficit and dependency as viewed from a biomedical perspective. At the same time the participants' narratives relating to their impairment or illness illustrate the influence of medical discourses of disability which they draw upon in order to understand their impairment or illness and to make meaning of their experiences. The participants' narratives are stories of competent nurses who have a variety of impairments. The participants have developed knowledge, skills and experience that contribute to the practice of the nursing profession in a variety of roles which they have sought as a means of managing within the nursing context.

Medical narratives of disability provide the foundation of the continuity of a predominantly disabling nursing environment influencing participant's experience of negotiating a disabled identity in isolation. There is a tension evident in the narratives between the individual and societal responsibilisation of disability. Issues of disclosure have been problematic for most of the participants within workplace environments that assume non-disability. The experience of impairment is viewed principally as an individual problem while the practices of organisations which perpetuate disabling environments were largely unquestioned. Findings from this research suggest that there are a series of tensions and problems associated with the experiences of the participants which are examined in light of social theories relating to impairment and disability. Theoretical understanding of the ontological and public narratives present in the participant's narratives in turn enable a set of discussion points to be drawn out to inform changes in policy and practice.

## **Overview of thesis chapters**

### **Chapter One**

The first chapter introduced nursing and disability literature which suggested that nurses with impairments may be subjected to discriminatory practices within nursing. This chapter also identified that it may be pertinent to explore ways in which nurses with impairments are recruited and retained due to effect of an ageing workforce on nursing capacity. I then explained my interest in exploring this topic. Discussion of the definition of disability was followed by overviews of the research methodology, research question, aims and findings. The chapter concluded with an overview of the thesis.

## **Chapter Two**

An overview of the literature pertaining to salient areas within this study includes three aspects to be examined. These include the theoretical perspectives of disability scholars, the relationship between the medical and social model of disability and the influence of the models on medical sociology and on nursing. The second aspect is the impact of acquired impairment on identity and how this has been explored through a narrative approach to identity construction. Thirdly, the portrayal of disability in nursing and the lived experience of disabled nurses is considered.

## **Chapter Three**

The methodology used in this research is identified in this chapter. The methodology described includes Somers' (1994) four interrelated dimensions of narrativity and Blaikie's (2000; 2007; 2010) abductive strategy based on a constructivist view of social reality. The research design, data gathering methods and analyses of interview material are outlined alongside ethical considerations related to the study.

## **Chapter Four**

This chapter is the first of three substantive chapters. This study utilises different theoretical lenses rather than an overarching theory in order to illustrate themes at work within each of the substantive chapters. This chapter presents the narratives of two participants and explores the theoretical constructs which contribute to the formation of identity and more specifically the place that discursive positioning plays in the configuration of identity through the lens of positioning theory (Davies & Harré, 1990). This chapter situates the onset and negotiation of impairment as a challenge to pre-existing conceptions of selves and demonstrates how identity is discursively negotiated.

## **Chapter Five**

Discursive positioning and the relationship to identity is extended in this chapter by considering how corporeality, space and time dynamically affect identity formation. Two participants stories are described to demonstrate how identities shift and change in response to being positioned within narratives that are contextually located.

## **Chapter Six**

This chapter explores the experiences of three participants who have invisible and, at times, hidden impairments. The framework of 'identity projects' (Harré, 1983) and theories of 'stigma' (Goffman, 1963) are used to explore the narratives in the face of highly stigmatised categories of health conditions that challenge the participants sense of self and self worth.

**Chapter Seven:**

The final chapter provides an overview of the research findings in the light of the theoretical lenses used to explore the experience of nurses who acquire an impairment. The findings draw on key ideas related to a disabled identity negotiation, the influence of medical discourses within nursing and the barriers and opportunities presented within the nurse's experiences. Methodological implications are discussed and recommendations for practice are identified. Limitations are addressed and the chapter concludes with proposals for future research and a closing statement.



## **Chapter Two: Literature Review**

### **Introduction**

The issues confronting nurses with impairments within nursing practice have not been studied extensively. There is much that is still unknown about the experiences of registered nurses when impairment affects both their identity and their nursing practice. There are three main aspects to this literature review. Firstly, it is necessary to consider the construction of disablement and the theoretical perspectives of disability scholars. The relationship between the medical and social model of disability is discussed. Examination of the process of disablement including how disability as a field of study has contributed to academic developments in medicine, nursing and sociology and how perspectives have changed over time is explored. The second aspect of the literature is the impact of acquired impairment on identity and how this has been explored through a narrative approach to identity construction. Literature with regards to disability and identity includes research about the embodied experience of impairment. Thirdly, the literature about the portrayal of disability in nursing and the lived experience of disabled nurses is considered. No literature has been found that explored the impact on the identity of nurses who have acquired impairments during the course of their career.

### **Construction of disablement**

Traditionally, the perception of those who have an impairment is that it is viewed as being tragic (Shakespeare & Erickson, 2001). This perspective includes seeing disabled people as objects of pity and/or recipients of charity. As a result according to Oliver (1992), disabled people were seen as both a social and educational problem and they became marginalised and segregated from society in special schools, workhouses and asylums. A paternalistic attitude toward disabled people was the norm as was institutionalisation in special homes or hospitals. Because disabled people were not perceived as possessing the expertise, knowledge, education and experience of the professionals, they were not accorded respect as their own decision-makers and doctors and social workers were the primary decision-makers (Oliver, 2010; Shakespeare & Erickson, 2001; Smart & Smart, 2007). As a result, disabled people found themselves largely excluded from society and from the decisions that governed their lives (National Advisory Committee on Health and Disability, 2003).

In health and nursing literature the concept of disability has been understood from a physiological orientation and conceptualized as a functional limitation which belongs to the individual (Boyles et al, 2008). This functional biomedical perspective defines disability as an individual limitation in performing certain roles and tasks that it is expected a person can

perform (Smart & Smart, 2007). From this traditional perspective, disability is the difference between what the person is capable of doing and the demands of the person's environment (Boyles et al. 2008). This perspective emphasised that the primary problem disabled people had was their incapacity to work and participate in society. The role of the government therefore, was to provide financial support and assistance in rehabilitation, thus creating a model of dependency (Oliver, 1983; Scotch, 2000).

The challenge to this perspective draws upon ideas formed with the civil rights movements of the 1960s. As women and social minorities gained political influence so too did disabled people, and the concept of discrimination against people who have impairments arose (Corker, 1999; Oliver, 1996). The aim of the initial phase of the disability rights movement was to decrease marginalisation (Corker, 1999; Oliver, 1992). This phase called forth the need for social inclusion regardless of a person's functional ability.

Legislative changes eventuated from the first stage in the quest for disability rights. There was the establishment and inclusion of disability rights in New Zealand within the Human Rights Act (1993) and the New Zealand Bill of Rights Act (1990) which aimed to protect the rights of disabled people to freedom from discrimination. The New Zealand Disability Strategy: Making a world of difference (2001) was introduced as a result of the introduction of the New Zealand Public Health and Disability Act (2000). This strategy provides a high-level framework to ensure all government agencies consider disabled people in their decision-making processes (Human Rights Commission, 2010). New Zealand is also a signatory of the United Nations Convention on the Rights of Persons with Disabilities which builds on conventional understandings of what is required to implement existing human rights as they relate to disabled people. Being a signatory means all new legislation and policy needs to be consistent with the Convention, or New Zealand will be in breach of its obligations (Office for Disability Issues, 2011).

The second stage of the quest for human rights was for a collective disabled identity; an exploration of diversity and what it means to have an impairment and experience discrimination in society (Smart & Smart, 2007). There was a necessity for identity to be self defined and a rejection of nondisabled norms (Oliver, 2010). Challenging the devaluing of nondisabled definitions has enabled disabled people to begin to celebrate themselves and to begin to uncover and formulate sets of alternate values derived from within the personal experience of impairment (Longmore, 2003).

## **Models of disability**

The pursuit for common identity amongst disabled people has rejected institutionalized definitions of disability and of disabled people (Oliver, 1996). This consciousness has repudiated the biomedical model which defines disability as physiological pathologies located in individuals (Oliver, 1983; 2010). The biomedical definition describes treatment aimed at curing individuals or correcting social and/or vocational functioning through medical advancement, research and genetics. Cure, or correction, meant that disabled people had the means of achieving social approval. Those who are not cured or corrected are marginalised (Longmore, 2003). This biomedical model of disabled people established itself as being based on science and as both objective and humane (Oliver, 2010). In fact, this biomedical viewpoint was subjective. It was heavily influenced by paternalism and social anxieties about people who look or function differently. The biomedical view has the authority to relieve society of any responsibility to accord civil rights to any individuals with impairments (Smart & Smart, 2007). Locating the predicament of disability in the bodies of individuals with impairments, the biomedical model cannot account for or address barriers and discrimination that disabled people experience. The implementation of the biomedical model in the health professions, social services, education, private organisations and social policies has institutionalized injustice and discrimination (Oliver, 2010).

Disability scholars have substituted a socio-political or minority group model in the place of the biomedical model. In the early 1980s, Michael Oliver (1983) introduced the idea of social as opposed to individual models of disability. The social model asserts that disability is not caused by impairment but results from the social restrictions imposed upon disabled people (Oliver, 1983, 1990). For the vast majority of people with impairments, prejudice is a far greater problem than any impairment and discrimination a far bigger obstacle to overcome (Finkelstein, 2001; Longmore, 2003; Oliver, 1996). Powerfully institutionalized oppression of disabled people by the wider society is the core issue affecting people with impairments. The change of the location of the problem from the individual to the social shifts the onus and responsibility for the solution to the problem from the individual to society (Smart & Smart, 2007). From this perspective, it is the translation of negative attitudes into discriminatory practices that exclude disabled people from the wider society and create barriers to inclusion.

In order to understand the social model there is a need to differentiate between the term impairment and disability (Oliver, 1983; Thomas, 2004). Impairment is the term used to refer to medical conditions, whilst disability refers to the social reactions to impairment, particularly experiences of discrimination, social exclusion and marginalization (Oliver, 1990). Thus in this

social model perspective, disability refers to the disabling barriers of unequal access and negative attitudes that are externally imposed on an individual (Boyles et al, 2008).

Disability rights ideology, based upon the social model, claims 'reasonable accommodation' as legitimately permanent differential treatment which is necessary for disabled people to achieve and maintain equal access (Asch, 2001). Equal access is a broad concept that has sought to achieve full participation for disabled people in society. The critique of the biomedical model has identified that in order for disabled people to be respected as worthy, and to be considered as whole persons, disabled people have continually been given societal messages that they must perpetually labour to 'overcome' their impairments (Longmore, 2003). Disabled people must display continual motivation to move toward some elusive and for some unachievable appearance of normality as defined for them by others.

Critique of the social model of disability has identified an absence of cultural processes in favour of attention to material and socio-structural phenomena (Thomas, 2004a). Shakespeare (1996) explored disablism with reference to the cultural meaning of impairment and highlighted the typically negative images of disabled people which prevail. Feminist analysis drawing on Simone de Beauvoir's 'otherness' model has been a suggested way of viewing how cultural processes subordinate one group over another (Morris, 1992, 1996). Just as women are construed as being closer to nature and 'other' to men, so disabled people become 'other' to non-disabled people (Shakespeare, 1997). Otherness is defined by those who have the power to construct and enforce definitions of the other (Butler, 1990). Oliver (1996; 2010) has countered that the social model cannot be assumed to 'do everything', as it cannot explain disability in its entirety, but it can encourage professionals to reflect on their practice. Oliver also suggests that whilst the social model had not adequately addressed social divisions this does not mean it cannot do so, it means that the model has not been used to study social divisions (Oliver, 2010).

Sherry (2004, p.776) acknowledged a "*debt to feminism*" which enabled the deconstruction of the public/private divide and the development of the analytical category of the 'other' which provided analytical tools upon which disability studies would later develop. Feminism established that the personal is political. Due to systemic oppressive power relationships, personal issues are political issues and both disability and queer theory have drawn upon this concept (Morris, 1992; Sherry, 2004). Disabled people separate impairment-physical or cognitive difference-from disability-the social reactions to that difference (Oliver, 1990, 2010; Sherry, 2004). It is common to hear such analogies being made between the experiences of disabled people and those of women, minority ethnic communities and lesbians and gays

(Shakespeare, 2006). Thomas (1999; 2002) views the concept 'disablism' as being on a par with other concepts such as sexism, racism and homophobia. But Shakespeare (2006) asks how far can the analogy between different movements and oppressions be sustained? Shakespeare acknowledges that as social movements women's liberation, gay rights, disability rights and antiracism are similar in many ways, in that each involves identity politics, each challenges the biologisation of difference and each has involved an alliance of academia and activism. Yet the oppression which disabled people face is different and more complex, than sexism, racism and homophobia although these may be experienced alongside being disabled, therefore indicating multiple structural levels of discrimination.

Functional diversity has been posited as a way of thinking about impairment and disability. The concept of constructive functional diversity (CFD) promotes a strengths based approach by removing the notion of a comparative state of 'normalness' against which people with impairments are judged. CFD offers a new language that is non-medicalized and constructive (Patson, 2007). Lipson and Rogers (2000) address the complexity of the topic of disability culture arguing that there are many disability subcultures. They highlight that the variations in type, severity and age of onset of disabilities make it difficult to talk about one culture of disability. Wendell (1996) states that it would be hard to claim that disabled people have a shared culture due to the diversity of experiences and identities, however there are ways of knowing not available to non-disabled people.

There is a division amongst disability theorists with regards to their views about the importance of theorising impairment. For some disability theorists, the distinction between impairment and disability is fundamental (Oliver, 1990). There is a concern that acknowledging pain associated with some impairments leads to a focus on functional and physical limitations (Shakespeare, 1996). The possibility of a return to the superior position of the biomedical model, which has its focus on blaming the victim, could lead to the dissipation of the disability political movement (Shakespeare & Watson, 2001; Oliver, 2010). Theorists argue that there are ideological reasons for not focusing on impairment (Oliver, 1996; 2010). Alternatively, disability theorists who advocate for a focus on the differences between disabled people are concerned to ensure that the social approach to disability also incorporates an analysis of impairment (Mulvany, 2000; Shakespeare, 1996). To ignore impairments is to ignore the lived experiences of disabled people (Hughes & Paterson 1997).

Impairments are inherited, congenital, and/or acquired, and hence disabled people contribute to a diverse range of life experiences in sociocultural and economic contexts (Lipson & Rogers,

2000). Within each type of impairment-developmental, psychiatric, sensory, neurological or physical-as well as within each condition, there is also a range of experiences. There is much debate in disability studies of how to conceptualise and theorise the concept of 'impairment'. There is some agreement on a definitional approach which is inclusive of diseases that are commonly referred to as 'chronic illnesses' (Thomas, 2007).

Through the development of a culture of resistance, disabled people have developed a discourse that repudiates personal tragedy narratives and that identifies impairment as a part of human diversity that is to be celebrated (Cameron, 2007). The affirmative model builds upon the social model and focuses on impairment as a physical, sensory or intellectual difference that is to be expected and also respected within a diverse society (Cameron, 2007; Swain & French, 2000). This model does not include any descriptions that have negative connotations such as those that describe limitations or deficits. The affirmative model continues to retain a social model definition of disability. The model enables disabled people to establish their personal and social identities as people with impairments, and at the same time, as disabled people, recognizing that both rights and opportunities to participate as equals within the mainstream society are restricted by barriers that are socially imposed (Cameron, 2007; Swain & French, 2000; Swain, French & Cameron, 2003). According to Smith and Sparkes (2007), the affirmative model is a narrative of disability and impairment that includes positive social identities, which are both individual and collective, that are grounded in the benefits and life experiences of being disabled and having an impairment.

Thomas (1999) identified a social relational definition of disability which identifies the socially imposed restrictions of activity on disabled people and also incorporates the dimensions of personal identity and the psychological and emotional dimensions of disablement. This inner world aspect is closely bound with the socio-cultural aspects that generate negative attitudes about impairment and sustain prejudicial meanings, ideas, discourses, images and stereotypes. Thomas suggests, that for most people with impairments, there are times when the prejudice and discrimination they experience succeeds in severely undermining their psycho-emotional wellbeing. Personal consequences of living in a disabling society should not be thought of as a natural consequence or a private response of being impaired, but rather as part of an important dimension of disablism in society that needs to be challenged.

The effects of living in a disabling society mixed with the experience of living with impairment are rich and multi-dimensional creating our social identities. Thomas (1999) uses first person narrative to illustrate the psycho-emotional dimensions of disablism. It has been widely

considered that people's identities are developed based, in part, on their perceptions of how others evaluate them. This common understanding is often called a 'looking glass self,' whereby we look into the eyes of others to assess our own self worth (Cooley, 1983; Hughes, Robinson-Whelen, Taylor, Swedlund & Nosek, 2004).

### **Medical sociology and the study of disability**

Disability studies use a social oppression paradigm which states that to be disabled, or to be discursively constructed as 'disabled' is to be subject to social oppression (Shakespeare, 2006). Medical sociologists theorise disability and enduring illness through a social deviance lens. This lens identifies themes within the societal response to people who are chronically ill or disabled and the social experience of living with stigmatised bodily states (Thomas, 2007). Most disability theorists acknowledge that there are a number of similarities between impairment and enduring illness, and accept that disabled people may require medical treatment on occasion (Barton 1993; Mulvany, 2000; Oliver 1996). All impairment though, cannot be studied from a medical illness perspective (Barnes & Mercer, 1996). There is concern that a focus on illness restricts the ability of the social model of disability to move ideology and understanding from an individualistic to a social structural analysis of disability (Mulvany, 2000; Oliver, 1983; 2010). Oliver (1996) identifies that a focus on individual illness within disability studies can lead to the posing of an underlying relationship between enduring illness and disadvantage. Some disability theorists are hesitant of the contribution medical sociologists can make to the study of enduring illness and disability (Barnes & Mercer, 2003; Shakespeare, 1996; Thomas, 2010). They argue that the research of enduring illness highlights the negative aspects of illness and neglects the structural context within which meanings are shaped. This then reinforces the 'victim' image of the person with an impairment and contributes to a negative sense of self and identity (Barnes & Mercer, 1996; Mulvany, 2000; Oliver 2010).

In contrast, there are disability theorists who contend that writing in the sociology of health and illness assists disability theorists generally to acknowledge that some disabled people experience both pain and bodily discomfort, a point which has often been ignored (Mulvany, 2000; Shakespeare & Watson, 2010; Thomas, 1999; 2002; Williams, 1993). Some scholars perceive the writing within medical sociology (Frank, 1993, 1998, 2000) as focussed on the relationship between health professionals and their patients and as not relevant to disability studies (Oliver, 1996).

Mulvany (2000) explains that:

*While the social disability theorists have avoided the mistake made by the anti-psychiatrists in their assertions that psychiatric impairments were total social constructions, they appear to have acceded too much to medicine. By so doing, they ignore the possibility of exploring the complex relationship existing between embodied impairment and disability. They also retreat from a critical analysis of all aspects of medical involvement in the lives of people with disabilities (p.50).*

Any recognition of a link between people with illness, impairment and/or disability would need to include an acknowledgement that some people with disabilities will and do seek medical treatment and that disabled people can be disempowered by the medical establishment (Oliver, 2010). It is contended that the distinction made by disability theorists between impairment and disability means that 'legitimate' medical work related to the treatment of disease and illness for disabled people is ignored. Mulvany (2000) further contends that the social model of disability must both acknowledge the legitimacy of medical activities and, at the same time, provide a critique of these activities in order to be able to identify a full range of social barriers disabled people experience.

Illness and impairment as narratives, some autobiographical, have appeared with greater frequency in disability studies publications (Ayometzi, 2007; Cameron, 2007; Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004; Loodin, 2009; Smith & Sparkes, 2008a). This writing differs from medical sociology by making an analytical linkage between the experiences and broader socio-structural and cultural agendas. As such, these writings contribute to disability studies as they locate the experiential concerns in a social oppression paradigm (Smith & Sparkes, 2008b; Thomas, 2007).

### **Disability and identity**

Writers and activists within disability studies have paid a great deal of attention to individual identities, to identity politics and to the nature of social movements (Moss & Dyck, 2003; Raggat, 2006; Reeve, 2002; Shakespeare, 1996; Thomas, 2007). Over the last few decades, self and identity have moved into centre stage within the social sciences. However, what these terms denote can be ambiguous, due partially to the fact that approaches to self and identity have emerged within different traditions and disciplines (Mishler, 1999). The ability to construct personal and social identities and make sense of experience is influenced by mainstream cultural texts. For disabled people these texts often only provide a narrow and negative range of stereotypes and representations from which to choose (Cameron, 2007; Oliver, 1996;



Shakespeare, 1996). Exploring the effects of the onset and ongoing experience of impairment in relation to disabled people's self-perceptions involves consideration of processes surrounding the formation of what has been referred to as 'the disabled identity' (Corker, 1999; Galvin, 2003). Denzin (1992) refers to the movement from one social world to another that occurs with acquiring an impairment and that this traces and identifies the concepts that we usually take for granted in relation to normative notions of 'the self'. Charmaz (1983) describes a 'loss of self' which is brought about by the disabling effects of long term illness and Bury (1982) refers to chronic illness as a 'biographical disruption'. Subjection to dominant discourses that view the self as impaired in a negative context means that some disabled people reject a disabled identity. Such a rejection means that they continue to struggle as individuals against structural barriers, believing both the cause of, and the solution to, the discrimination they experience lies within themselves (Cameron, 2007; Smith & Sparkes, 2007; Watson, 2002).

An identity of disability, which at its core contains notions of power, of control and of respect, provides alternative discourses which are empowering as opposed to disabling by rejection of the passive roles expected of disabled people (Cameron, 2007; Watson, 2002). Swain and French (2000) propose that the affirmative model of disability establishes what they term a counter-narrative. This can be liberating for some disabled people and can assist in the process of reconstructing identities by providing a sense of communal consciousness and expanding the cultural collection of stories from which to draw when re-configuring a life experience. Smith and Sparkes (2007.p.230) contend that the affirmative model "*can also enable the reconstruction of selves by resisting and deviating from standard plots and dominant assumptions about disabled people (e.g. disability is a tragedy that results in life being perceived as effectively over*". The affirmative model enables the storyline of tragedy to be displaced and replaced with a storyline which proposes a range of future possible positive identities (Charmaz, 1995; Smith & Sparkes, 2007).

The affirmative model as a counter-narrative, may provide a liberating, beneficial, and/or a transformative possibility for some individuals by both making available and legitimising alternative ways of living as a person with an impairment (Swain & French, 2000). The affirmative model may also compliment the social model which, whilst not without problems, may assist to liberate the lives of some disabled people (Oliver, 1983;1990). As an example, identifying and actually removing the barriers that restrict people's access to social spaces might, for some people, aid the process of enabling different stories to be told and thus connections to counter-narratives to be made (Smith & Sparkes, 2007).

There is also an acknowledgement of the similarities within disability identity theory to that which has also developed in queer theory. Sherry (2004) identifies the power relationships inherent in identity politics which he terms “*presumptive nondisability*” which acknowledges the social dynamic around categories of unmarked categories of identity (p.778). Both theories of disability and queer epistemologies have contributed to the deconstruction of binaries (Sherry, 2004). Both the heterosexual and non-disabled norm have been compared as “*masquerading as a non-identity, as the natural order of things*” (McRuer, 2006, p.79). Scholars within disability studies claim that there is no core self that gives rise to a singular ‘disabled’ identity but that personal identities are always multi faceted and attributed through discursive practices (Cameron, 2007; Charmaz, 1995; Davis, 2006; Galvin, 2003).

### **Narrative approaches to identity**

The mainstream perspective within sociological thought has endorsed the view that research into the effects of enduring illness enables understanding of the social and provisional nature of identity and that identity can be viewed as a continually constructed narrative (Frank, 1993; Galvin, 2003; Radley, 1993). Narratives are therefore a locus for the expression of the analysis of identity. Narratives are a mode for tying together existent analogies between life, biography and story. Narrative coherence is viewed as the way that people signpost how their lives are actually lived and how they make sense of their lives in meaningful ways (Bamberg, De Fina & Schiffrin, 2007). This coherence enables location of the self with a beginning, middle and an end. This structure imposes a point of origin and an orientation towards closure and thereby structures potentially meaningless experiences into meaningful ones (Ayometzi, 2007). Sands (1996) contends that narratives may contain examples of dominant discourses as well as submerged stories and that we need to build stories about ourselves to create a sense of continuity and cohesion. Frank (1995) argues that while people tell their own unique stories of their experience of illness or disability, they create these stories by adopting and combining the types of stories that are available to them within their cultures or societies. There is a contention that personal stories are both personal and social at the same time (Carless & Douglas, 2007).

The act of narration, of telling the story, structures and projects our sense of selfhood and identity over time (Riceour, 1984). Along with what is referred to as the ‘tellability’ of personal stories, this is an embodied process (Williams, 1996b). Tellability refers to not all stories having equal status. Some stories are more acceptable than others which results in some being heard whilst others are ignored or actively silenced (Smith & Sparkes, 2007). Norrick (2005) proposes a two-sided view of tellability. The lower threshold of tellability is sufficient to warrant the listener being interested, whilst the generally ignored upper threshold is where tellability merges

into the no longer tellable. These become the stories that are too personal, too embarrassing, or too frightening to hear. This upper threshold may invalidate people's stories by not recognising them and therefore, the processes of reconstructing identities and developing differently valued body-self relationships becomes even more difficult. As Taylor (1994) suggests, identity is partly shaped by recognition. Misrecognition or the absence of recognition by others may cause a person or group of people to suffer damage and distortion, if the people or society around them reflects back to them a confining or contemptible picture of themselves. A narrative approach to identity credits people with the possession of agency, conceives of identity as fluid, and locates identity in biographical context (Ayometzi, 2007; Faircloth et al., 2004; Frank, 1993; Nelson, 2001; Thomas, 2007).

Eakin (1999) identifies how the body shapes the stories that come out of it and that the selves can be heavily invested in people's bodies. Frank (1995) supports this and draws attention to the earthly or corporeal character of bodies as an unyielding fact, thus providing people with the means of acting, as well as placing constraints on their actions. Frank (1995) believes that we not only tell stories *about* our bodies, but the telling of the story is *out of* and *through* our bodies. Hence, the body not only becomes simultaneously the cause and the topic, but also the instrument of the story told. Therefore the type of body that one *has* and *is*, becomes important to the kind of story told. As Hughes and Paterson (1997) stress:

*Disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning . . . Most importantly, the (impaired) body is not just experienced: it is also the very basis of experience . . . Disability is, therefore, experienced from the perspective of impairment. One's body is one's window on the world* (p. 334–5).

A number of disability theorists have drawn on work from the sociology of the body to refine their analysis of the relationship between impairment and disability because they are concerned to incorporate the significance of impairments into the social approach to disability (Mulvany, 2007; Parr & Butler, 1999; Samuels, 2003; Siebers, 2006; Thomas, 2002). Butler and Bowlby (1997) argue that the social model of disability must see impairment as 'embodied', as opposed to presenting a reductionist view of the body where the body and society are seen as separate. The experience of embodiment is the result of a complex relationship between society and corporeality (McRuer, 2006). Embodied experience is both sensory and shaped by social relations and ideas about normal bodily form because the body is a social and corporeal construct (Butler & Bowlby, 1997; Smith and Sparkes, 2008a; Thomas, 2002; Williams, 2006).

Hence an individual's identity becomes, in part, a product of their experience of embodiment (Moore & Kosut, 2010; Somers, 1994; Thomas, 2007). The mind/body dualism incorporates the metaphysical stance, that the mind and body are two distinct substances with a different essential nature. That the mind is perceived as an immaterial but thinking substance, and the body as an extended, material but unthinking substance, has not encouraged exploration of how people make sense of their physicality and corporeality and how this in turn impacts on their identity (Mehta, 2011). Sparkes and Smith (2006) have developed ideas surrounding the embodied self by using the narratives of sportsmen who have spinal cord injuries that identify that experience is shaped actively by the lives people lead and represented by narratives.

Thomas (2002) argues that the lived experience of impairment involves contending with not only societally constructed barriers to participation, but also with what she terms the psycho-emotional dimensions of life, which involves the material body and the effects of impairment. For Thomas, understanding the experiences of disabled people and the ways in which disability is a form of social oppression must begin with an engagement with people's bodies as lived, social and biological entities. The psycho-emotional dimensions of disability are central to the idea of a disability identity being a fluid concept which is not fixed in time or place and which varies between people with impairments. Like individual differing experiences of structures that create disabling environments, not all disabled people experience the same degree of psycho-emotional disability, as personal biography, intersecting identities, impairment and context change the daily experiences of disability (Reeve, 2002).

### **Portrayal of disability in the context of nursing**

Numerous nurse researchers have explored the theories of disability in nursing within the context of enduring illness (Goodall, 1994; Marks, 2000, 2007; Northway, 1997, 2000; Scullion, 2000; Thorne, 1993, 2001; Thorne & Paterson, 2000; Winland-Brown & Pohl, 1990). These researchers assert that nurses may be viewed as part of a system that disables people living with impairments. The presentation of disability and impairment within nursing practice is problematic as it supports oppression and minimal emancipation of people living with disability by portrayal of an individual, medically influenced model of disability (Boyles et al, 2008; Smeltzer, Dolen, Robinson-Smith & Zimmerman, 2005). Northway (1997, 2000) suggests that nursing literature by its continuation of the labelling of disabled people as tragic victims has provided a form of oppression which nurses need to be aware of. Given that there is an unequal distribution of power between nurses and people with impairments, Northway (2000) argues that research is needed which examines professional behaviours within the disability and impairment context. An awareness of the nurses' positioning within this power

relationship and an understanding of the impact of oppression is seen as being essential (Northway, 1997, 2000). Richardson (2000) supports the notion that nurses need to be acutely aware of disability as a social construct and the nursing profession needs to redevelop the dependency image of disabled people and adopt a partnership approach. Boyles et al (2008) suggest that the adoption of the social perspective of disability is required in order to inform an understanding of disability that addresses stigmatization and oppression.

The need to adopt the social perspective of disability has been echoed by other nurse researchers who have concerned themselves with understanding both enduring illness and disability through a social rights framework (Blackford, 1998; Northway, 1997; Scullion, 2010; Thorne, 1993, 2001; Thorne & Paterson, 1998). These researchers identify that an alternative to the biomedical model establishes the 'insider' perspective based on the lived experience. This viewpoint enables disabled people to no longer be the recipients of health care, but to now be active partners who are experts in their own health care needs (Thorne & Paterson, 2000). This expert role highlights the competence in skill and decision-making in self-care management for people with impairments. Thus the role of nurses is redefined, from that of the role of caregiver to that of a partnership role (Marks, 2000, 2007; Thorne, et al., 2002). Lipson and Rogers (2000) identify that nurses rarely examine their own attitudes to the disabled population, nor do they recognize the social nature and lack of effort to remedy the environment that is the basis of many problems experienced by disabled people. This area of research which examines the intersection of nursing and disability is growing and there has been repeated calls for consciousness raising amongst nurses and an integration of social understanding of barriers for disabled people. Nursing researchers have called for recognition of the social and equality dimensions of disability and consideration of the potential of the social model of disability to address discrimination within nursing (Marks 2000; Northway 2000; Richardson 1997). A review confirms that this call has gone largely unheeded (Boyles et al. 2008). The implication for the social model of disability to inform and critique the traditional dependency model of disability has been noted, however, and is part of the research agenda in this study.

### **Student nurses with impairments**

There has been research that addresses supporting nursing students with impairments focusing on their experiences in the classroom and clinical educational settings. Kolanko (2003) found that impaired students worked harder than those without impairments and that the barriers of negative attitudes from faculty and staff in the clinical setting were greater than any physical barrier. Students also perceived that disclosure of their impairment would have negative consequences for them (Maheady, 1999). Storr, Wray and Draper (2010) identify that support

for disabled students has tended to be reactive rather than proactive. Furthermore, Kane and Gooding (2009) report that the level and quality of support for impaired students has varied widely between organisations and that there is no evaluative literature about the success or otherwise of supportive interventions. When staff were unaware or did not have specific knowledge of the student's impairment and the support available, students reported adverse experiences (Blankfield, 2001). Equally, when staff were well briefed the students reported positive experiences (Dale & Aiken, 2007). One study identified ongoing disability awareness training and education for nursing education and clinical staff as key to bringing about a positive change in undergraduate nursing culture in order to support nursing students with impairments (Griffiths et al, 2010).

Literature also identified a proactive approach to supporting nursing students with impairments with reasonable adjustments which separated the language of 'competency' from that of 'fitness and health', enabling staff to respond effectively to students needs and address negative perceptions of disability (Wright and Eathorne, 2003). Storr, Wray and Draper (2011) identified that there is little research exploring the effectiveness of adjustments that have been made for nursing students with impairments and that further research would better inform support for nursing students. Tee et al. (2010), in their analysis of support strategies and adjustments made in practice settings, concluded that implementing adjustments requires a multi-disciplinary approach in order to support students and their mentors, and to enable the development and application of coping strategies to overcome potential restrictions or barriers. Generally the literature on students was supportive stating that impairment itself should not be a barrier to people entering nurse education as long as the individual is supported to achieve the required competencies irrespective of their impairment or health condition (Maheady, 2006; Marks, 2007).

### **Research about disabled nurses**

The portrayal of disability in nursing informs nursing attitudes and approaches to working with colleagues with impairments. This section explores the research in relation to nurses who have impairments. Disabled people have traditionally been underrepresented in the nursing workforce (Doe, 2003; Yox, 2003). French (1988), conducted research into the experience of 24 health and caring professionals with impairments including nurses, physiotherapists, social workers, counsellors and medical personnel and concluded that a majority of people had experienced positive attitudes from colleagues and clients at work. However, a sizable minority had experienced negative discrimination which was more apparent when attempting to gain access to training courses and/or during training. It was surmised that the individuals had no

professional status during training which may serve to reduce the stigma associated with their impairment when they qualify within their profession. The research concluded that professionals with impairments were not less capable and brought unique assets such as empathy to their work. Winland-Brown and Pohl (1990) explored nursing administrators' attitudes with regards to employing nurses with impairments and found that administrators were not willing to hire nurses who used wheelchairs for clinical positions, and furthermore, they perceived that the need for modifications that would accommodate nurses with impairments were too invasive and they were unwilling to employ them. The authors suggested that the role of nurses has expanded enabling a focus on nursing practice which identifies not only purely technical skills but a wider range of competencies which means that nurses using wheelchairs can contribute at the bedside. Pohl and Winland-Brown (1992) conducted a qualitative study of six nurses with impairments to identify strategies for employers that would encourage nurses who became impaired to return to nursing. These authors identified a caring environment, with the practicalities of flexible working arrangements as the key to the return of these nurses to the workforce. More recently, Wood and Marshall (2010) surveyed 219 nurse managers with regards to their attitudes toward work performance and the perceived abilities of impaired nurses working in administrative roles. The authors found 70% of managers rated the nurse's performance as exceptional or above average. They concluded that nursing needs to move beyond advocacy and personal story sharing of nurses with impairments, to research on the promotion of effective means of recruitment and retention of nurses with impairments.

Research has explored work experiences, including the way people perceive their work environment and the impact of this environment and used the term "*climate*" (Glisson & James, 2002,p.768). A climate which maintains negative connotations of disability may contribute to disabled nurses choosing to leave their nursing positions. Matt's (2008,p.1526) research offered a glimpse into what she termed a '*disability climate*'; the perceptions of people regarding the overarching organizational attitudes toward nurses with impairments employed in the organisation. Matt interviewed nurses who entered the nursing profession with sensory or physical impairments and concluded that for these nurses providing reasonable accommodation to address physical barriers might not be enough to retain them in the workplace. Furthermore, the hospital administrators, nurse managers and staff nurses needed to support their colleagues with impairments by creating a more disability-friendly work environment.

When disabled people are in a nursing position, there is evidence that they are pigeon-holed into particular areas of work. A study by Morrell, Munro, O'Cathain, Warren and Nicholl (2002) explored the 24 hour telephone health helpline established in the United Kingdom, which was

seen as an initiative to support nurses including those with impairments, who had left the health service to return to work. One in ten of the helpline respondents identified as having an impairment and this was identified as the reason they now worked in the health helpline area. Wright and Eathorne (2003) identified that there are a lack of role models for disabled people working in the nursing profession across a range of roles. Disabled nurses can use insights from their own experience which may benefit the nursing profession in many areas. Eathorne (1990), Carol (2003), Heazell (2007) and Fitzgerald (2008), contend that nurses with impairments may bring personal understanding and insight into what it is like to be unwell, in hospital and having an impairment. Although there has been a recognised acknowledgement of nurses with impairments identifying they have a better ability to empathise with clients in some cases, there should not be an expectation that these nurses perform better than other people in order to be accepted within the profession (French, 1988). It is suggested that the numbers of nurses with impairments, both hidden and evident, are growing largely due to a general increase in perceived social acceptance of disabled people and a nursing workforce that is ageing and that frequently sustains injuries on the job (Fitzgerald, 2008; Ferguson et al. 2009). Due to the nature of direct patient-care management requiring physical performance, nurses have an increased likelihood of experiencing a physical impairment or working alongside colleagues who have sustained incapacitating injuries (Ferguson et al. 2009).

Guillett, Neal-Boylan and Lathrop (2007), in their study involving disabled nurses with physical impairments and nurse recruiters, explored how nursing work changed after nurses became impaired. The study found barriers in getting and keeping jobs for these nurses. The authors recommended several strategies that the nursing profession should consider to improve retention of nurses with impairments, including creating work environments that foster acceptance of and support for people with impairments, promoting flexible working arrangements, changing the way the work of nursing is defined, and also reviewing job descriptions to ensure that they accurately reflect the essential functions of the job. This research focused on nurses who had physical impairments and who were no longer in nursing practice.

Grainger (2008) provided an analysis of disabled registered nurses' views on health and illness in relation to nursing employment. This researcher compared the collective experience of nurses with a physical impairment with that of non-disabled nurses in hospital environments in the United Kingdom. Grainger suggested that an awareness of disability issues is placed on the curriculum of nurse education programmes so that newly registered nurses are not influenced by the negative views of disability from those who have been in the nursing profession for significant periods of time. Furthermore, she supported managers and the occupational health



staff listening to what the disabled nurses have to say with regards to how the job description is, or is not, related to the practicalities of doing the job. Kontosh, Fletcher, Frain and Winland-Brown (2007), surveyed employment practices and attitudes towards nurses with impairments who are employed in clinical settings and concluded that nurses are more likely to be willing to work with an nurse with an impairment if they had worked previously with such a nurse and that in general, the acceptance of nurses with impairments was not evident.

Literature pertaining to nurses who experience mental illness revealed high levels of reported mental health problems among nurses, and mental health nurses in particular (Nolan & Smojkis, 2003; Sin, Kreel, Johnston, Thomas & Fong, 2006). Some research has explored the workplace experiences of nurses who have mental illness and identified the need for policies, education and support programmes for nurses who have or are developing a mental health problem (Joyce, McMillan & Hazelton, 2009; Kidd & Finlayson, 2010). The overall experience of being a nurse with a mental illness is largely a pessimistic one due to the effects of stigma (Joyce et al. 2009). Sin and Fong (2008) were concerned at the potential for discrimination of disabled people within the interpretation of the regulatory fitness standards for nursing practice in the United Kingdom. The authors concluded that there was variability in the implementation of the fitness requirements which meant that they were ineffective and could be used in discriminatory ways and indicated that mental health conditions are judged most unfavourably.

Much of the literature on nurses with impairments has focussed on support and accommodation, or addressing attitudes toward nurses with impairments. Much of the methodology within this research is qualitative. As no literature explores the impact on the identity of nurses who have acquired impairments during the course of their career this thesis contributes to the gap in this body of literature.

## **Summary**

The literature explored in this review examines the construction of disability and discusses the theoretical understanding of disability including the biomedical model and social model.

Exploring literature in relation to identifying as a disabled person highlights that whilst this identification process is complex, it can however, be aptly explored using a narrative approach. Narrative identity is influenced by dominant stories available to people, and stories are both temporal and corporeal.

Research pertaining to nurses with impairments has been conducted from a variety of approaches. Studies focus on supporting students into the profession, on the experience of the nurses themselves, on the barriers disabled nurses experience and on the methods and supportive environments that can be achieved in nursing. There have been isolated calls for the inclusion of the social model and understanding of disability in undergraduate nursing and the recognition of the disabling encounters some nurses have experienced in the profession. There are certainly gaps in our knowledge and understanding of the effect on a nurse of gaining impairment and the effect that this has on identity within the context of nursing. The following chapter discusses the methodology and method used in this research and includes discussion of the suitability of narrative methodology in exploring constructions of identity. In order to elicit the nuanced and complex context in which a person's identity is affected when they acquire impairment, a methodology that is able to illustrate a personal experience in this way is beneficial.

## **Chapter Three: Methodology**

This chapter explains why narrative methodology is best suited to exploring the research questions in this study. Choosing a research method involves a commitment not only to the conventions of the particular research method chosen, but also to the ontological and epistemological assumptions from which the method is generated. The choice of research methodology also illuminates the thinking of the person who is doing the research. Seale (1999) states that methodological awareness is a valuable mental resource. In the first section of this chapter Somers' (1994) work on relational narrativity is outlined in order to draw out the theoretical relevance of this research study. The next section considers narrative methodology alongside an abductive approach and how narrative is supported within disability scholarship. The chapter then provides an overview of the method and design of the study which identifies how narrative guides the data collection and analysis of the interview material within the substantive chapters. The next section identifies ethical concerns involved in the research process and concludes with a discussion regarding the credibility of the study.

### **Narrative methodology**

I have chosen a qualitative approach for this research which is influenced by narrative methodology and Somers' (1994) four interrelated dimensions of narrativity comprising ontological, public, conceptual and meta-narratives. Somers argues that narrativity is not simply epistemological, a way of knowing the world, but also an ontological condition of social life, a way of being in the world. Narrativity provides a basis for exploring personal narratives through incorporating the influence of time, space and relationality. Ontological or personal narratives are the stories that people draw upon in order to construct identities through locating themselves or being located within a repertoire of social, public and cultural narratives. Ontological narratives of the self shape the individual choices that people make with some courses of action being more acceptable than others (Phibbs, 2008). Public narratives are those narratives attached to cultural and social formations that are larger than the individual, such as family or work. Individuals draw on public narratives to construct identity and may in turn recognise and locate themselves within a range of public narratives. Meta narratives or 'master narratives' are associated with the large scale historical processes in which people live out their lives such as democracy, freedom or epic dramas of patriarchy and its antithesis feminism. Meta narratives can be influential as they may be beyond our awareness, therefore becoming part of the theoretical core of social theory. Conceptual narrativity is the theoretical explanations that we construct as social researchers (Somers). In this study, theories relevant to the notion of

identity and disability for example involve exploration of theories relating to the medical and social models of disability (Oliver, 1983; 2010), positioning theory (Davies, & Harré, 1990), identity projects (Harré, 1983) and Goffman's (1963) social theories about stigma.

Narratives are interconnected to wider narratives and stories are connected to the world of stories with some stories being more acceptable than others depending on the context (Frank, 1995). Social change is charted in how it is lived and experienced in the everyday sense (Barbour, 2008). Narrative research is both a way of telling about our lives and a means of knowing (Richardson, 2000). The epistemological assumptions of the underlying abductive research strategy used here, and reflected in Somers' (1994) concepts of ontological and public narratives, is that social scientific knowledge is comprised of everyday concepts and meanings, derived from socially constructed mutual knowledge. An abductive strategy is based on a constructivist view of social reality (Blaikie, 2000; 2007; 2010), a paradigm that rests on the claim that there is not one single truth, but rather multiple socially constructed realities. The abductive research strategy produces accounts of social life by drawing on the concepts and meanings used by social actors and the activities in which they engage (Blaikie, 2007; Douglas, 1996). Much of this social life and the knowledge derived from it is taken for granted. Blaikie (2000) posits, when social lives are adversely affected or disrupted, people have to consciously renegotiate the shared meanings and interpretations that are given to actions and/or situations. Abductive research explores the specificity of individual stories in terms of language, meaning and context as opposed to creating general themes that cut across transcripts (Blaikie, 2007; 2010). Somers' (1994) concepts guide the researcher to explore the temporal and spacial location of stories suggesting that narratives cannot be repeated. The space and time in which these participants were interviewed and in which their stories were located will not occur again and therefore, cannot be replicated. Abduction is a developing strategy with on-going debate around analysis of stories related to how best to move from lay language to technical language. There are differences of opinion with regard to retaining the integrity of the phenomena when moving first order constructs, people's views and explanations, to second order constructs the social scientist's interpretations. Abductive methodologies work with the 'whole' of a phenomenon of inquiry (Wolf, 2004).

The methodology employed within this research acknowledges that there is no neutral way of establishing the truth, but that the stories that people tell are real to them and that people are experts of their experiences. The movement from lay descriptions of social life provided by the participants, to technical descriptions of social life provided by the researcher, form the process

of analysis within the abductive methodological approach (Blaikie, 2000; 2010). An abductive research methodology is therefore interpretative.

### **Narratives and disability**

One way in which the social world may be accessed is through documenting the stories told by the people who inhabit it. Stories about social life include both ontological and public narratives that people use to order or structure their world (Somers, 1994). These dimensions of narrativity include the meanings and interpretations that people adopt and the motives and intentions that they use in everyday life which directs their behaviour. There are a limited range of public narratives available to disabled people (Swain & French, 2000), and the representation and public scripts about people with disabilities are overwhelming negative (Wall, 2007). Narratives of people who experience impairment and disability are not often heard; narrative inquiry centres on their perspectives and perceptions and this attention to discourse as a means for understanding human experience and action is central to this research (Holloway, 2007).

Individuals have a unique perception of their own selves. This unique perspective however, is implanted in their social and cultural location, thereby fitting into the collective narrative of the group. Whatever the differences and variation in interpretation of cultural rules, there are shared cultural values and beliefs that pervade the consciousness of each individual. The narrative is a construct of the individuals' realities within the context of culture and as such is socially located. Narratives are social creations, meaning that people have access to cultural narratives which they draw upon in order to perform everyday social interactions (Smith & Sparkes, 2008a). As Coffey and Atkinson (1996) state, stories of personal events may be unique to the individual, but the story is structured according to socially and culturally shared conventions of telling and the narrative resources that people have access to within a particular social and cultural location. Somers' (1994) ideas on the narratively constructed self have found favour within disability studies (Thomas, 1999; 2007) as it is recognised that people with both lifelong and acquired impairments, make sense of who they are and their experiences, by constantly weaving stories about themselves that draw upon the public and cultural narratives they are exposed to about '*people like them/us*' (negative and positive) (Thomas, 2007).

Goodley and Tregaskis (2006) also recommended narrative as useful for disability studies. Their reasons were that narrative offers insights into the experience of impairment. Goodley and Tregaskis state that impairment is a social phenomenon that is storied, negotiated and constructed in diverse ways. Narrative methods contribute to a kind of scholarship that seeks to

practice an understanding of the possibilities of societal and individual transformation, including resistance and living life differently.

The emancipatory potential of stories may be demonstrated when stories are used as counter-narratives (Nelson, 2001). Certain narratives such as the affirmative model of disability (Swain & French, 2000), quest narrative (Frank, 1995) and collective stories (Richardson, 1997), may provide alternative maps with regards to disability and impairment. These narratives refuse and displace the tragedy story thus challenging and resisting social oppression by allowing different body-self relationships to emerge. Therefore, if stories change through their telling, then the link is made to the possibility of transforming both lives and society too. Thus narrative as the means of inquiry can be seen as both important and useful for researchers in disability studies (Smith & Sparkes, 2008a). Efforts to empower participants, through telling emancipatory stories, and the study of their responses to research questions as co-constructed narratives are closely linked.

One of the significant ways individuals make sense of and give meaning to their experiences, is to organise them in a narrative form. Structuring an interview that encourages narrative enables the participants to find their own voices. Mishler (1986) suggests that;

*...through their narratives people may be moved beyond the text to the possibilities of action. That is, to be empowered is not only to speak in one's own voice and to tell one's own story, but to apply the understanding arrived at to action in accord with one's own interests (p.119).*

In narrative research, there is still the question of researcher control during the interview. Although this control might be described as minimal, this does not mean that it is any less powerful or influential. In essence, the narrator controls the talk and follows their own agenda rather than being compelled to follow that of the researcher (Elliott, 2005). Researchers it is suggested need to ask questions that encourage reflection (Blaikie, 2000).

Brody (2003) suggests that narratives unite both the historical and temporal aspects of our existence. It is the intention of narrative researchers to minimise the potential of expressing a reality that is not reported by the participants, one that is foreign to them. Narratives, it is anticipated, can enable the uncovering of professional discourses on disability, mainstream cultural messages about disability and insights gained from the participants' life experience. I considered that using narrative methodology would uncover the complexities embedded in the experiences the nurses in this study have had in their professional lives in relation to an acquired

impairment. Telling individual stories and sharing experiences would create the opportunity to identify the uniqueness of participants' experiences in ways that would contribute toward knowledge about what happens for nurses who acquire impairment.

Narrative methodology has been adapted by a range of different disciplines (Burke Valeras, 2010; Cameron, 2007; Elliot, 2005; Frank, 1993), including nursing (Holloway, 2007; Holloway & Freshwater, 2007; Loodin, 2009), thus creating an eclectic and versatile methodology which is also contextually bound and specific. Narratives that seek to illuminate people's experiences offer opportunities to understand and construct the distinctive meanings behind life events.

### **Method and design**

In discussing the methods used in this research, consideration was given to how participants were recruited, including who was invited to participate, where and how the interviews were conducted, the ethical considerations that guided the study and how the data is analysed in the study. The first deliberation outlined below, identifies the recruitment processes involved in undertaking this study.

### **Recruitment**

The nurses were recruited as the result of the researcher emailing an advertisement to her nursing networks (Appendix 1). Potential participants made contact directly with the researcher to discuss the project. They then received the participant information sheet (Appendix 2), and the consent form (Appendix 3). A total of 10 enquiries were fielded by the researcher within the first two weeks so the need to recruit more widely was not required. I recognised that this process of recruitment in itself limited the scope of the research, as the participant's work contexts reflected my wider nursing networks. Choosing to advertise as opposed to networking may have had differing results in terms of the experiences and contexts of the nurses interviewed. It became evident very early on after contact from the first participants, that there was a strong positive response from those people wanting to participate. Urgency was apparent, as some expressed concern that I had potentially reached my quota and I would not want to hear their stories. One participant said as soon as she saw my research 'Yes, I *have to* do that (participate)'. The prospective participants were given a copy of the interview guide (Appendix 4) and consent form and introductory letter to enable time for them to consider their participation. In order to gain a sense of the range of impairments within the nursing workforce, I asked for participants who self identified as having an impairment and/or as being disabled. The approach of not limiting the area of impairment being investigated, but being inclusive of all impairments was taken in order to explore the range of experiences and to elicit potential

tensions and issues within the narratives of participants. Individuals, who fall into categories of difference, either through self identification or as a result of medical diagnosis, can be linked by frustrating experiences of mind and/or body characteristics, similar disabling structures, social responses or embodied acts of resistance in wider social life (Parr & Butler, 1999). Whilst some participants did not talk about the criteria for inclusion in the study, others sought clarity as to whether they were eligible by identifying the nature of their impairment. In response, I explained about the criteria being about self identification.

### **Participant characteristics**

Seven participants were interviewed. The participants ranged in age from 38 to 58 at the time of the interview. There is a focus on Māori and other ethnicities in New Zealand research. Māori disparities in health (Robson, 2004), economics (Chapple, 2000) education (Bishop, Berryman, Cavanagh & Teddy, 2009), and impairment and disability statistics (Cormack & Harris 2009), means that there is a focus on identifying the ethnicity of research participants in order to gain the requisite knowledge to bridge these disparities. There are researchers who do not agree with this trend, as it promotes deficit thinking which blames the victim and promotes narrow explanations of disparities resulting in “*paralysis by analysis*” (Reid, Robson & Jones, 2000, p. 45). Kidd (2008), in her research on nurses with mental illness states that,

*My identity as a Māori woman contributed to the decision not to ask about ethnicity. I, my whanau, and many Māori friends are affronted by the current trend in research to isolate ethnicity as a feature that requires special attention, thereby othering Māori (p.69)*

The ethnic composition of the participants in this study consisted of two Pacific participants, one Māori /Pakeha and four participants who identified as Caucasian. Ethnicity was not analysed separately in this research because ethnicity did not feature overtly in any of the participant’s stories. This was possibly due to the fact that the topic of primary focus was disability rather than ethnicity. All the nurses were female. The nurse’s impairments included postnatal psychosis, depression, fibromyalgia syndrome, traumatic brain injury, back injury, multiple sclerosis, hepatitis C, neck injury, panic attacks and polyarthritis. Three of the nurses had more than one impairment. Most of the nurses had impairments which had been diagnosed some years earlier whilst in practice. Three were diagnosed within two years of the commencement of their nursing careers; four of the nurses had been diagnosed between 20 and 30 years prior. All the nurses were currently working, most full time, and the nurses’ scopes of practice included nursing education, managerial positions, nursing advisor positions, hospital based nursing, and primary care roles. The nature of the stories meant that some of the nurses discussed their experiences over a range of work environments. One of the features of the



nurses' self management was that they deliberately sought alternative practice settings or workplaces in an effort to find a style of nursing practice that suited their needs, thus incorporating the influence of space in identity formation (Somers, 1994).

### **Data collection**

The data collection took place via individual interviews. The interviews were designed to elicit narratives from each participant regarding their experience of impairment within the nursing context and the impact of their impairment on their identity and practice. The participants had access to the interview guide prior to the interview, as it is ethical to both plan the questions and to share this with the participants (Berman & Slobin, 1994). This action enabled the participants to give consent that is informed by access to the interview guide. Some participants used the guide as a self prompt, however more commonly the interview proceeded as a free flowing conversation. I used minimal prompts in the interviews, as the interview can be more productive when the researcher suppresses their desire to speak and enables the participants to guide their own narrative as much as possible (Holloway & Freshwater, 2007). It is not uncommon for people to tell the researcher things that they had not told anyone else, to articulate things that are sensitive and shameful. This was the case with my first interview. In this circumstance I recognised the requirement to listen empathetically and non-judgementally while remaining comfortable dealing with complex and painful emotions in my role as researcher as opposed to nurse.

The location of the interview was chosen by the participants. This choice resulted in one interview taking place in my home, one in a participant's home, two in my work place and the remaining three in the participants' workplace. It is not possible to be a neutral interviewer but instead is important to be aware of what one's influence may be and whether to attempt to reduce this impact. I was fully aware that I was a nurse interviewing nurses – this is an emic position (Pike, 1971) - I was a person from within the culture of nursing. The principles of reflexivity require the researcher to regard findings as relative to their standpoint as an observer (Josselson, 2011). I interviewed participants, read the transcripts and interpreted them as a person who is a psychodynamically orientated nurse. I am accustomed to hearing people's accounts and am attuned to affect. I do not have an impairment but I have a theoretical understanding of disability as social and a lived experience and a personal understanding of discrimination and marginalisation by being a lesbian.

Some participants were professionally familiar with me and there was a flow of narrative, for others who were more unfamiliar with me they sought reassurance at times that I 'was getting

what I wanted' and that they 'had been useful'. This uncertainty in interviews has been acknowledged especially when the interview guides are open (Holloway & Freshwater, 2007). Frank (1995) posits that the participants express what it is they want to say rather than what the researcher wants to hear. But there is always a power relationship at work evident by the participants confirming that what they were telling me was what I wanted to hear. Some participants would often use the phrase '*you know?*' to gain my agreement to what was being said. I set the boundary of the interview time as I had suggested that it would take between an hour and an hour and a half, all of the interviews fell within this time frame. Although all the participants were offered the opportunity of meeting again if they wanted to add anything to their transcript once they had reviewed it, none did so. There is no agreement to the utility of returning transcripts to participants for comment with it being suggested the decision to do so is made on a case by case basis (Wells, 2011). I offered the opportunity for the participants to review their transcripts and six of the seven participants chose to. I considered this process demonstrated approachability by myself as the researcher, and was part of a 'process consent' method which means consent is ongoing.

### **Ethical considerations:**

As with any research involving human subjects the ethics of this study have been considered. Formally I obtained ethical approval for this study from the Central Regional Ethics Committee (Appendix 5). It is suggested that all interviews are interventions but unlike a therapy situation the research interview is orientated to the researcher learning something. The power differential generally favours the researcher who is already seen as the expert in relation to the topic (Josselson, Lieblich & McAdams, 2007). In order to address issues of power the researcher must be reflexive, mindful of their impact with the participants and open to the critique of supervisors. The researcher is required to have an ethical attitude. A sensitive subject is at the core of this thesis, namely the experience of disabled nurses. The subject of disability warrants an ethical approach which takes account of the distinctive needs of research participants, in particular ensuring that they are not exploited by the research process (Oliver, 1992). There is also a demand that the researcher demonstrates sufficient theoretical sensitivity in all aspects of data handling analysis and writing.

### **Privacy issues**

There are mechanics required with regards to ensuring free informed consent is sought and explained within agreed ethical guidelines, that material is kept confidential and securely to protect privacy and that the researcher is mindful of protecting participants from harm. However in a narrative research approach it is also argued that one cannot give informed consent when

much of what will take place is unforeseeable (Josselson, et al, 2007). It is also suggested that we tell participants that we can do all we can to ensure identities are not disclosed or recognisable to readers rather than assure an absolute confidentiality. In a narrative approach the researcher has to be mindful of using any material that identifies the participants. If participants stories are recognised it will be because the participant has disclosed the stories or part of them to others.

The nursing world in New Zealand is a small one. Practice settings were usually discussed by the participants during the story telling and to protect confidentiality these are not named in the study. Although participants came from more than one locality in New Zealand they, in some cases, were connected through their national networks. In the interests of maintaining the participants' confidentiality details of both context and demographic characteristics are not provided for each individual.

#### Informed consent

Each participant received the consent form prior to the interview and had the opportunity to discuss any concerns before signing. The consent form ensured that they knew the interview was being digitally recorded what the process was and that they could raise concerns or withdraw at any time without giving a reason. Each participant chose a pseudonym. Original names on the consent forms were kept secure away from other study data. Transcripts had identifying details changed or removed and were stored electronically within a password protected computer. Confidentiality in the use of findings will also be maintained as they are disseminated via professional conferences and/or in academic journals.

In order to address risks such as potential harm to participants I identified that if any of the participants become distressed I would offer to terminate the interview. I made clear to participants that they could stop the conversation at any time or withdraw from the research without stating a reason. Participants were also informed that they could address all or only some of the suggested areas in the interview guide. Participants were all employed and had access to Employment Assistance Programmes (EAP) which provides free counselling sessions. Five of the participants were conversant with the research arena as they had completed their Masters and were aware of ethical processes and ways of protecting confidentiality.

### **Analysis of interview materials**

Once stories have been gathered, narrative researchers have the task of analysing or interpreting the stories in order to understand the participants' experiences and to try to find meaning in those stories. Narrative analysis has two hermeneutic traditions, one of faith which aims to restore meaning to text and one of suspicion, which attempts to decode meanings that are disguised (Josselson, 2011). This dual position enables the narrative analysis to both represent the participant's narrative and explore issues beyond literal and conscious meanings. The process of analysis in narrative research is complex. Constructing ordered accounts out of internal experience means that accounts are dialogical and that aspects of identity are likely to emerge in conversation with or alongside other aspects (Josselson). All attempts to simplify narratives are just that. The content, themes and structures all intertwine, but analysis requires that they at least be partially disentangled. I transcribed all of the narratives myself. This process meant listening and listening again to the narratives, this took many hours and I became very familiar with the narratives. One of the arguments for researchers doing their own transcription is that by listening repeatedly they will become more familiar with not only the content but also the way in which participants express their stories (Holloway, 2007). One of the strengths of narrative enquiry is that it enables the researcher to adapt their analysis to the understandings that are emerging through the thorough and repeated listening to, and readings of, the text.

Transcription of the interviews traced seven different versions of conversation of similar topics and is an indication of the interactive and co-constructed nature of interviewing. The reading of text multiple times creates a hermeneutic circle in which an understanding of the whole illuminates the parts which in turn create the whole. Thus

*analysis from the stance of the hermeneutic circle involves gaining an overall sense of meaning and then examining the parts in relation to it – which will involve changing our understanding of the whole until we arrive at a holistic understanding that best encompasses the meanings of the parts*

(Josselson, 2011, p. 228).

The first act of analysis – that of identifying themes began with transcription of the interviews. Notice was taken of the emphasis of the participants, the metaphors used, the subtext and assumptions that participants used in their descriptive language. The narratives were then read several times. Each transcript was summarised individually to highlight the themes that reflected the tensions and issues that the participants were explaining. Once these grouped themes are identified the passages within each theme were re-examined. The boundaries of

these themes are interrelated, one affects the other, and thus the disentangling process begins. Then a comparison of the themes within the stories between each participant was undertaken. This comparative method involved taking themes - from different participants - and regarding how one theme is different from or similar to the other. The abstract similarities and differences generated the themes that characterised the overall experience of the participants. As a researcher interested in how the qualitative data illuminates aspects of note to social science research in the area of subjectivity I also identified talk pertinent to the theoretical underpinnings of the disability literature.

In this research I wanted to explore the ontological and public narratives with regards to disability and nursing (Somers, 1994). Ontological narratives are the stories people use to make sense of, and to act within, their lives. These personal narratives are defined in relation to broader public narratives. This study does not utilise an overarching theory instead different theoretical lenses are used to illustrate themes at work within each of the substantive chapters. Two stories are predominantly explored in Chapter Four; these stories highlight personal narratives that show differences in the experience of acquired impairment were influenced by the public and cultural narratives that were available to actors. Positioning theory is used to explore how identities are linguistically influenced (Davies, & Harré, 1990). Two more stories are considered in Chapter Five; the themes explore the embodied experience of impairment and incorporate the temporal and spacial influences on identity formation apparent in both stories (Somers, 1994). The stories in Chapter Six, though unique, are interconnected by the participants having highly stigmatised health conditions, which were powerfully experienced through influential public narratives, which feature significantly in their accounts. Harré's (1983) theory of identity projects and Goffman's (1963) theory of stigma are the theoretical lenses used within the chapter.

While each story and each participant is unique, multi layered and contradictory there are, nonetheless, similar threads intersecting across and through the stories, providing interconnections. Some experiences are similar, such as the negotiation required to incorporate the embodied experience of impairment into a working life, and some different, such as the experience of participants who have choices around disclosure of their impairment and others who do not. The stories are not meant to be representative of nurses who acquire impairment but they do say something about the experience and impact on identity of acquired impairment in nursing in New Zealand.

### **Consistency and credibility issues**

Consistency is often viewed as an indicator of validity and reliability. Validity and reliability are concepts that suggest a replicability of results and have their roots in a positivist tradition. The naturalistic approach of this research emphasising illumination and understanding using qualitative methods means that replication would not be possible and is not viewed as a sign of trustworthiness in the research. In narrative research each individual tells a unique story that is context dependent so replication of the study may well generate different results. The aim of narrative research is not to generalize- this cannot be achieved based on small purposive samples which are not gathered to be representative. What narrative research offers is the possibility of exploring interrelationships and nuances among aspects of lived experiences that the reader may apply in order to better understand related situations (Josselson, 2011).

The abductive approach used means that there is no objective means of measuring truth. The stories that people tell are real to them and people are the experts in their own experiences. Validity in this research relies on the degree to which the arguments I am making about the personal accounts of impairment are justified by the research methods I have used and by the stories represented. The intent is to make the research accessible to the reader but retain the original intent, purpose and passion of the participant. Credibility is about whether this account of the research/narratives is accurate. As part of the ensuring of credibility there are provisions that can be made by the researcher such as the adoption of an appropriate, well recognised research method, being engaged in debriefing sessions with supervisors, having the research open to peer scrutiny and examination of previous research to frame the findings (Shenton, 2004).

This research study draws upon both investigator and theory triangulation as part of addressing credibility (Denzin, 1970). Investigator triangulation involves using more than one observer in the study. To improve the analysis triangulation is a step taken by researchers to involve several investigators or peer researchers' interpretation of the data at different times (Thurmond, 2001). Thus the interview topics were developed by the researcher in collaboration with supervisors. The interview guide was subjected to rigorous peer review by the Central Regional Ethics Committee. The interview guide was trialled with one participant, transcribed and then analysed by the researcher and supervisors for 'fittingness' or relevance. As Thurmond states *"Researchers must collaborate during the entire study to effectively neutralize biases"*(p.254). Theoretical triangulation is the use of multiple theories or hypotheses when examining a phenomenon (Denzin, 1970). The intent is to conduct the study with numerous lenses and questions in mind, to lend support to or contest findings. Theoretical triangulation incorporates

diverse lenses that come into play throughout the research process including the perspectives of participants and the researcher and those found within the literature. Thus triangulation is achieved through consistency across interviews, the literature in the area in question and the researchers own knowledge on the topic.

### **Summary**

Narrative has found favour among researchers as a methodology designed to understand and make sense of people's experiences and their identities. I have identified the rationale for choosing narrative methodology informed by Somers' (1994) four interrelated dimensions of narrativity in this chapter. My aim was to uncover the complexities embedded in the experiences the participants in this study have had in their professional lives concerning acquired impairment, adopting a narrative approach offers insights into the experience of impairment. The method and design, data collection and data analysis considerations have been discussed in detail making processes explicit.

The following three substantive chapters introduce the stories of the seven participants. In keeping with the abductive methodological approach the stories are analysed individually to identify the meanings and context and then themes that interconnect are also considered. The stories say much about the complex, fluid and multidimensional process of identity formation and how this process is influenced, both from a personal, experiential perspective and by the social and cultural contexts. The stories uncover aspects of the journey to being who you are.

## **Chapter Four: Disabled identity, life circumstances and the workplace**

This chapter explores the theoretical constructs which contribute to the formation of identity and more specifically the place that discursive positioning plays in the development of identity. The chapter incorporates consideration of a 'disabled' identity from essentialist and constructionist viewpoints, and extends the constructionist discussion of identity formation through the theoretical lense of positioning theory (Davies & Harré, 1990). The analysis consists primarily of narratives from two participants' who have contrasting experiences of impairment and disability; Tessa copes with a degenerative illness and Vicky is recovering from an accident which requires ongoing rehabilitation. The chapter also includes extracts of the narratives of Mary, Bella, Lonnie and Jo in order to illustrate the theoretical points. The beginning of this chapter explores how identity is situated within disability and mainstream social sciences through consideration of theoretical debates influenced by essentialist and constructionist ideas. The chapter explores how the onset and negotiation of impairment challenges pre existing conceptions of self and demonstrates how identity is discursively negotiated.

### **Negotiations of identity**

The first half of this chapter involves the exploration of the participant's stories which identify essentialist views of a disabled identity and how these views identify the dominant narratives concerning (dis)ability and (a)bility and how questions of inclusion and exclusion become salient. Positioning theory attempts to articulate an alternate way of reading and understanding the dynamic of human relationships within a social constructionist paradigm and is used to illustrate how both essentialist and constructionist ideas are transmuted through discourse (Davies & Harré, 1990).

This chapter demonstrates how a social or relational definition of identity, in which subjectivity is constructed and performed in and through discourse, is a contrasting view point from the ableist construction of the autonomous individual as the locus of identity. A socially situated construction of identity recognises the ways that individuals are positioned by, or position themselves with and in relation to others, echoing the shared versions of knowledge that are part of dominant narratives regarding disabled and non-disabled categories (Davies & Harré, 1990). From a social constructionist perspective, individuals make identity claims on the basis of their negotiated understandings which are constructed in the interactions between people and the practices of their everyday lives. As Mischler (1999) states "*people align or contrast*



*themselves with others*” (p.112). It is this process which underpins the shared versions of knowledge that is constructed.

The concept of ‘identity’ is a contested and abundant field of research (Davis, 2006; Davies & Harré, 1990; Smith & Sparkes, 2008b). It is through a person’s identity that an understanding of the complex relationship between individuals and society emerge (Shakespeare, 1996). In disability studies identity and self have been viewed through an analysis of oppressive social relations (Green, 2009; Shakespeare & Watson, 2002). The analysis of oppression has enabled examination of the ways in which disabled people are disabled by society, with a view to empowering disabled people and challenging societal values.

Shakespeare (1996) has also argued that identity is a major area of conflict between disability studies and other areas of social science. Within social science there are two main approaches. The first approach is that there is a natural intrinsic meaning to identity. This approach is based on essentialist understandings of a shared social experience, origin or structure. Essentialism is classically defined as “*a belief in true essence- that which is most irretuctable, unchanging and therefore constitutive of a person or thing*” (Fuss, 1989, p.2). Essentialism is a way of understanding the world that sees things, including human beings, as having their own particular essence or nature (Burr, 2003). Within the essentialist perspective identities exist as binary opposites and propagation of the concepts of disabled and non-disabled identity strengthens essentialist arguments. Furthermore, essentialism is signified when common sense assumptions of unproblematic continuity between biology and disability occur. Essentialists have been accused of being simplistic in their viewpoint, for example, being a woman or disabled or black was coupled with the body, a reductionist viewpoint that does not observe the influence of social structure on the formation of identity (Shakespeare, 1996; Davis, 2006). Within disability studies an understanding of identities as socially constructed is thought to undermine any concept of a unitary identity or self.

Much of the traditional theoretical approaches to disability in social sciences, influenced by biomedicine, could be considered to be essentialist. Identity as a ‘disabled person’ is presented as something that is unitary or stable. Social essentialism, however, is a shared experience based on common experiences that are grounded in biology (Campbell & Oliver, 1996; Finkelstein, 2001). Differences, biological and sometimes psychological, separate disabled people from non-disabled people (Chaskes, 2010; Turner, 1996; Watson, 2002). An essentialist viewpoint serves to ‘trap’ people into accepting identities that are perceived as restraining for them.

An example of this perceived restraint is described by Mary, a nurse who had a work-based accident over 22 years ago and who developed fibromyalgia syndrome (FMS). When discussing the notion of being disabled Mary highlights the essentialist ideas that underpin this label. She explains that she does not identify as disabled

*When I consider a 'disability' that to me is extremely limiting and to me it's a word that puts me in a box and keeps me small. Whereas when I think of things as a 'limitation' it means that I can open the box and climb out and expand it without feeling tied in.*

Mary describes a disability as 'extremely limiting'. Her comment that disability 'keeps me small' suggests that her personhood is compromised. Mary acknowledges that what she describes as a 'limitation' is an effect of her impairment. For Mary identifying that she has a limitation opens up possibilities that imply that agency is constrained for people who are disabled. The use of active language such as – 'climb', 'open' and 'expand' - also suggests that a disability is associated with passivity and a lack of action. This viewpoint echoes biomedical understanding that a 'disability' resides within the person as a personal characteristic.

Social approaches based on constructionism, which insist that essence is itself a historical construction, counteract essentialism by demonstrating that it is exclusionary policies, environmental barriers and a process of social oppression which create the concept of disability (Fuss, 1989). This perspective is a social constructionist analysis which underpins the social model of disability (Dewsbury, Clarke, Randall, Rouncefield & Sommerville, 2004). Some constructionists argue that "identity is constructed in relations of discourse and power and fixed identities of disabled people are enforced through regulatory regimes" (Watson, 2002, p. 510).

Tessa is a nurse who has had multiple sclerosis (MS) for the past 15 years. In relation to her employment opportunities, Tessa recognises that her choices are constrained by assumptions that are made about her ability to do her work because of her impairment. "In this city they all know each other... So I don't feel that I have the option of not telling people that I've got MS and then I'm absolutely sure that I am not employed for those reasons". There are underlying assumptions encountered in the social world about MS that construct attitudinal barriers which may limit employment opportunities. Despite these barriers broader constructionist positions argue that the person has the ability to reflect and challenge the social worlds in which they find themselves enmeshed (Burr, 2002). The social constructionist approach makes the assumption that identity is a process that takes place in concrete and specific interactional occasions, a process which produces constellations of identities rather than individual constructs. Identity

does not simply emanate from the individual, but results from more complex processes of negotiation which involve others (Burr, 2003). The social constructionist approach has similarities with positioning theory as social order is viewed as grounded in ongoing interpretive work (Wilkinson & Kitzinger, 2003).

### **Discursive positioning**

Smith and Sparks (2008c) contend that we live in a world shaped by stories and the meanings people give to them. Stories are culturally embedded in sets of understandings about the relationship between disability and the non-disabled social world. This ontological position posits that social life is storied, that identity is narratively constructed in conversations between people and that there may be a dynamic sense of having many selves or identities. Davies (2000) states that “*through stories we constitute ourselves and each other as beings with specificity*” (p.22). A key principle within this concept is that language is not simply neutral or objectively representative of reality but that language is imbued with culturally located meanings. Transitions and understanding of new experiences, such as the new circumstances of a permanent or temporary impairment, require a renegotiation of identity which is likely to be encountered in a highly interactive environment (Chaskes, 2010).

Building on Foucault’s concept of subjective positioning, Davies and Harré (1990) suggest that the value of thinking in terms of discursive positioning is that it is a concept that enables us to see the ways in which people take up positions in relation to discourse. People make sense of who they are from understandings and interactions with others and are influenced by the wider social narratives and the dominant stories that shape their world views. Whilst personal positioning refers to how individuals privately organise and narrate their lives, social positioning arises from societal definitions that bear down on the person from the outside, shaping both their experience and their stories. Social positioning is more marked when there are power differences in social hierarchies or dichotomies such those that exist between disabled and non-disabled people (Raggat, 2006). An example of this is inherent in the following comment from Tessa in relation to her non-disabled colleagues. “*What I get really frustrated about with my colleagues I guess is that they don’t respect that (I am limited, not disabled)*”. Tessa’s frustration occurs as her colleagues do not acknowledge the same definition of limited but impose their own understanding of ‘disabled’ which positions Tessa differently to how she positions herself. Davies and Harré (1990) argue that positioning is largely a conversational phenomenon. Verbal interaction is intrinsic to the process through which positioning is accomplished (Wilkinson & Kitzinger, 2003). Stories and narratives contribute to identity construction and to our self-understanding. Furthermore Davies and Harré posit that taking up a

particular position requires a process that involves initially learning the appropriate binary categories that apply, such as, male/female, disabled/non-disabled. This learning then enables participation in various discursive practices that allocate meaning to the categories and then allows recognition of the self as belonging to a position through adopting a world view commensurate with that category. The concept of positioning, therefore, is one in which:

*Having taken up a particular position as one's own, a person inevitably sees the world from the vantage point of that position and in terms of the particular storylines and concepts which are made relevant within the particular discursive practices in which they are positioned*

(Davies & Harré, 1990, p.46).

The participants in this study identify themselves predominantly as nurses, wives, partners and mothers. These are categories that the participants have learnt the meanings of and allocated to themselves. However, this identification does not indicate a fixed and inflexible position. Holding a worldview/position does not disregard the fact that individuals have multiple affiliations and a sense of different identities. The participants were not only nurses, but they were also identified as managers, advisors, clinicians, educators. The nurses further identified as Pacific nurses, whilst others were New Zealand nurses, some also identified as lesbian. In this way the nurses have multiple identities. If impairment is seen as an important factor that defines identity then complexity abounds as there are recognised divisions amongst the type of impairment, the age of onset, the severity and so on (Swain & French, 2008). This complexity is also evident in the differing types of impairment and the experiences the participants discussed in this study. For some participants they perceived that social stigma attached to the nature of their illness. Green (2009) states: *Identity is both more flexible and more overtly selected than hitherto, which creates a sense of emancipation, as you can be anyone you want to be, and key traditional identity markers...have less salience* (p. 34). Green believes that the types of identity available have changed over time with postmodernity, which enables choice of identity.

Davies and Harré (1990) discuss the metaphor of identity as an unfolding narrative, where we may negotiate our position by refusing some positions and posing alternative positions. The ways in which changes in our identity are experienced and made sense of are socially situated (Patterson, 2009). A position may closely resemble the concept of a role; however whilst positions are dynamic, a role is static (Taylor, Bougie & Caouette, 2003). The participants' narratives, as demonstrated in Tessa's story below, suggest that some identities are more socially valued than others.

### **Tessa's Story: I wish nobody knew I had MS.**

Tessa's story illustrates how her experience of MS has been markedly shaped by social positioning and an essentialist viewpoint in which 'disability' is integral to the person. Tessa's narrative demonstrates that being positioned as a disabled person within a medical model dominates her social identity and the way she is viewed by others. Tessa's claim to her own identity contrasts with how she is positioned by her colleagues and her story traces her resistance and refuting of this positioning. The underpinning assumptions made about Tessa's positioning demonstrates not only essentialist ideas of a disabled, inflexible identity, but the continuing creation of the binary of disabled and non-disabled.

In the interview Tessa described her life, her nursing career, the diagnosis of her MS and her nursing practice over a period of more than 15 years. She interweaves the events of her life in her story about her illness; the births of her children, the change in government policies which meant she received treatment, other health events that impacted on her, and the financial and family events that affected her.

### **Finding out and getting support**

As a student nurse, Tessa described how her first patient had been a woman with fulminating MS who was 'demented' and 'catheterised'. Hence Tessa was "absolutely terrified" when the consultant neurologist said "well you've got MS, go home and get over it". From her perspective the diagnosis finalised her identity. The consultant's dismissive manner demonstrated a reductionist viewpoint whereby Tessa was reduced to a neurological diagnosis. Tessa recognised being positioned in this way and actively attempted to reposition herself as in control. Tessa states;

*I did all the things he told me I shouldn't do, like I joined the MS society and I went and read up about MS and I found people who had MS and talked to them and I gradually regained my confidence in myself, but it probably took about two years.*

Despite being terrified, Tessa reacted to the diagnosis by attempting to regain a sense of control over her life. She developed an understanding of living with MS and sought support from others experiencing MS from outside of the medical establishment. She explains;

*I did everything that I could find, so I was gluten free and I was very careful about what I ate and I minimised my saturated fats and I lost a huge amount of weight and I got very fit, 'cause I wasn't working, I swam every day. I think*

*that's probably what got me through otherwise I would have been so depressed I would have wanted to slit my throat. I had something to sort of do.*

Tessa needed to 'do something' to preserve her own wellbeing. Socially approved forms of managing her body through weight loss, a slimmer body shape and increased fitness are recognised as a means to gain some self esteem and control back in a situation in which she felt she had little control. Tessa found herself confronting the task of actively creating a new identity and a new life.

### **Disabled identity and impact on working life**

After this diagnosis, Tessa was off work for a period of three months. On her return to work and following another significant health event Tessa states; *"that's when I realised I needed to do something different... I just couldn't do it (this nursing role) anymore; it was just too much hard work"*. So she *"reluctantly"* changed her work to a position that was less physically taxing. Tessa had to *"rethink"* and *"accept"* what was happening and what her *"limitations"* were. *"I suppose I grieve, I did grieve, for a long time about not being well enough to work in (that practice area) anymore"*. She began the process of adapting her work to account for her changed circumstances.

A few years after her diagnosis Tessa had the (unexpected) opportunity to receive medication funded through a governmental policy change. The affect of this on her was;

*it changed my life... It really revolutionised my life, in terms of no pain, I could sleep , I could lie down without feeling like I was on glass, on a bed of nails, that sort of thing, so that was huge.*

Tessa identifies the impact that MS has had on her life through talking about how the medication alleviated many of the physical symptoms that she associated with the illness. This treatment also meant that she could return to work full time. Her experience of MS was significantly changed through this medical intervention.

Tessa states that *"having MS has affected my professional life dramatically"*. Tessa describes *"MS affects your life in so many subtle ways. All those tiny little things that have to be negotiated as part of working"*. Here Tessa describes aspects of what she has to take into account such as the physical environment, the steps to the building, the distance from the car park and the lack of time given for her to get lunch. It is the cumulative effect of all these *'tiny little things'* that Tessa has to manage. Everyday things occur in an environment that is constituted for people who are non-disabled which does not take consider someone who has an

impairment. As Williams (1996a) states “*The reality of life for most disabled people is not the heroic overcoming of dramatic obstacles, but the daily struggle with the mundane activities*” (p.103). Tessa’s journey has perhaps been about overcoming both dramatic obstacles and mundane activities. She identifies that the ‘drama’ of MS, for her, is played out in her work environment with her colleagues because it is with her colleagues that she experiences some of the most disabling affects.

Tessa began to experience limitations, which she associated with belonging to her body, as opposed to recognising limitations in an environment which was not adapted for her. The social constructionist and social oppression viewpoints of disability begin to emerge through Tessa’s experiences when environmental barriers are recognised but not addressed.

*I’m quite often bumped out of a car park because somebody is working after hours and so they have priority over the car park they don’t actually realise what it does in terms of my ability to actually get there and work.*

In her experience Tessa notices the ways that the physical environment is structured and she negotiates this environment as best she can. It is the physical environment which begins to ‘disable’ Tessa in a social model sense. It is her work environment and more specifically how her colleagues view her and respond to her which reinforces the positioning of her ‘disabled’ identity.

### **Disability and social identity**

Of significance for Tessa is that her symptoms were known to her nursing colleagues prior to her diagnosis and as such she has never had a choice around disclosure. She states; “*nobody was surprised that I had MS so I haven’t ever had that ability ... to (not tell).. several of my colleagues had already made that diagnosis*”. Her colleague’s knowledge of her diagnosis and their perspective of her resulted in her identity becoming over determined by her diagnosis. The result of this was that Tessa recognised that; “*I can’t be who I am. I have to be better than everyone else.*” Tessa experiences a loss of the multiple identities she has, that of a colleague, a mother and a nurse and experiences a reduction of self to one identity, that of ‘MS sufferer’. This ‘MS identity’ means that Tessa feels that she is now not perceived as being valued as she had been previously in her nursing role as a colleague.

Tessa describes her struggle with her colleagues as follows; “*It’s like I’m not allowed to have any other issues in my life*”. She identifies how emotionality is now judged by her colleagues; “*I can’t have an emotional meltdown because if I do have an emotional meltdown, because my colleague’s just died, then ‘it’s Tessa, she’s got MS, it makes her more emotional’*”. Within this

context Tessa's emotionality is not valued but becomes pathologised as part of her MS. Tessa states that "...you have to be better than better". Tessa is aware that signs of weakness, such as her emotionality are labelled as excessive and have become part of her symptomology. Not being '*better than better*' means she will be judged and devalued. Tessa's struggle is to reposition herself in response to the viewpoint of her colleagues so that her impairment does not become her one sole identity marker.

Tessa's work life is a turbulent and emotional journey where she experiences living under scrutiny, "*that feeling of being under the microscope all the time is really hard, really stressful. I don't think it does me any good at all. When people talk to me I cry because I feel really disadvantaged*". Tessa has experienced dramatic changes and events in her life and it is her emotionality which she feels most judged for. She finds this is the hardest aspect and the most isolating aspect of her experience.

*(My colleagues) make assumptions and I'm not allowed to have bad days. I think ultimately when push comes to shove (they say) 'Oh but she's got MS'. And the fact that everything has gone to custard in my world is actually irrelevant, which is really sad because it means that you can't actually get help, get the sort of support you need. Because when things have gone to custard I don't tell people. That's the reality, that if I don't have to share with people then I don't.*

The experience of feeling powerless and of being exposed means that when Tessa has choices around disclosing personal information about her emotional world when she "doesn't have to", she chooses not to. This choice results in Tessa not receiving support, but she considers that this is still preferable to being exposed and perceived as powerless.

Chaskes (2010) suggests that "*The permanently impaired person gets cues, is fed lines and prompted to play the role in a manner negotiated with an audience who are more like producers, directors and writers at an audition*" (p.64). Tessa does not want to play the role being offered her by her colleagues and refutes being positioned as emotional or less able. Positioning theory emphasises the power dynamics that shape interactions and positioning processes through the concept of moral orders (Davies & Harré, 1990). Every position has a moral order, associated with rights and duties whereby dominant groups have more legitimate voices. Tessa has at times been positioned as 'other' and has also felt powerless to address some of the responses from her colleagues who position her as less than.



Tessa is subject to essentialist viewpoints about her identity from her colleagues whereby her behaviour is viewed as characteristic of MS which is now an inflexible and intrinsic part of her biology. These viewpoints form the platform of positioning Tessa as disabled. “*Everyone says ‘oh you better be careful of Tessa cause she’ll get tired and then she’ll burn out’*”. Tessa recognises that she is positioned as being ‘less than’, and to refute this means that she has to be ‘better than’. However ‘less than’ is at odds with how she perceives herself. She rejects this position and at the same time attempts to hide any signs associated with her illness that could be interpreted by her colleagues as weakness. Tessa refuses her social positioning and in doing so the social construction and positioning of her ‘disability’ is revealed. As Davies (2000) suggests, Tessa’s strategy is “*to avoid the storyline in which (she) can be positioned as marginal to the group*” (p.25). Being positioned as part of a disabled group also suggests that Tessa no longer knows what is good for her and cannot make decisions for herself in her work. When Tessa explains that “*...everyone tells me I shouldn’t be working full time*”, this can be understood as her becoming infantilised through paternalistic supervision (Gelech & Desjardins, 2010).

Tessa would like to tell her colleagues how their responses impact upon her however she acknowledges that “*it just makes them feel worse*”. Instead, Tessa accommodates her colleagues by taking responsibility for their reactions thereby prioritising how they feel over her own needs. Chaskes (2010) suggests that “*it is the burden of the disabled person to manage the situation and put the normals at ease*” (p.60). The response of the person with the impairment to manage other’s reactions and to provide education to non-disabled people further reinforces the position of the ‘other’. It is through the responses of her colleagues that the perception of Tessa’s changed social status emerges and we can see how this status is constructed and communicated to her.

For Tessa, her colleagues attempts to define who she is, through disabled positioning, means that her dominant identity at work is her ‘disabled identity’. Tessa describes the effect of this positioning on her; “*It’s like everyone forgets the rest of me, as a person*”. Wright (1960) first identified the concept for disabled people of ‘identity spread’. Wright recognised that non-disabled people tend to view disabled people as limited in all areas. This concept reinforces essentialist thinking about disability. Shakespeare (2006) recognises that identity spread means that a person’s individuality, including all of their personality, their gender, sexuality and ethnicity are ignored. This is the result of the impairment label dominating interactions and becoming the most prominent and relevant feature of their lives. There is also a tendency for people with long term conditions to be defined by others on the basis of their condition (Green,

2009). The responses of Tessa's colleagues to her create a binary between her and them and through her narrative it is evident that Tessa is aware of this binary.

### **Disabled identity and normalisation**

Tessa's own perspective of her MS is, "*actually, MS...is no big deal. OK there isn't a day goes by that I don't have to take into account my realities, but no-one else has to do it, I'm quite capable of doing it all by myself*". It is important for Tessa to be capable of taking into account the realities of her MS. As time passes, that which may have been disruptive or distressing becomes taken for granted and is viewed as familiar and customary (Charmaz, 2010). Thus Tessa describes how an ordinary event such as shopping with her family has been adapted to take into account her ability

*often now we go down to the supermarket with the kids and its 'now you go and get this and you go and get this' and we'll meet and I pay for it. You just do it like that because that's just the best way to do it.*

In her personal life Tessa's role and identity as a mother dominates and her family do not react to her differently. This suggests that her 'disability' is situationally located. Tessa recognises that for colleagues who are supportive of her and do not label her they also have to manage her other non-supportive colleague's responses,

*The person who does our roster has to constantly deal with everybody saying 'you shouldn't let Tessa do that, you shouldn't let Tessa do that'. She says 'well why? Tessa's fine doing it. She does a great job and when she comes back to work she's usually fine.*

It appears that 'everybody' in Tessa's workplace has a response to her MS, and each deals with it in their own way. Thomas (2010) calls the effect of this type of positioning the psycho-emotional dimension of disablism; "*this refers to the harms that non-disabled people can inflict on disabled adults through their words and actions, sometimes well-intentioned: the undermining of self-esteem, confidence, emotional wellbeing and willingness to take chances (are the affects)*" (p. 46). It is through the responses of her colleagues and their well-intentioned attempts to 'support' her, that Tessa experiences the most disabling effects of her condition.

Positive support is experienced from the response of the person who does the roster and from some other colleagues. Tessa describes one manager's response as supportive "*My immediate boss would let me do anything I wanted and if I didn't cope that would be fine. She's great...*" Tessa's manager's response is an example of positive positioning. For Tessa, it is important that who she is, is not determined by her MS. This is demonstrated to her when her manager

‘allows’ her to do ‘anything’ even if the result is that she doesn’t “cope”. Being positioned as ‘capable’ and that not coping would not be viewed as a weakness is an important distinction for Tessa in how she is treated and she contrasts this as a preferable response to how some colleagues treat her.

When Tessa’s colleagues overcompensate for her, Tessa’s perspective of her own capabilities is affected. She makes efforts to find alternatives to the emotionally charged label of ‘disabled’. Tessa defines her ‘limitations’ as something she lives with rather than something that defines her sense of self. In relation to identifying as disabled Tessa states;

*I don’t identify myself as being disabled; I identify myself as a registered nurse who has limitations. The bottom line of professionalism, I have to be honest and that’s the most important part of me and who I am as a nurse, is that I have to identify myself, not as disabled, but as limited.*

Whilst some of her colleagues define her as disabled Tessa does not define herself in this way. She talks about the most important aspect of her identity as a nurse is her ‘professionalism’. She means that she prioritises safety in her professional practice and that she identifies and addresses any limitations in her practice.

*I have to recognise when I can’t do something. You have to be really honest with yourself as well, about what you can and you can’t do. Because if you aren’t honest about that you’ll trip up all the time in terms of being safe to practice.*

Here Tessa recognises her interdependence with her colleagues, “*I know that I can call a colleague and say this has happened and can you deal with it for me and that will be fine*”. Hence Tessa has not notified Nursing Council of her MS “*There’s nothing that I can’t do in my scope of practice so nobody’s ever been concerned*”. Tessa’s perspective is that her ‘limitations’ do not define her as being disabled or dependent and do not affect her ability to complete her nursing role.

Another example of positive positioning from Tessa’s story is how she is being encouraged by a colleague to become a nurse practitioner. Tessa is struggling with this idea, she acknowledges that there are limitations that affect her nursing practice in some areas and she wonders how she can be in a practitioner role. She states; “*Is there a scope for a nurse practitioner who doesn’t work clinically... physically? That’s not what I would consider to be a nurse practitioner. Not something that I have envisaged a nurse practitioner being*”. However she also acknowledges that; “*With the advances in telemedicine (nursing) is changing and I have to rethink*”. Tessa

wants to accept repositioning herself into an able category. Her resistance to this may be seen as a psycho-emotional effect which results in her being unsure about taking chances given that her abilities have been questioned by some colleagues (Thomas, 2010).

Tessa's experience of her MS and her shift in social identity is played out in a highly interactive, intricate and nuanced environment. She has a day to day experience of being treated at times as being 'incapable', feeling unsupported. She is also aware of people normalising her experience, including her manager, the person who organises the roster and the colleague who envisions her as a nurse practitioner. Tessa experiences multiple responses to her identity, some impacted by her MS and some not and she has to negotiate these responses. The overarching experience for Tessa is that she wishes nobody knew she had MS because this ultimately changes how she is perceived and how she is treated. Tessa's narrative is one of personal agency and a determination to overcome obstacles and forms of adversity that are created by others. Tessa presents herself as someone who is attentive to the ways in which others define her and how she also defines herself.

### **Repositioning the disabled identity**

This section combines some of the participants' perspectives of how they see themselves in relation to identifying as 'disabled'. Overall the accounts of nurses interviewed for this project suggest that their sense of identity demonstrates that they do not see themselves as disabled, in a medical or social model understanding. The participants resisted and negotiated the formation of a disabled identity and the meanings attached to this from a medial model perspective. Their awareness of the 'self' is based on a notion of what the participants feel themselves to be, not what others suggest they are. The agency exhibited through refuting the label of disability is a political action, in that people reject identities others may wish to enforce on them (Watson, 2002).

The nurses interviewed for this project rejected a disabled identity as echoed by the dominant narrative that to be disabled is to be constrained. Three of the participants, Bella, Lonnie and Jo have very different experiences of impairment but have similar responses to the idea of considering themselves as disabled. This similarity of response demonstrated how they distanced themselves from the notion of disability and the assumptions about what being disabled means. These participants, by downplaying the significance of their impairment, sought access to a mainstream identity. Lonnie, who has polyarthritis, explains;

*I don't see myself as disabled. (My) joints are starting to get a bit funny but nothing like some of my patients I've had in the past who have had huge disabilities.*

Lonnie benchmarks her condition against that of others who have arthritis by stating; *"I don't put myself in that category"*. She is not disabled in her own mind and repositions herself to reflect this. Lonnie also provides a downward social comparison to some of her patients. For Lonnie, a disabled person is *"someone who is crippled with rheumatoid (arthritis) and had the joints and pain every day"*, as opposed to the intermittent periods of pain which is the nature of her arthritis. This comparison is suggestive of the hierarchy of disability, which is the notion, that some disabled people are 'better off' than others, based on the grounds of severity and, at times, the type of impairment (French & Swain, 2008). This response associates disability with the body and identifies essentialist ideas of binaries between disabled and able - Lonnie is not like 'them', she is 'better off' as she is not defined by her impairment.

Similarly, Jo, who has hepatitis C, distances herself through a combination of generalisations about (in)capacity, identifying the severity of impairment as a distinction between being classed as disabled or not. Jo uses the image of the wheelchair user as the prototypical disabled person. Hence, she considers that someone with a disability is; *"ten times worse, maybe I've got some ancient idea of what disables you like a wheelchair or something"*.

Bella has experienced post natal psychosis, depression and a back injury. She has been told that she has *"a ten per cent disability... and as I get older I think it might be getting worse"* but Bella distances herself by treating 'disability' as a past event. *"I had that, it's over; I dealt with it and want to get on with my life"*. This distancing of her experience enables Bella to *"live in the maximum level that I can."* Living a full life suggests an acceptance that had she not left her 'disability' behind her, living would be constrained. As Bella states; *"Perhaps I haven't got a disability at all? I feel like a physically well, mentally sound human being, you know?"* Bella's ideas in relation to identifying as disabled means that she is not necessarily getting on with her life and that she does not feel either physically or mentally well if she is disabled.

The analysis of participant's narratives also suggests that having an impairment becomes part of everyday experience thus their experience is positioned as normal. This viewpoint suggests that having an impairment is a fact of life that is ontologically unimportant because it is normal. Impairment has become part of the person's being, their ontological existence, and therefore their identities are self-constructed in such a way as to minimise their impairment as an identifier (Watson, 2002; Chaskes, 2010). Normalizing impairment fosters an adaption to an

impaired body rather than struggling against it (Charmaz, 2010). Thus, Jo states “*I would just see it (my condition) as something I have, that’s all*”. There are echoes here of the affirmative model of disability which supports the notion that perhaps at the most basic level, impairment is simply a fact of life and may not be incorporated into a person’s identity (French & Swain, 2008).

Not conceptualising one’s identity as disabled may reflect the hierarchy of social values prevalent within New Zealand society which accords little or no status to disabled people. Describing oneself as disabled cannot be seen as a positive step. There is little social status to be gained by identifying as disabled. To do so would identify the participants with people who have fewer opportunities to improve their economic standing, are socially isolated and have a less visible social profile which contributes to further marginalisation (French & Swain, 2008). The narratives of the participants presented in this chapter suggest that they are faced with an identity transformation involving a transition to a contested identity category whose members are constructed as biologically and socially flawed. Being positioned in the flawed category is reinforced by conversations and responses of others as they are, at times, positioned as being less than and less able. The nurses refute being affiliated with such a flawed category and being positioned as ‘other’ by renegotiating their position (Patterson, 2009). One perception held by some participants is the refusal to identify as disabled. This refusal may be seen as a result of ‘internalised oppression’ or a ‘false consciousness’ by some within the disability movement (Shakespeare & Watson, 2001). However this perception may also be viewed as patronising and oppressive as the agency of the individual is not taken into account (Shakespeare, 2006). It is also suggested that the participants’ denial of disability is implicitly based on the rejection of the idea of an exclusive ‘normality’, against which difference is defined indicating that the definition of ‘normal’ is subjective and that they refuse to be categorised on the basis of bodily difference (Shakespeare).

There are also normative expectations about the conventions of a nurse - patient relationship that affect both the way people position themselves and respond to being positioned within conversational discourses. Conventions of the nurse - (disabled) patient narrative include a normative expectation that the disabled person needs and accepts care that the nurse provides (Davies & Harré, 1990). Tessa, who is positioned as the disabled person, experienced this. Her nursing colleagues express pity and respond with their perception of ‘care’. They positioned Tessa as not able, being weaker than them and considered that they were being helpful to someone who needed help. As Tessa states; “*They want to look after me and be supportive and they want to make extra provision*”. Conversely, Tessa refutes this positioning but is

disempowered to respond by rejecting this pity outright. Instead she chooses to avoid situations where her colleagues can interpret her reactions.

*They were protecting me. I wasn't allowed to work too much and I wasn't allowed to do night shift, it was really tough. ..Everybody's watching, they're waiting for you to fall over... I love night shift because there is (literally) nobody watching me...*

There is an assumption in disability discourse that an epistemological self created through knowledge built up from others opinions, predominates in constructions of subjectivity consisting “*of social narratives rarely of our own making*”(Somers, 1994, p.606). Somers identifies ontological narrative identity as the way that the individual makes meaning and sense of their experience and their relationship to the world. This narrative identity provides a structure from which choices and activities are made, which in turn produce new narratives and new identities. Hence narrative identities are never complete but are always being formed. It may be argued that disabled people adopt strategies in their own constructions of their sense of self. Their feelings and personal values carry broad political and social implications and that these values expose wider dominant stories that need to be explored (Watson, 2002). There is also a caution in considering constructionist viewpoints of identity as Dewsbury et al (2004) state “*Constructionist versions of experience can slip easily into essentialist positions, whereby members of one social grouping are held to be incapable of experiencing the experiences of another social grouping and this, in turn, means a failure of understanding*” (p.157). If essentialist thinking predominates then a binary approach is being reinforced. It is important to consider the ways in which selves are involved not only in being defined or labelled but also how resisting definition and constructing identity categories occurs (Shakespeare & Erickson, 2001).

### **Constructing the ‘other’**

Having an acquired impairment is a unique situation which can exemplify the ways in which identity as a process of labelling, differentiation and social positioning joins the personal to the political and the subjective to that which subjugates (Galvin, 2003). Tessa’s MS is viewed as a socially accepted category; she has a disease and is a victim of forces beyond her control. The emphasis here is on a response to her as a victim or sufferer. This is only the case if the cause of illness is not considered to be the result of an unhealthy lifestyle (Grytten & Måseide, 2005). For other people such as Jo, whose story is discussed in chapter six, the association of hepatitis C with intravenous drug use and resultant infectiousness and chronicity means that it is a highly stigmatised illness (Harris, 2009). Hence Jo is potentially subject to a moral view which sees her as responsible and ‘deviant’. This can result in people who have ignored the moral

prescriptions of society and fallen ill, to be perceived to be paying the consequences for their behaviour (Lupton, 1994).

The concept of positioning highlights how discourse constructs who is perceived as the 'other', and how certain social groups are defined by the dominant orthodoxy as belonging to the status of 'other'. Construction of the 'other' echoes essentialist viewpoints by creating and reinforcing the binary of 'us' and 'them'. In relation to being described as the 'other' in our society, impairment and disability is the only category that can happen to anyone, in an instant, transforming that person's life and identity forever (Chaskes, 2010; King, 1993). The purpose of categorising people as 'other' from our own subject positioning whatever that may be, is to group them together as objects of experience instead of regarding them as subjects of our experience with whom we might identify. If someone is 'other' they are primarily symbolic of something else- usually something that is rejected or feared and therefore projected on to. People also psychologically distance themselves to reinforce the sense of 'that won't happen to me'. That Tessa's illness is degenerative is frightening for others. Distancing is not a symmetrical process as more powerful groups of people can produce a world that suits their own needs and validates their own experiences (Shakespeare & Watson, 2001; Wendell, 2006).

Disabled people are perceived as 'other' to non-disabled people. The consequences of this are that they are socially, economically and psychologically oppressed. Saussure (1959) identified dualisms within language and based his linguistic theories on the premise that *'in language there are only differences'* (p.117). From these theories comes the practice of defining what is 'normal' against that which is 'other' through the use of binary oppositions. The diametric construction of identities, such as good versus bad, strong versus weak, desirable versus undesirable, can be argued as being fundamental to the oppression of people who fall outside the prescriptions of the norm (Galvin, 2003).

Vicky's story, below, is one of a life changing event that occurred in an instant and highlights differences as well as similarities to Tessa's experience. Vicky's journey is a contrast as she experiences an accident that leaves her incapacitated and then follows a period of rehabilitation and recovery as opposed to a progressive degenerative illness which Tessa experiences. Vicky's experience is predominantly informed by her nursing knowledge and identity and it is this identity which underpins her secure sense of her recovery.



### **Vicky's Story: I'm alive, I can get through this.**

Vicky describes a “*sudden change in what I could and couldn't do*” when she was hit by a car and received a severe head concussion. From this point on there was a journey of “*hurdles*” and “*milestones*” that marked events on the path towards her recovery and return to nursing practice. Vicky's story has a different trajectory to that of Tessa's. Illness is associated with biological essentialism as opposed to an accident and recovery narrative. Vicky describes “*a crazy administration time*” and “*a nightmare*” in the first week following the accident as she began negotiations between two employers, compensation organisations and the medical and rehabilitation teams. This was a time “*that was quite frightening*” as she initially faced the effects of her concussion and was unsure of the permanency of her injuries.

Vicky had two employers at this time and considered both to be very supportive, she was consulted by and able to negotiate with her employers about her needs following the accident. Vicky's work adapted to her needs. The nature of her work altered to allow her to recover and her employers acknowledged her fluctuating ability and became flexible in response. Vicky was not isolated, nor was her experience seen as her problem and there was a shared responsibility with her employers who worked with her to support her recovery. She was able to make choices regarding her abilities and her gradual return to work. Vicky's return to work was a process of trial and error whilst she healed and tested her capabilities. “*I knew that I couldn't push myself too fast for my own health, I couldn't do any permanent damage so I was aware (that) those were the things I had to balance*”. This trial and error meant that she could control the effects of her concussion and take time to heal.

Vicky always held a view of her recovery “*I read a lot around it and educated myself so I knew there was a two year full on recovery period for the trauma*”. This response reflects Jones et al, (2010, p.356) comment that “*awareness of one's deficits as a result of injury is associated with improvements*”. Vicky was “*very confident*” of her recovery and focussed on her rehabilitation. Medical and social supports reinforced her storyline of rehabilitation and recovery. Vicky was pragmatic and secure in her sense of regaining her abilities that were affected by the accident.

Vicky is mindful of many aspects of her experience that assisted her recovery. She viewed her initial emergency treatment from the viewpoint of a nurse, “*as a nurse you know what's serious and what isn't. I wasn't taken into resuscitation (which would indicate the seriousness of her injuries). It's quite interesting because as a nurse you get a different view*”. When Vicky was later taken to the resuscitation area, she thought “*probably precautionary*”, thus downplaying the potential seriousness of her condition. Of interest is that her focus when in the resuscitation

area was, in fact, *“I could hear next door someone being resuscitated and the family were right outside the curtain in the room I was in and I thought I just want to go over and be a nurse. It was fascinating”*. Vicky recognised a role conflict as she is used to being the specialist who comforts families in these circumstances rather than a person requiring treatment. Despite her circumstances Vicky continued to identify strongly with her nursing identity.

### **Labelling disability**

Vicky was told to identify herself as disabled *“I had to, they said that’s how it is to get the support, you know, everything is accounted for and funded”*. But this is not how Vicky would identify herself; *“No, not at all. Even now I still notice some limitations ...I think the label enables me to carry on with those limitations without being pressured”*. Whilst Vicky clearly resists the personal labelling of disabled she has *“had to”* accept positioning in some form, if only on paper... *“it was a tick box thing to get me from A to B”*. Vicky recognises that it is just a ‘label’ and prefers to use the term ‘limitations’ to explain how she sees herself. Diminishing the terminology in this way serves to reduce the psychological salience. To be able to access the support Vicky has adopted the label, but not the identity. Labelling is a complex and paradoxical process. Shakespeare (2006) posits the contradiction between defining an individual with an impairment as normal within the family or community, whilst at the same time needing to identify them as ‘abnormal’ to get services and benefits. Vicky exhibits a temporary acceptance of a particular position (disabled) as a functional status rather than a personal identity label. She identifies the advantages of this label, at times, within a social system that enables her to receive support. She is mindful of this advantage within the cultural/social system of New Zealand.

*If this happened outside of New Zealand where there are less support(s), I don’t think people’s attitudes would have been the same and there would have been more burden on family, to get through and as a woman I think it (the support system) has a lot to offer women.*

Vicky identified that *“one of the things that occurred to me during the accident was that awareness of how strong we are, despite what had happened”*. Vicky is amazed at her own survival given the seriousness of the accident. She can be perceived as constructing or reconstructing a survivor identity or experiencing survivorship, an overcoming of obstacles (Jones et al, 2010; Thomas, 2010). This identity is enlarged and deepened by the social processes of the support provided by the social, medical and rehabilitative systems she engages with. Vicky experiences a supportive stance from her employers that reinforces the acceptability of the survivor identity. The result of being perceived as a survivor is that Vicky is *“kindly judged and rewarded by society”* (Little, Paul, Jordan & Sayers, 2002, p.176).

The survivor identity shares some commonality with social narratives of impairment or disability as survivors can also be viewed within paradigms of heroism and victimisation. There is a stark contrast between Vicky and Tessa's experience illustrated by the diagnostic encounters. Tessa was initially dismissed by the medical establishment as untreatable. This response contrasts sharply with the enveloping and supportive stance that Vicky experienced. The contrast between the response to Tessa and Vicky's circumstances speaks to the socially acceptable position of the survivor versus the challenging and unacceptable position of having a progressive condition to which people may respond with discomfort. A person who has a visible medical condition is subject to forms of 'othering' based on their category of impairment. The response of a supportive work environment means that Vicky did not experience negative connotations associated with being 'disabled' except for the labelling required in order to receive support services which she viewed as positive as it meant she could receive the support.

Whilst Vicky experiences others feeling sorry for her she quickly repositions herself, being viewed with pity is "*totally off from how I feel (about myself)*". Attempts to position Vicky as a 'victim' contrast with her sense of self and consequently she recognises and corrects the incongruence within her narrative. She does not allow others to impose discourses of loss or change and does not allow her experience of her accident to be linked to personal inadequacy or inferiority. Vicky maintains a self perception of a stable inner self throughout her experience of concussion despite threats to the continuity of her work posed by functional and performance expectations.

### **Being supported**

Vicky's experience of formal support was critical to her recovery and return to work. In the organisation of these supports she demonstrates agency and control "*I felt (the caseworkers) were just really there to do the administration. I don't know who makes the decisions but I pretty much knew what I needed in terms of home help*". Even though Vicky continues to experience residual psychological effects from her accident these do not significantly affect her ability to work or how she currently sees herself. Vicky is, however, cautious with regard to her abilities and her recovery progress "*I don't want to risk anything. No one knows how well I've recovered, only by what I am able to produce or by my own judgement*". Being a productive person is of value to her and a measure of her progress in her rehabilitation.

In this study Vicky is the only nurse who discloses her experience to the Nursing Council of New Zealand (NCNZ) in her annual practicing certificate application; *“I usually write the date of the accident and write about general brain trauma. I’ve had a medical clearance and a psychologist’s assessment. That was part of the recovery process”*. This declaration is about her ongoing safety in practice. *“The brain’s a funny thing and I know things can develop from other causes, but I don’t want anything bad to happen as a result of previous injury”*.

In regard to her employment Vicky states

*With every employment I declare it... I knew that people understand when you’re not able to do things but I didn’t want people to feel sorry for me. I just wanted them to know that this is where I am at in my journey and this is what I’m willing to take up. And should there be any reason that it’s not quite the right time I’m open to just making sure I’m not pretending that I’m OK.*

Vicky is very clear about the journey she is on and is open about sharing this with others. She positions herself in relation to others and expects them to understand and to respond to her abilities and limitations.

Vicky never ‘lost’ her sense of her own positioning as a nurse, or as an ‘able’ productive person during her recovery. When Vicky’s accident happened she demonstrated agency in her role as a nurse by initiating the emergency response to the accident;

*I just knew what I needed to observe for, if you can call it that. Then I looked up “Has anyone called the ambulance?” My mother in law was sitting by me and she said “oh, has anyone called the ambulance?” and sure enough no one had called.*

Vicky’s story is about maintaining a continuous narrative of professional competence uninterrupted by the accident. Vicky demonstrates competence and control from the moment of her accident. Vicky embraced the support of the medical and rehabilitation services and maintained her confidence around her personal ability to recover. She recognises the process of her journey and where she is situated presently in relation to her perspective in this study and explains;

*When your request (to volunteer in the research) came up, I thought oh (it will) be interesting to go back and revisit some of that thinking, I don’t think about it as much now as I used to. It’s definitely moved on I’m ready for the next phase.*

Vicky’s next phase involves deciding to test her abilities by pursuing postgraduate study.

There is also a temporal dimension to Vicky's sense of positioning herself. Vicky finds it acceptable to have had a '*time of disability*' which is now past. This is similar for Bella, whose story is discussed in chapter six, who states that she was now '*over that*' and she perceives her disability was a past event.

There is a comparable awareness of the self for both Vicky and Tessa where their identities are based on the notion of what they both feel themselves to be, rather than what their colleagues suggest they should be. These are both reflexive stances. Vicky mentions her colleagues in her story almost in passing. She does not perceive them as central characters. Their dialogue has not impacted on her sense of herself. In contrast, Tessa's colleagues have a far greater presence in her narrative. Their responses and Tessa's concerns and fears in how they position her are prominent in the story. We hear that for Tessa colleagues are significant "*like family*". Her colleague's opinions and feelings are taken into consideration by Tessa and their responses dominate much of her work experience. Hence, being positioned as 'disabled' for Tessa has a greater impact on her experience. Her response to this subject positioning and her attempts at repositioning herself are also more significant.

Tessa and Vicky both embody an able bodied nursing experience. For Tessa seeking and gaining knowledge has enabled her to acknowledge her diagnosis and engage in treatment and also to understand her limitations. Tessa used her knowledge to deal with a health system which was not addressing her concerns.

*The (orthopaedic specialist) said everything was just in my head ...and he just wouldn't listen to me so I wrote him a letter. The advantage of being a nurse is that you know... I detailed all the issues such as I don't know when I want to go to the toilet I have very limited control over my bladder and bowel function, I have difficulty getting to the toilet, I can't walk down steps, I can't do this, I can't do that, I'm numb here, this, this, you know I detailed it all very clearly. He never said a word about getting the letter but the next time I saw him he said I'm sending you to a neurologist.*

As Tessa uses her knowledge to her advantage she is also in a context where her colleagues use their knowledge about her. Her colleague's nursing knowledge means that Tessa's behaviours are interpreted through a nursing lens. In her working environment Tessa's reactions are judged as being inherently connected with MS. With her familiarity of the nursing/medical environment Vicky uses her knowledge and ability to maintain herself in a position of power. Both Tessa and Vicky interweave different aspects of their multiple identities throughout their

stories. Tessa and Vicky's experiences of impairment are very different. Tessa lives with a long term condition whilst Vicky has an expectation of a full recovery, even though she recognises small changes as being permanent. For Vicky there is a stronger sense of resolution linked to the ongoing improvement rather than deterioration in her condition. The perceived temporary nature of her impairment has a significant effect on the meaning of her experience. It is acknowledged that *"injury can provide a basis for people to develop a strong personal sense of themselves"* (Jones et al, 2010, p.366). This appears to be the case for Vicky. She became involved with teams of people who assisted her to work her way through processes and systems designed to support her recovery. Tessa by contrast, was dismissed and had to seek out support and spend time coming to terms with her diagnosis and treatment by the medical establishment. Vicky had her treatment funded by the Accident Compensation Corporation (ACC) which provided greater options than was the case for Tessa who was reliant on the publicly funded health care system. In addition to this Tessa reinforces her confidence in herself and her identity by group association with others who have had similar experiences to her by joining the MS Society.

Shakespeare and Watson (2001) state *"...while all living beings are impaired - that is, frail, limited, vulnerable, mortal - we are not all oppressed on the basis of this impairment and illness. Only a proportion of people experience the additional disabling processes of society"* (p. 28). Tessa experiences disabling affects predominately by the attitudes of some of her colleagues and their consequential actions towards her that result in psycho-emotional affects (Thomas, 2010). For Tessa, renegotiating her sense of herself in relation to others is clearly an emotionally charged process. Vicky, however, does not appear to experience disabling affects. She is not obviously affected by others' attitudes and has not yet experienced barriers in her rehabilitation, her work or her career path. She expects others to understand and assist her as long as she is clear about what she needs *"people genuinely wanted to support me but a lot of people didn't know how. I'd have to be really clear about what kind of help I needed"*. She is also pragmatic about her abilities and her journey.

Vicky's marriage ended at the same time as her injury occurred. This affected not only her reaction to her injury but also impacted on her return to work. *"I remember it was so emotionally terrible (at that time) that in some ways I was quite glad that it was about my head injury I knew that my first priority was to get well no matter what"*. This distressing personal circumstance assisted Vicky to prioritise her physical recovery. She recognised that not doing so could have affected her ability to be economically secure at a time when this was required. *"I thought in terms of being focussed on my career and work, I don't want that to suffer because that is the means of how I can support my family"*.

Focusing on her work gave Vicky an anchor point for stability and a way to construct her future and provided a pathway for her to navigate her way.

Tessa and Vicky demonstrate access to a range of subject positions. An assumption that disability or impairment is pivotal to a persons' identity echoes the error made by essentialists and those who espouse a medical model that people are defined by their impairment (Shakespeare & Watson, 2001). Unwillingness to identify as disabled, both from a socio-political and a medical viewpoint, is present in disability research and viewed as a reaction to a socially constructed unfavourable category (Shakespeare & Watson, 2001; Watson, 2002). Disability is not an identity readily embraced by people with impairments. Usually disabled people "*define themselves under their own terms and using their own terms of reference*" (Shakespeare & Watson, 2001, p. 73).

This chapter has explored the impact of discursive positioning on the identity of nurses who have acquired an impairment. As Bamberg (2011) states "*versions of self-differentiation and integration are negotiated with others, tried out, rejected, or accepted. In short they are part of a continuous navigation process rather than anything that is built on pre-existing givens*" (p.37). Issues of agency in relation to how people act are also dynamic. Whilst some people draw on interpretive discursive repertoires that pre exist, in the sense that others have used them before, these people are also active agents who position themselves and are positioned by others.

Davies and Harré (1990) suggest that positioning theory highlights the nuanced and evolving aspects of identity through the discursive practices we engage in with others. Stories are told at certain points in time. Both Vicky and Tessa describe what happened in the past, the points of significance in their journeys and their considerations for the future. Their narratives are continually moulded and able to be restoried as new experiences occur. These participants' experience of being positioned and their response demonstrates an active identity construction, which displays reflexivity, creativity and distinctive identities that are not based on essentialist characteristics.

A major critique of the diametric construction of identities and the essentialist and constructivist underpinnings of the medical and social models of disability is the participant's inability to incorporate the corporeal element of the experience of impairment. The following chapter considers the experience of corporeality. The participants talk about the effects of their impairment on their body. This chapter explores how people are not only positioned in

discourse but how positioning also has corporeal, spacial and temporal dimensions of influence. The body has an absent presence in social constructionism and within positioning theory. Corporeality, however, influences the way in which people are positioned, and how people want to be positioned not just in terms of discourses but as non-disabled beings.



## **Chapter Five: Corporeality and identity development**

This chapter extends discursive positioning and the relationship to identity development by considering how corporeality, space and time also dynamically affect identity formation. The participants in this chapter construct identities which shift and change due to them being located and positioned within certain narratives. The narratives are spatially and temporally located. This chapter begins with a discussion of how corporeality has arisen in disability studies in the last decade and how recent research incorporates the individual's lived experience of impairment and reveals the social narratives which shape this experience. The themes of essentialism and constructionism that are consistent with the medical and social models of disability continue to influence individual and societal responses to the corporeality of the 'impaired' body. Somers (1994) identifies that narrativity provides a basis for exploring personal narratives through incorporating the influence of time, space and relationality. The influence of corporeality, time and the politics of space on identity formation are discussed alongside two of the participants' narratives. These concepts illustrate how identities are influenced by interaction within context, and as such, the participants positioned identity changes within the time and space in which they are set. The stories of Mary and Lonnie are included in this chapter and discussed in relation to the nursing context which produces professional discourse demonstrating how a nursing space can impact on identity construction.

### **Impairment, corporeality and disability theory**

The biomedical model of disability considers corporeality, that is, the physical body, as an object to be treated through the application of medicine and rehabilitative care (French & Swain, 2008). The biomedical model relies on a reductionist idea of the body. As such it has been problematic as it views the body as being 'normal' or 'abnormal'. This viewpoint positions people with impairments within the dominant discourse which perceives them as being abnormal. Biomedical and rehabilitative models have been criticised for creating an individual experience of impairment as opposed to a shared experience with others. Thus many disabled people are isolated from a sense of political community (Sieber, 2006).

In contrast, the social model of disability seeks to understand disability as a socially generated category and as a related series of experiences that are external to the body and as such this model has played a role in challenging biomedical models of disability. However, with the focus on the physical and attitudinal barriers that disabled people experience, one aspect that has been overlooked is the corporeality of the body. Oliver (1996) has highlighted that the social

model did not deny that impairment is closely related to the physical body. However problems arise when disability rather than illness becomes the focus of treatment and there is no acknowledgement of society's disabling barriers. Oliver (2010) identifies that the social model is not about the personal experience of impairment but the collective experience of disablement.

In seeking to surpass the division and differences between the biomedical and the social models, the notion of embodiment framed as impairment has now become relevant (Thomas, 2002). Disability scholars have become concerned with including embodied conceptions of people contending with impaired bodies. Proponents of the social model are still wary of incorporating impairment in theorising disability as they do not want a return to the dominance of the biomedical model (Chouinard, Hall & Wilton, 2010; Edwards & Imrie, 2003). Consideration of corporeality has also been influenced by social constructionist perspectives within disability studies which suggest that the categories of 'impaired' bodies and 'normal' bodies are social constructs (Thomas, 2002). This suggestion highlighted the 'body terrain' and posits that *"people with an impairment are culturally constituted as such and do not have bodies that in some real sense are essentially different. Their body differences are (cultural) representations"* (Thomas, 2002, p.71). Siebers (2006) also identifies that the disabled body provides insights into the fact that bodies are socially constructed.

Social constructionism makes it possible to see disability as the effect of an environment hostile to some bodies and not to others. There is acknowledgement however, that 'body theory' has never confronted the disabled body, although the disabled body constitutes a powerful image of the 'other' (Shakespeare, 2006). A constructionist viewpoint regards disability as an effect of the environment and argues against any impact of the body or the lived experience of impairment so that the focus is on a disabling society and not a 'disabled individual'. There is also a tempered view within disability studies that acknowledges essential biological based differences. These differences are overlaid and defined through meanings and cultural interpretations (Thomas, 2002). This viewpoint has developed as a response to the *"strong versions of constructionist thinking found wanting, like their biologically reductionist counterparts"* (Williams, 2006. p.22). Approaching any discourse of binaries or dualisms in the context of understanding the body, such as disabled/ non-disabled entails a tension of holding two sides without valuing one over the other (Moss & Dyck, 2003).

Thus the embodied experience of impairment has become a field of research in which lived accounts of embodiment give rise to the cultural discourses of disability and difference. These accounts highlight how disabled people experience their embodied selves as visible and

invisible across sociomaterial places (Zitzelsberger, 2008). As Smith and Sparkes (2008b) state; *“the corporeal character of bodies is also an obdurate fact, often providing people with the means of acting, and moreover placing constraints on their actions”* (p. 19). The means of acting suggests an agency (as opposed to a dependency) and also a reflexivity as people interact with their environments. The body is the site of the first performance of self and identity, that is *“our expression of agency whilst at the same times its structural location in stratified worlds that limit that very agency”* (Moore & Kosut, 2010, p.2). Shakespeare and Erickson (2001) suggest that in order to make sense of social phenomena we need to consider both the material conditions, including embodiment, and the cultural and social processes in which they are located. Disabled people are fully aware of the affects of their impairment; they all know and are aware of their bodily difference (Shakespeare & Watson, 2001).

Sullivan (2001) also identified the need to acknowledge discursive representations of bodies and the interaction of people’s subjectivities as they interact with the cultural discourses of embodiment. Disability scholarship has been both informed by, and has informed the scholarship of medical sociology. Williams (2006, p.11) notes, *“The call therefore is not simply for an approach to the study of chronic illness which explicitly focuses on the body, but one which incorporates both social and biological facts in doing so”*. Disability scholars have called for a sociology of impairment which takes into account the physical and personal experience of impairment and the social dimensions which includes cultural patterns and representations which influence how disabled people are perceived (Shakespeare & Erickson, 2001; Thomas, 2002). Thus there is a blended form of individual lived experience which is influenced by the societal and cultural narratives within the given context that the person inhabits. Thomas (2007) has identified ‘impairment effects’ that refer to the restrictions of bodily activity and behaviour that are *“directly attributable to body variations designated impairments”* (p.136). Thomas has called for a non-reductionist, materialist ontology of the body that includes the real effects of bodies.

### **Corporeality and the self**

Merleau-Ponty (1962) identified that our experiences are grounded in our bodies and our experience of the world is as an embodied person. If we accept that the human body mediates experiences of the self and the world, then there is value in recognising someone’s embodied experience, rather than defining them by the experience alone. Somers (1994) identifies what she terms an ontological self, a mode of being in the body, of living in the body, a sense in which the self becomes embodied. This embodied self is in contrast to what she sees as a sense of knowledge about the self derived from others, a disembodied self, a self away from the body,

although still the result of the body. One way to avoid turning a category such as disability into a rigid framework for identity is to introduce the ‘*categorically destabilizing dimensions of time, space and relationality*’ (Somers, 1994, p. 606). Charmaz (1995) suggests the body and self are not the same but each informs the other. Thus the embodied self, the experience of the body contributes to the formation of identity alongside discursive positioning, which is knowledge derived from self and others.

All of the participants talk about their bodies and the physical impact of their experiences, however their bodies are not described as ‘thing’ but as a ‘self-body’ through which they act (Frank, 1995). It is suggested that for people who acquire impairments the body may have been perceived as absent, taken for granted and that an illness or accident, brings the body into focus (Leder, 1990). Experiences that result in a sudden loss of physical control, a threat to existence, an unknown and therefore fear inducing experience or a slower unfolding of an explanation for bodily changes are pivotal points in the narratives of participants in this chapter. Davies (2000) suggests that when bodies cease functioning they become subject to different discursive discourses. Williams (1996b) identifies the term embodiment to describe the body unbeset by illness or disability. This is when the body is taken for granted and therefore only “*marginally present*” (p.24). There is a different trajectory for people who become ill or impaired than those who have developmental impairments. Scholars acknowledge that we live through our bodies and the expression of impairment as corporeal feelings linked to the social, political, economic and structural contexts are important. Taking a body out of its context ignores the implications of what living through bodies looks and feels like (Frank, 1995 ;Moss & Dyck, 2003).

### **Corporeality and space**

Negotiating disability constructs and discourses happens in complex and geographically uneven ways. Critical social geographic research focused on disability has demonstrated the complexity of how ways of being in place are central to the embodied experiences of illness, impairment and disability (Crooks, Chouinard & Wilton, 2008). Social geographers have suggested that bodies are constituted through space and that space is both social and physical.

*Conceiving space simultaneously as a social and physical entity whilst holding socially constructed, meaning laden space and the physical layout and contents of space in tension can provide insight into how people with illness deal with being ill and healthy at the same time*

(Moss & Dyck, 2003, p. 15).

Moss and Dyck (2003) suggest that bodies are sites where conceptions of body and bodily experience come together to constitute meaning and corporeality. Merleau- Ponty (1962) recognises that the body is the centre of spatial and temporal matrices. The awareness of being embodied in landscape, that is in the narrative space people occupy, is something that researchers have little practice in observing or articulating (Davies, 2000).

Mary and Lonnie's stories below, highlight the interconnection between their lived reality, their negotiations of the impact of pain and fatigue in their lives and how their experience is influenced by space and temporality. Although the embodied experience of pain is subjective, how it is perceived, communicated and explained and its effect upon a person's relationship to others and themselves is shaped by cultural beliefs and social practices within certain contexts. The language, expectations and sentiments of families, friends and colleagues shape the world of those who experience pain and in this way the experience can link the body and self to the social world (Morgan, 2002). Disabled people confront tensions between body and self identity that everyone faces but as Charmaz and Rosenfeld (2006) suggest, they can experience these tensions in an intensified, magnified and accelerated form. Mary and Lonnie's experience of pain and their relationship to their embodied selves and to others is located within a certain space, the situated dimension of where positioning takes place (Davies & Harré, 1990). Their stories of being nurses, the context of their nursing and the nursing space, influences their own and others' responses to their impairment. The temporal aspect of narrative, that is how we make sense of our experiences over time and how the concept of time influences our experience, are also strong elements in both these stories. Both Lonnie and Mary set up their stories of the onset of their impairments in the context of their nursing.

**Mary's Story: Over the years most of my colleagues wouldn't have had any idea of what my pain levels were.**

Mary has had a sudden life altering experience, initially from a work-related injury in her second year of nursing practice and then a diagnosis of fibromyalgia syndrome (FMS). As a result of these events she also experienced associated depression. For the past 22 years, Mary has actively negotiated, navigated and managed her work environment so that she can remain in the nursing workforce. Mary's story begins as she explains how the embodied experience of her FMS dominated her nursing experience as she adapted in order to continue nursing.

*I was off work for the 4 months that it took my shoulder to heal. I went back ... and found it extremely difficult managing my pain levels so I went bureau nursing and that helped because I could pick and choose. Pretty much I was two years before I got back into full time nursing again. So over the years my*

*pain levels have come and gone, depending on my stress levels. For probably 13 or 14 years I used amitriptyline for pain relief and spent probably the whole time feeling drugged. And came off that about 6 or 7 years ago and haven't used it ever since. I use alternative treatment options.*

Mary's narrative includes reference to the dominant medical narrative in regards to FMS being a contested category. Medical treatment resulted in Mary feeling 'drugged' for many years. Mary, like many other people who are aware that there is currently no cure for this illness, has resorted to complementary and alternative therapies (Terhorst, Schneider, Kim, Goozdich & Stilley, 2011). Mary's narrative illustrates a temporal context in which she makes meaning of her experiences by locating them within a past, a present and the future.

### **The temporal context**

Narrative is the organising principle of our psychology and the defining feature of narrative structures. It is through narrative that events are sequenced depending upon the perception of time. The concepts of time and space are fundamental to human life as narrative cannot be built without these concepts. The narrative of a person has a temporal structure - that is people have a past, live in a present and are orientated towards a future (Carr, 1986). As Luborsky, (1995, p. 1450) suggests

*The self is sensed as a seamless flow of past-present-future(s). Impairments limit the unfolding of future biographies. But disabilities also redefine the past. They put into question the meanings of past events and experiences in light of the present and future lived experiences.*

For the majority of Mary's nursing career she has been highly sensitised to the needs of her body, to the connection between her mind and body and the affect of her stress levels on her FMS and the affect of this on her nursing. The temporal organisation of Mary's story enables her to reflect and refer to times and aspects of her life with FMS and locate times in the past which give meaning to the present. Mary accepts the label of disability and also reframes the potential impact of this label. Mary states "*what I have is a disability and I have to live with that but I don't allow it to rule what I do*". Mary 'lives with' the effects of FMS rather than being in opposition to the effects. Mary admits "*it probably wasn't until about 10 years after my diagnosis that I actually accepted that what I had was a disability*". Mary's acceptance of being disabled as an authentic aspect of her identity occurred over a period of time as a result of her corporeal reality. Mary reluctantly accepts the construction of disability from a biomedical perspective (Crooks, Chouinard & Wilton, 2008). Sarbin (1986) notes that people impose a

temporal structure on their experiences and that this is present in narratives that are told to others. The sense of identity that Mary demonstrates is an ontological identity as the way in which her identity is narratively constituted and reconstituted occurs both in and over time as a response to her body. In another time and another place her sense of identity could be different (Somers, 1994).

### **Managing corporeality by being strategic**

Mary has strategically chosen work that enables her to accommodate her bodily experience. Her bodily experience is heavily characterised by fluctuating pain levels and fatigue so Mary has chosen employment where bodily performance was not a core part of the role. She situates herself within her nursing environment as non-disabled by navigating her way through certain work positions. Mary has left work positions that were non-supportive and did not allow her to be flexible in managing her time and thus her pain. She has also chosen to complete higher education with the intent of moving to administrative roles in order to manage her pain levels.

Mary acknowledges that sometimes others do not ‘allow’ her to do her nursing role and this has impacted on her mental health as she feels that others position her in a place of powerlessness.

*I didn't want people feeling sorry for me...I guess it's about managing my mental health because living with chronic pain is depressive and if you're limited in what you're allowed to do in your employment then that just feeds that feeling of unworthiness.*

Mary believes that living with pain is a struggle and whilst she feels depressed she acknowledges that it is a private struggle. As Charmaz and Rosenfeld (2006, p. 38), note “People who blur or hide views of their frailty or disability employ a range of dramaturgical techniques to produce a publicly and privately valued self”. When Mary’s colleagues respond to her as though she is not ‘able’, reflecting an undesirable identity, she feels limited. For disabled people the dominant narrative means that difference is interpreted negatively and when measured against dominant societal norms difference is interpreted as meaning ‘less than’ (Northway, 1997). Mary describes being ‘protected’ by colleagues who “wanted to put cotton wool around me so it (the work) didn't hurt me”. Whilst the imagery of being wrapped in cotton wool suggests shielding from the world, for Mary there are no such simple solutions. Mary has managed her ‘impairment effects’ for years, at times more successfully than others (Thomas, 2007). Somers, (1994) would say that her sense of herself is embodied as Mary pays attention to her body continuously in order to control her pain and maximise her abilities. When her colleagues suggest she is not managing, Mary has an experience of a disembodied self as she does not relate to their perception of her.

Mary retells an experience of powerlessness when a manager wanted to prevent her completing some aspects of her role; “*She wanted to stop me... But I consider it’s my choice, if I chose to do that, it’s when choice is taken away (that it is not OK)*”. Not being able to make one’s own choice indicates to Mary that a value judgement about her capabilities is being made. Being perceived as non-disabled implies that Mary is able to make judgments for herself. Mary’s FMS has been responded to by her colleagues in a way that she perceives as helpful and caring and also in ways that she perceives as being misunderstood and judged

*I’ve had colleagues come up to me and say ‘I can see you’re getting sore and what is it that we can do for you?’ and that’s different. That’s empathic as opposed to pity or sympathy. Once there was a colleague that told me that if I continued to do what I was doing I was being my own worst enemy, in which case she was telling me that I couldn’t make a decision or judgement of my own, and that was hard and extremely challenging. She had no concept of what my pain was, she thought I had hurt myself physically and she couldn’t understand the difference between my brain telling me that I was sore and tightening and tensing everything up and actually pulling a muscle and hurting yourself. She couldn’t see the difference or understand what fibromyalgia was and what I was able to do myself. Mostly the colleagues who do know are supportive. If I’m sore they will jolly me along and cheer me up and focus me. One challenges me, but that’s in a good way in a peer supervision type way – ‘so what is it you’re going to do to make this right for you? What are you going to do to look after yourself? It’s always at a time when I am usually really, really busy or really stressed, just as a reminder. ‘Hey I care about you and you need to make some decisions here’. I appreciate that more, especially from my current colleagues.*

The response of Mary’s colleagues demonstrates that some of them misunderstand the effects of her impairment and some understand. Crooks, Chouinard and Wilton, (2008) argue that navigating an identity is part of an emotionally volatile process of renegotiating one’s own and others’ understandings of the body within certain contexts and spaces.

### **Corporeality and the nursing context**

Mary’s embodied experience, her pain levels and how she manages them are reflected back to her in the nursing work environment. Her positioning by others is influenced by being in a professional nursing context (Davies & Harré, 1990). This context means that Mary’s colleagues are monitoring her experience. These nurses are trained to notice pain in others



through their understanding and intimate knowledge of the body. In this way, Mary's actions are scrutinized at times by her colleagues. The nursing role provides access to people's bodies in a socially permissible sense. It is not out of context to have nursing colleagues enquire about bodily experiences with each other. This is a cultural practice of nurses (Lawler, 1991). Mary's embodied experience is influenced by the nursing space she occupies. There is an acceptance of dialogue in this context that is intimate and that would potentially be seen as being out of place in other non-nursing contexts. In this way, this dialogue signals the cultural norm in nursing (Moore & Kosut, 2010).

Mary's self consciousness increases as she becomes more aware of how others see her. There is a distinction between the process of disability due to social restrictions, the contribution to identity formation and the influence of the space on identity. There is an inextricable interconnection in the nursing context between nursing narratives that connect to a larger matrix of dominant discourses. Mary occupies a space where nurses hold medical and nursing knowledge, where they make judgements about each other's health and capacity. Mary states *"I've worked with other nurses who have different types of disabilities and I don't know that nursing in general is supportive"*. Having health and capability are both accepted aspects of a nursing identity that are intrinsic to being a nurse. The traditional dominant discourse in nursing regarding disability is a dependency narrative; nurses and other health professionals are the experts and disabled people are dependent on them for help (French, 1988). It is a discourse of dependency that influences the dialogue that some colleagues have with Mary. Although she is aware of the influence of this narrative Mary refutes positioning as dependent in the nursing context and also the dependency narrative of disabled people. She herself has advocated on behalf of another nurse she felt was being discriminated against due to a physical impairment.

In contrast, nurses who assist Mary in an empathetic and collaborative way, echo some of the more contemporary influences in nursing practice that redefine the role of nursing in response to disabled people from that of a caregiver to a partnership (Marks, 2000, 2007; Thorne et al. 2002, Thorne, Paterson & Russell, 2003). These colleagues ask Mary what is required of them to support her, knowing that she understands what she needs. These contemporary influences demonstrate some changes in the cultural practices of nursing and in relationship between nurses and people with impairments.

Nursing advice from others colleagues with FMS has also influenced how Mary has come to manage FMS. One such colleague said *"a lot of positive attitude changes our perspective on pain. It was her that talked to me about meditation and working with that"*. Mary sees herself as

someone who is “*about creating opportunities and that’s my mindset, that’s my attitude*”. This approach means that Mary creates and explores opportunities for herself in her nursing. Mary recognises that her experience of FMS produces positive effects, not just barriers, and as such her attitude echoes the affirmative model of disability which provides new storylines for positive future identities (Charmaz, 1995).

Mary has strategically and actively sought ways of managing her work environment in ways which contribute positively to her work. Arranging work activities around the physical sensations of pain, fatigue and the uncertainty of bodily function has led Mary to practice nursing in different ways. She describes one time working with new mothers and enabling them to do all the lifting and handling of their children as opposed to her doing this. This practice was commented on and was perceived as empowering practice by both her colleagues and the mothers. These people were unaware that Mary was unable to lift due to her pain. Instead Mary’s action is seen as creative, as being advanced, client-centred practice as opposed to a limitation around not being able to complete aspects of her work. Her actions and the interpretation of these by others create a narrative of nursing competency and also a counter story to one of impairment equalling limitation (Nelson, 2001). As Holloway and Freshwater (2007) suggest, “*Characters have agency and can cause things to happen. Further during action characters reveal who they are their motives and their strengths*” (p. 43). Mary’s strength was her creativity to adapt her practice.

Having experienced depression that she associates with FMS, Mary is protective of her emotional/psychological wellbeing by being mindful of the language she uses to describe herself.

*If I had to think of myself as disabled I’d get quite depressed by that. So I use an alternate word (limitation) that kind of means the same thing but it’s the connotation that goes with it (that is important).*

Mary does not want to accept a negative connotation and have that affect her mental health. The lived experience is said to enhance understanding (Holloway & Freshwater, 2007). The ability to empathise is valued in a nursing arena. Mary identifies that her experience informs her nursing practice and her ability to understanding and empathise. Frank (1995) explores what he terms the dyadic body – how by the very nature of having a body becomes the basis for empathy, (p. 320) “*She sees others who are pained by her pain*”. The professional boundaries inherent in the nursing profession means that the nurses do not generally share their personal

experiences in their work - only once when Mary's condition was noticed by a client she worked with did she admit to her condition.

*She picked my pain. She said that the way I hold my body and the way I do things (told her). I disclosed to her, but I never felt like it limited our relationship or my care of her.*

Mary's story demonstrates how being situated within a nursing context impacts on the discourses that occur in response to her impairment and consequently how she views herself in response to being positioned as a nurse and as someone with an impairment within this context. Being a nurse means that Mary moves in a working environment where her colleagues are engaged in the narratives of health and healthy bodies. A dependency model of impairment influences some of Mary's colleague's responses to her. The nursing context is also variable in the roles available to her and she manoeuvres herself into roles that are not physically demanding. *"The social order is grounded in contingent, embodied ongoing interpretative work...processes are continually created and sustained (and- sometimes- resisted)"* (Wilkinson & Kitzinger, 2003 p.158). Mary's story demonstrates the way there is interplay between a person's self concept, their lived experience and the repertoire of self categorisations that enable positive self positioning and responses to being negatively positioned.

Similarly Lonnie's story below demonstrates both a corporeal experience and also one of being positioned in certain physical spaces within the work context. She experiences social and physical restrictions in her work environment which echo the medical model of disability. However Lonnie manages her arthritis so that the impact on her work environment is minimised. She responds to authoritative discourses that suggest that contributing as a functional independent nurse is highly valued.

**Lonnies' Story; I guess for me then this doesn't look like a real disability, you know, I'm managing it better because I'm not having to burden my work with it.**

Lonnie describes her journey

*My arthritis started coming up in my 30s when I was working in theatre and that's when it started impacting on me particularly as I was a scrub nurse and as a scrub nurse you have to hold retractors for hours on end and I was starting to get it in my hands, and later on I sort of have flare ups, good and bad 'cause it's a poly arthritis. Then it became more of a problem probably in the last 10 years and that's when it started affecting a lot of my bigger joints, hips, knees, things like that. So now I'm on quite a bit of medication and under a rheumatologist. Really in the last year I've been more affected probably because I've got it a lot more in my hands and had to have steroid injections and what have you and complicated by that I've had three whip lash injuries to my neck from car accidents. So I've got an unstable cervical spine, so I've had to modify a lot of what I do because of that, because I get pinched nerves. I end up with a lot of pain in my head and face. I've had to really work around my... I don't like calling them disabilities, my problems, and modify what I do and I also have to say no to some things because I can't do them physically. Otherwise I'll end up compromising my quality of life by suffering a lot of pain and having to take a lot of pain relief. So that's my journey.*

Lonnie's story focuses on the practicalities of managing her condition, her pain, the treatments and how this impacts on her work. Her narrative above draws attention to the immediacy and obdurate reality of the biological body. Not *all* restrictions of activity are framed and shaped by the social environment. They can on *some* occasions, be directly associated with having a physical impairment and being a material body that is unable to do certain things (Smith & Sparkes, 2008c). Thomas (1999, 2002, 2004) would describe aspects of Lonnie's experience as effects of impairment – the restrictions of activity which are directly associated with being impaired but which do *not* constitute disability as a form of social oppression. Lonnie's subtext is that she does not give in to her condition, it's "*hard*" and she just gets on with it. Lonnie identifies "*her problems*" in order to create an understanding of her impairment that most aligns with her sense of herself and Lonnie's approach to her limitations is pragmatic and orientated to problem solving.

### **Managing conditions by allowing time**

Lonnie's story demonstrates how she manages her work environment in order to minimise the effects of her impairment and how successful she is at this directly impacts upon how she identifies as being disabled or not. The use of space in Lonnie's story places her within supportive environments that assist in her work, and hostile environments which create barriers. "*Managing*" is very important to her and means that her condition is not then so noticeable to her colleagues. If it were more noticeable, then it may become a "*real disability*". This disability would then become a burden, not only for Lonnie but also for her colleagues. Lonnie works to overcome barriers that undermine her realizing a recognizably competent identity (Charmaz & Rosenfeld, 2006). She downplays the significance of her impairment whilst emphasising that her condition is well controlled with medication. Her joints are not overly swollen and noticeable thus referring to surface inscriptions on the body, that is visible images of crippled bodies and marks that are perceived as being abnormal, disabled and disabling (Moss & Dyck, 2003).

There is also a strong temporal element in Lonnie's story which is emphasised as she is in a sole charge position at her workplace. There is a challenge for Lonnie in taking time off from her work to attend specialist appointments. In Lonnie's work space she has a particular time frame to complete her work. Making alterations to this timeframe when she is at work means it is more noticeable to her interdisciplinary colleagues. Time is a commodity in Lonnie's work environment, it is not expansive, and completing work within the allocated time frame demonstrates her ability to perform her work which is important in defining her as being the same as others. The context and the space Lonnie occupies have a direct impact on how she views her identity in relation to the embodied reality of her lived experience. Iwakuma (2002) identifies that the physical body embodies time and is subjective; some disabled people perceive a different time flow. One of the most important themes in the study of disablism, the social beliefs and actions that oppress/exclude/disadvantage people with impairments, is the control that health professional exercise in the daily lives and destinies of disabled people (Hall, 1999, 2000; Thomas, 2007).

Lonnie is sensitised to the response of her colleagues around taking time to attend appointments "*Sometimes you get comments made... sort of 'Oh so there's no one to cover you?'*". Lonnie experiences that "*for them it's annoying*" and "*they find that a bit of an inconvenience*", although "*No one has actually said can you not do it (go for treatment) at another time?*" There may not be what Lonnie considers as an overt response but nevertheless she is aware of a

negative response. The response of Lonnie's colleagues in this productive, working space has a direct impact on how she perceives she is viewed by others and how she manages her condition.

Lonnie describes the sense of discomfort she feels around taking time out of work to attend appointments. She states it is "*one of those burdens you can feel guilty for*". The metaphor of the burden suggests that the embodied experience of carrying a load and being weighed down, and encumbered, for her is a physical experience. Lonnie states that taking time off work is, "*Like you're being favoured I suppose and you don't want to feel like that*". She does not want to feel that she is being treated differently because this emphasises difference, and her goal is to avoid feeling different or being noticed as different by her colleagues.

Consequently, in attempting to subvert her feelings of dissonance associated with being treated differently, Lonnie 'makes up time' in her lunch breaks and she starts early or works late, even though this is not witnessed by her colleagues. "*They don't see me working late most nights and not leaving till 6, so I work extra time anyway, so it shouldn't be a big deal*". Lonnie also attempts to use her lunch breaks to receive treatment; "*I dash over to see the rheumatologist and dash back again*". Her story demonstrates how she negotiates her space and time to not inconvenience others and to avoid feeling as though she is not a contributing member of her team and also potentially being treated differently.

The nursing work environment Lonnie occupies impacts on her both in a physical and a psycho-social way (McGillis Hall, 2005). Somers (1994, p.618) states "*People act, or do not act, in part according to how they understand their place in any number of given narratives - however fragmented, contradictory, or partial*". Lonnie deploys an ontological narrative – the story that she has created to make sense of her actions. The social and structural interactions relating to her work performance demonstrate that she is sensitive to the affect of her impairment on her nursing role, her actions to remain autonomous result in the creation of new narratives about self. The social and structural interactions described in Lonnie's stories may be thought of as public narratives (Somers, 1994).

Lonnie describes "*the only time*" she has taken half a day off

*when I got (a steroid injection) because the previous time that I had it done I rushed off in my lunch hour, got it done, drove back to work and carried on working and I was in agony and it never really worked. So I thought this time... I took the afternoon off. So I don't let it stop me working generally. That's the only time really.*

Lonnie continues working even when she is in agony such is the priority of being an able member of her team. For Lonnie it is important that her impairment does not stop her working. Lonnie had this injection/treatment because she was “*getting pretty desperate*”, Lonnie is used to ‘*just carrying on*’ and describes doing so

*I hobble around and can't bend my knees properly or my hands throb, I have to sit at my computer with my hand up in the air but, you know, I just carry on. For me pain is part of life now. So you just get used to it. It's tiring but you get used to it.*

### **Corporeality and managing day to day practicalities**

Lonnie also describes her work and how she has focused on managing through negotiating the practicalities of using equipment; “*I can lower or raise the (consultation) bed accordingly and I can do the same with my chair*”, and of ensuring she has assistance “*if somebody is disabled we have a carer with them so they can do the lifting, 'cause I can't do that*”. Ergonomic accommodations are considered by Lonnie as an “*absolute priority*” to enable her to continue working and remain ‘able’. Without these accommodations Lonnie would experience a loss of bodily ability, impacting on her perceptions of her physical status which threatens her personal autonomy. Charmaz and Rosenfeld, (2006) suggest this perception of loss of ability can prompt feelings of being defeated by our bodies and viewing ourselves as unacceptable. For Lonnie, avoiding tasks that cause pain is also a priority.

At times Lonnie has to admit that there are physical aspects of her work that she cannot complete without requesting assistance. She reflected; “*When I first had to say that, it made me feel like I was letting the team down*”. This reliance on others for tasks may cause concern about how others interpret this behaviour, Lonnie identifies that “*you have to feel like you're doing your fair share of work*”. She values being an able contributing member of the team. Whilst Lonnie has an autonomous position in the team as the only nurse, she does recognise the interdependence of her position with that of her colleagues. Lonnie has come to accept, that at times, when she requests help that “*my team are very supportive*”, “*They're all very accommodating...so I'm very lucky*”. She describes her disclosure “*right from the beginning*” to her colleagues as

*some days when I'm really sore I have just said 'look I can't do that my arthritis has really flared up at the moment' and they are very, very understanding, and very accommodating too when I have those problems.*

Lonnie asks for help when she is “*really*” sore, when her arthritis has flared up “*at the moment*” thus locating the issue to being just here and now. Her colleagues at these times are “*very, very*” understanding and “*very*” accommodating of the “*problems*” that she has. There are echoes here of the medical/ individual model of disability that locates the problem with the person and the person’s biology. The fact that Lonnie considers she is very “*lucky*” indicates that she has no expectation of assistance and accommodation. The barriers that Lonnie encounters become ‘her’ barriers to overcome. Lonnie does not see her actions as political and although she prioritises her need for accommodations she does not have a sense of any rights to accommodation or a consciousness in regards to these barriers being discriminatory.

The fact that Lonnie is included in her workplace by colleagues is important for her. When she is involved in the decision making process around purchasing new equipment that *she* uses in *her* consultation room she is both surprised and pleased. When her colleagues asked her “*will this bed be OK (to purchase for you)?*” Lonnie states, “*I actually got a say in what I thought would be good*”. She did not expect this, “*These are expensive (pieces of) equipment... (after all)*”. This involvement meant Lonnie is able to have equipment that enables her to do her work without discomfort and pain, and she is delighted. “*... what they got is fantastic, it’s just awesome, it’s just the bees knees*”, and she reports feeling grateful, “*I’m very lucky*”.

Lonnie experiences bodily differences and restrictions as a direct result of her impairment. How she views these differences and consequently herself demonstrates the cultural narrative about how disabled people are viewed. Dominant cultural themes have been communicated through channels such as media that contain messages that often include stereotypes about minority groups. Cultural narratives of disability include assumptions that disabled people are incompetent (McDonald, Keys & Balcazar, 2007). Disability has been used to exclude people from community life and work. An aspect of Lonnie’s ‘*luck*’ is her continued inclusion and competency within her work environment. Subjection to dominant discourses that perceive the self negatively as being impaired means that some people continue to struggle as individuals against structural barriers believing both the cause and the solution to the discrimination they experience lies within themselves (Cameron, 2007). Lonnie negotiates these barriers as much as possible.

Not being able to autonomously complete work tasks has had the biggest impact on Lonnie, on her sense of self “*I guess the word that springs to mind is deficient because I thought well I can’t do everything that will probably be expected of me in my role and that I would want to be able to do myself*”. The word ‘*deficient*’ implies a lack, a wanting, and an incompleteness and



suggests Lonnie views her “*limitation*” and ‘*disability*’ in that way. Frank (1995) identifies that people define themselves in terms of their body’s changing capacity for control. Illness (and impairment) is about learning to live with loss of control. Frank states that, “*When adult bodies lose control, they are expected to attempt to regain it if possible, and if not then at least to conceal the loss as effectively as possible*” (p. 319). Lonnie’s narrative identifies how she works and is seen to work on optimising function and minimising her deficiency and difference.

### **Managing conditions by allowing space**

Asking for assistance is a reminder to Lonnie of her ‘*deficiency*’ and of how ‘*lucky*’ she is. She gives examples of when she requests help, only when there is no other choice;

*We keep the baby scales on the top of the cabinet and sometimes I’m too sore to get it down so somebody else will get it down for me or put it up, or my knees are too stiff and I can’t get down to get the controlled drug out of the safe so I get the receptionist to do it.*

These examples also serves to demonstrate how the space that Lonnie occupies in her work becomes a space of dependence when assistance is necessary. These examples highlight how an environment can disable people. Lonnie is not disabled because she is unable physically to reach up or down. She is disabled by the fact that the scales and the safe are located in the positions that are unobtainable to her. But Lonnie accepts this ‘problem’ as hers, as part of her condition and does not know how to negotiate this space therefore reinforcing this as her ‘problem’. Her reluctance to ask for assistance is a reluctance to reinforce that she is different and unable. Again the location of the ‘disability’ is within Lonnie rather than how the workplace is organised creating barriers to her participation. “*Attention to the situated dimensions of social interaction suggests that it is not just discourses, but also corporeality and spaces that make certain subject positions available to actors*” (Phibbs, 2008, p.4).

In the nursing profession definitions of disability follow the medical model and disability is often perceived as a medical problem that gives little consideration to opportunities for environmental accommodation (Hubbard, 2004). The most frequently identified loss that affects the identity of a person with an impairment is the loss of their independence (Galvin, 2005). Wendell (2006) identifies that independence is highly esteemed within our culture. Independent nursing practice is also part of the scope of practice for registered nurses in New Zealand (NZNC, 2009) and working autonomously is also valued.

The fact that Lonnie is only affected ‘*sometimes*’ by her arthritis, enables her to craft an identity as ‘not disabled’ “*I don’t have constant pain every day, I get flair ups...Disability for me would*

*be ...pain every day*". The fact that Lonnie has been able to negotiate equipment also reinforces that it is only 'sometimes' that she is unable to manage independently. Lonnie's language about her arthritis echoes her focus on the practicalities and tasks in her work and her pragmatic approach to her situation. *"I've worked through it. I don't let it stop me working. For me pain is part of life now"*. Lonnie's story identifies what she experiences in relation to managing her arthritic condition; *"It's hard"* and also *"I'm very lucky"*. She contrasts this present luck with her previous work experience *"I couldn't have changed that workplace and they wouldn't have wanted to because it would have cost too much money, so that would have been a problem for me"*. The working space when viewed as unchangeable becomes a place of entrapment. This reinforces for Lonnie how lucky she is that her present workplace is willing to accommodate her. She recognises how her life would be altered if she was working in an environment in which accommodation had not been made.

### **Corporeality, identity and thinking of the future**

Lonnie is presently contemplating changing her employment. The perceived limitation of her future is seen in her story as she struggles to complete the job application form in regards to the disclosure of her arthritis. Lonnie's application for employment has become complex and problematic. She has not disclosed her condition but recognises that this may mean she is deployed in work areas that are unsuitable for her. Alternatively if she does disclose then judgements may result in her losing an opportunity for her preferred type of employment. Lonnie is mindful of the choices employers may consider should her condition be known. She feels *"confronted"*. Whereas previous disclosure had not been an issue in her workplace *"I just said right from the beginning this is how it is for me at times...they were really good"* Lonnie now experiences *"the first barrier"* in the application process.

*I was asked about my theatre experience and I thought 'oh I don't want them to put me in there because I can't do scrub nursing and I can't hold retractors back for hours on end'. That's when I thought I'm going to have to tell them why I can't do it.*

Lonnie is concerned here that disclosure would mean an attitudinal barrier could be erected by employers judging her application. Having to tell people in this way then opens up the possibility that *"they may not want me because of my arthritis and because there's certain things I can't do"*. This possibility of outright rejection means that her narrative is being restoried through this new experience. Lonnie's story now changes from the action and achievement to a story with a potentially problematic future.

Lonnie had not disclosed her arthritic condition because “*If they ask me what my health problems were then I would have to disclose, but I haven’t been asked so far, directly*”. In this way she is not volunteering this information until she is asked. Lonnie has stopped her application because “*someone looking at it on paper, they might say no, no she’s got these problems she won’t be any good...I think I don’t want to be told that*”. She understands the process in making such a decision which she views as practical and being made in the best interests of the applicant.

*I’d probably feel the same if I was screening, I’d want to put the right person out there plus I wouldn’t want to put anyone at risk of being reinjured or of getting worse. So it’s practical when you think about it. It’s not unrealistic.*

For now, Lonnie is indecisive about continuing her application due to this perceived barrier. She has experienced barriers before that have proven to be flexible, permeable and negotiable. At this point in time in relation to future employment, this barrier does not seem to be so.

Lonnie’s story is of negotiating practically and personally managing her lived experience of impairment. Her story highlights the importance of being the same as others and of not being noticed due to a bodily difference which impacts on her ability at times to perform her role.

Lonnie experiences a bodily difference, a limitation in some of her activities and a psychological salience that means that at times she considers herself ‘*deficient*’. Her difference is emphasised when she is unable to fully negotiate and accommodate her condition so her work availability and performance is unaffected. For Lonnie, being a good nurse is being in control of her body. She seeks a high level of predictability in regards to her limitations (Frank, 1995).

### **The nursing space and the lived experience**

Mary and Lonnie both demonstrate that as they engage in their work environments they continually negotiate the material limits of their body in the context of the immediacy of their surroundings. These participants negotiate the changing relationships with their work spaces. Their narratives identify how the body becomes a site of oppression when others make judgements about their ability, and a site of resistance when actions are enacted to maintain ability. Moss and Dyck (2003) argue that people with impairments experience the limits of their bodies, not as solid impervious boundaries but as fluid permeable borders. In this way, their subject positioning changes and the fluidity of how and who they identify with changes accordingly. Whilst there is a real biological aspect to the body, Lonnie and Mary’s lived experience is also constituted by narratives, metaphors and discourses that are socially produced and influenced by the spaces they occupy. Mary has dialogue with her colleagues and bosses about her bodily experiences in order to negotiate her work environment and access to extended leave due to her health needs. Lonnie asks for physical assistance when required and her

colleagues accommodate her limitations in the procurement of new equipment to assist her. Although it is unknown if this act is perceived by her colleagues as political, it ensures the inclusion of Lonnie by her colleagues. Bodies are said to convey a range of statuses ranks and relationships and also communicate the effects of institutional discrimination (Moore & Kosut, 2010). Both nurses sustain an existing valued identity as working professionals and negotiate mixed feelings of what identifying as disabled means as they negotiate social barriers. Both participants identify that they have sought and seek support from others who have similar experiences of impairment to them. This however is not an aspect that they overtly bring to their work with patients. The professional boundary expected of nurses' means that personal experiences however relevant are not always shared. Their ability to empathise with their patients is enhanced and they may act accordingly however they do not share personal health experiences. Mary explains;

*I don't put my experience on other people because how I manage my pain, we all manage it differently. I certainly wouldn't recommend people to do any of the things that I've done. If someone says to me hey you've tried that or if they ask my opinion of something, I can say what my experience has been but I wouldn't put that on anybody.*

Lonnie says, "Oh certainly I have a lot more understanding and empathy with people with arthritis. I always make sure they are receiving an adequate amount of pain relief, anti inflammatory, whatever they need ...I know how important that is". Lonnie's practical approach to supporting someone with arthritis echoes her own self management. This is also seen in Mary's approach

*Because I have experienced chronic long term pain I can understand the concepts. I know what can and can't happen as far as emotional things, I guess I'm a more empathic nurse for that. So I certainly understand and support.*

As Mary's journey is affected by her mental health she is attuned to this in others. Approaching the body as 'lived', as opposed to a social construct or abstract object allows us to begin to understand the unspoken knowledge and meanings that bodies hold (Moore & Kosut , 2010). This chapter explored how people are not only positioned in discourse but that positioning has corporeal, spacial and temporal dimensions which influence the way in which people want to be positioned as non-disabled beings. This chapter has considered the role that space and time play in the development of identity. The lived experience in relation to space and time, enables us to see how Mary and Lonnie's stories are positioned and mirror wider social narratives that are temporally and contextually influenced.

In the following chapter three participants' stories are reviewed to explore the link between social and personal identities when impairment is invisible, or hidden. There is a discursive interplay between ontological and social narratives of identity that individuals experience when questions of disclosure become salient. Invisible impairment defies the outward social construction of disability. While people with hidden impairments can be afforded a sense of anonymity, they have different challenges, including in some cases, learning about the nuances of strategic disclosure. When and how to disclose, thus making impairment visible, and when to give people the impression of a '*non-disabled*' person are choices that have to be made. These choices to have or to not have impairments have implications for the way we understand and perceive disability, in relation to the concepts of social and personal identities. In addition to this complexity, this chapter will consider the ways a hierarchy of impairments becomes visible as the participants stories also include more highly stigmatised health conditions.

## **Chapter Six: Invisible impairment and identity**

This chapter explores the experiences of three participants who have both invisible and at times, hidden impairments, through examining identity development related discussions using the framework of Harré's (1983) identity projects. As such the chapter builds on chapter four's discussion of positioning theory identifying that the person is linguistically positioned and chapter five's discussion of how corporeality, space and time dynamically affect identity development (Davies & Harré, 1990; Phibbs, 2008; Somers, 1994). According to Harré, identity formation has two core projects. The first project involves the acquisition of a social identity that secures a position amongst others that is considered respectable. The second project involves the location of and protection of one's distinctive individual identity (Koski-Jannes, 2002). In this chapter, three participants, Jo, Riro and Bella, share stories that illustrate how they are active and strategic about the disclosure of their impairments in their work environment. This chapter discusses the participant's identity projects in the face of highly stigmatised categories of health conditions that challenge their sense of self and self worth. Identity is explored as a concept that is discursively constituted and deeply enmeshed in contemporary political processes, power relations and moral values. An overlap of the public and private domains is also identified through exposing what is known or not known about the participant's health conditions and how people respond in order to protect one domain from the other.

### **Identity projects and stigma**

Harré (1983) posits that there exist two identities, one as a social being and the other as a personal being. In addition disparities can exist between personal self beliefs and self presentations in a public forum. Resolution of this disparity can lead to the possibility of social identity projects. Harré suggests that marginalised people have social identity projects that consist of efforts to acquire the attributes of an existing social identity in order to convince others that they have these attributes. Social identity projects also involve constructing an appropriate biography or alternatively concealing an inappropriate one. The participants in this chapter, Jo, Riro and Bella, have health conditions to which an inappropriate biography may be attached and consequently are subject to being stigmatised and marginalised. The participants strive to demonstrate their honourable social identity by negotiating the disclosure of stigmatised health conditions. Two of the participants, Bella and Riro, describe how they assist others who have similar stigmatised conditions by manoeuvring around unacceptable social expectations and finding expression for their personal identity to improve their damaged social identity.

According to Goffman (1963), a stigma is an attribute that discredits an individual diminishing them and causing them to be tainted, discounted and viewed as inferior. Stigmatising features may be visible or invisible, controllable or uncontrollable. Stigma aligns with the notion of deviance. Deviation from prevalent or valued norms leaves the person perceived by others as being negatively different. This is a classic functionalist perspective that also views illness as a failure to conform to societal expectation and norms in some way (Lupton, 1994). Goffman's (1963) study of stigma proposed that maintaining an invisible illness alongside the metaphor of being 'in the closet', and careful considerations about disclosure are strategies that demonstrate management of the deviant attribute (Joyce, McMillan & Hazelton, 2009). Individuals who have invisible deviant characteristics are termed discreditable (Goffman). As such discreditable individuals need to engage in strategies that manage stigma and their social identity. Goffman refers to individuals who do not have any deviant characteristics and who do not deviate from expectations of their social group or the wider society as '*normals*' (p. 5). If people control and manage their discreditable attributes they can attempt to pass as 'normal'. If they are unable to, then they will become stigmatised.

Though stigma is often seen as a characteristic residing within the individual, Goffman (1963) posits that a language of relationships and interactions rather than characteristics is required when discussing stigma. Stigmatised categories often change over time and in relation to context. This indicates that stigma is socially constructed and can also become either more or less salient depending on what is considered to be acceptable in particular social contexts. Stigma reinforces social norms and strengthens groups by removing undesirable characteristics and creating a boundary between 'us' and 'them' (Goffman). The stigmatising of 'others' therefore, is an identity-producing practice.

Goffman's (1963) central idea is that stigma spoils identities. Stigma can contaminate, and hence globally devalue, an individual's entire identity. Coping with invisible stigma involves a variety of strategies which include the decision as to whether or not people will/should disclose a condition and experience further stigma, or attempt to conceal the condition or aspects of the condition therefore attempting to pass as 'normal' (Joachim, 2000). Barriers to disclosure include the potency of the stigma with mental health disorders and infectious diseases being particularly stigmatising (Corrigan & Kleinlein, 2005; Stanley, Ridley, Manthorpe, Harris & Hurst, 2007). There is an assumption that Goffman's research is based on a reductionist viewpoint, that the fear that leads to the stigmatisation of people is a normal facet of human psychology. Stigmatising behaviour can be seen as produced by a series of social structures that

are powerful and significant, such as the media, the medical profession, the church and charities, which are deeply influential in society (French & Swain, 2008).

Others suggest that people's choices around identity categories and their reaction to stigmatised categories have changed since Goffman's analysis. For example, Frank, (2000) states, "*stigmatized individuals no longer play by the rules Goffman observed*" (p.137). Frank is referring to the political movements of illness and impairment/disability as being resonant of the black pride and gay pride movements in relocating a power base. The influence of these movements has enabled disabled people to take back control of their lives by reclaiming the labels of illness, madness and impairment and no longer allowing stigma to affect their choices in life. However a tension exists in that there are only a comparatively small number of disabled people who have been politicised in this way (Shakespeare, 2006).

The definition of disability is not fixed and absolute and has been defined in different ways throughout history depending on the social context (Oliver, 1989). Definitions of disability are developed within the powerful institutions of medicine and psychology, notably in relation to specific criteria. Hence, non-disabled 'experts' continue to dominate the discursive spaces around disability. This dominance prevents disabled people from becoming experts on their own lives and experiences. This is the case for the participants in this study.

The politicisation of disability has made few inroads into this institutional discrimination. There is evidence internationally of the continued acceptance of the individual model of disability in policy circles (Barnes & Mercer, 2003). This acceptance has led to the systematic exclusion of disabled people from paid work under industrial capitalism (Wilton & Schuer, 2006). Within a neoliberal environment the capacity to work, earn and consume, the central evaluation for citizenship strategies places disabled workers "*in a precarious position between an increasingly hostile welfare state and a labour market in which the 'able-body/mind' remains a largely unquestioned norm*" (Wilton & Schuer, p.186). It is suggested that neoliberal ideology actively marginalises the disability movement from the political process (Soldatic & Chapman, 2010).

Oliver (1990) argues that disabled people generally have not found stigma a useful concept because it focuses on an individualistic approach as opposed to understanding the effects of stigma resulting in a widespread and patterned exclusion from economic and social life. In New Zealand disabled people are more likely to be affected by stigma by having less dispensable income compared to the able-bodied population and being disproportionately located in low income areas of housing. 44% of disabled adults are in the labour force compared with 74% of



able-bodied people (Statistics New Zealand, 2008). Within this neoliberal context, the participants in this study have actively prioritised maintaining their employment and therefore the social status that this provides. The participants have retained their claim to citizenship within the neoliberal environment as income earners and consumers by negotiating their nursing roles thus maintaining their employment and avoiding the associated stigma of being a beneficiary.

Jo's story below, demonstrates her experience of being stigmatised and the resultant isolation, humiliation, and at times, powerlessness that she feels. Her response to being positioned as deviant is that she becomes a strategic actor who takes particular courses of action and engages in identity projects that ensure her illness remains invisible. These actions guarantee that she retains her social status through ensuring she is seen as a worthy professional by her colleagues. According to Nelson (2001), damage to a person's body, identity, and emotions is created if a person internalises other people's oppressive, dismissive or exploitive perceptions of them. They can then lose or fail to acquire a sense of themselves as a worthy person full of moral self-respect. Jo acts to avoid this damage and to maintain her most salient identity marker, that of being a professional nurse, thus securing a perception from others of being respectable.

**Jo's Story: I don't want to be 'that'. I don't want to be sick. I don't want people to know about that because it changes how they think.**

Jo has felt overwhelmed, both by her illness (hepatitis C), and by the tasks required of her to continue her nursing practice in order to stay economically secure. Jo's priority is being employed and she has had to manage negative responses from the occupational health team and from her manager and colleagues. Research emphasises that people who experience stigma are active managers of their own situation. They employ a number of strategies that help them to maintain a positive sense of self, despite belonging to a perceived low-status group (Miller & Major, 2000). Being an active manager is evident in Jo's story.

**Setting the scene**

Jo became unwell in her second year of registered nursing practice. After the onset of her illness, she took extended time off work. On her return to work her capacity fluctuated, resulting in her taking unpaid leave when she had taken all her leave allowances. Hence Jo's additional unpaid leave became noticeable to the organisation. She was '*hassled*' into seeing the occupational health team. It was in this part of the organisation that she first experienced powerlessness and humiliation when her personal medical records were accessed initially without her knowledge. Jo "*had to go and see that guy*" from occupational health. This left her feeling she was powerless not to. Jo explains that "*He just ordered them (my medical notes)*

*and read everything*”, without her consent for this to occur, and then they just told her about having read them. This situation left Jo vulnerable. Her private health information becomes part of a public workplace review and as a result she feels that “*it was really embarrassing*”. Dismissive comments were made about her illness at a subsequent meeting, Jo recollects that one member of the occupational health team said, “*you probably had this for ages anyway, looking at your past history* “. In contemporary health discourses that emphasise health as an enterprise of the self, the onus is on individuals to engage in behaviour that protects and bolster their immune systems by engaging in responsible habits and healthy lifestyle choices (Peterson & Lupton, 1996). Jo understood from the meeting that she was responsible for her health condition because of her past history as the manger implied that she had not acted in socially responsible and acceptable ways. As Harré (1983) states “*an individual’s problem is to retain a given social identity against various destructive influences*” (p. 275). The exclusionary and marginalising practices and the pattern of rejection by the ‘normals’ had begun (Goffman, 1963). In the meeting with occupational staff Jo encountered the institutional construction of stigma whereby she perceives herself as being disrespected and judged.

As a result of this meeting Jo was told that there were areas of nursing practice that she could not work in, including operating theatre, intensive care and the emergency department, due to the higher risks of percutaneous injury and the possibility of transmission of infection. The impact of these restrictions on Jo’s emotional or psychosocial wellbeing was disregarded by the organisation at this meeting. The logistics of her work boundaries and extended sick leave allocation were prioritised instead. The result of this encounter left Jo feeling “*that was horrible*” and she determined to prevent a repeat occurrence of this scenario happening. Nelson (2001) suggests that a person’s identity is damaged when powerful organisations or individuals, treat people as morally sub-normal or abnormal. Nelson terms this treatment ‘*deprivation of opportunity*’ (p.24). This response by the organisation attempts to prevent people from either occupying roles or imposing restrictions on activities that are identity-constituting (Nelson). Goffman (1963) states, that when people are viewed as unacceptable “*shame becomes a central possibility*” (p.18). It can also be reasonable argued that the mark of shame should not reside with the individual but with those who behave unjustly towards them (Sayce, 2000). Jo’s health was treated as problematic by occupational health as opposed to being framed positively and her being supported to ensure safety in her work environment. Jo was negatively framed as contaminated and contaminating. Jo also describes having no choices “*I had to go there (to occupational health) and if I didn’t go there I would probably lose my job*”. She acknowledges being motivated by her own socio-economic needs “*I had to work*”.

### **Disability, being silenced and silencing**

Jo felt pressured by one manager when she was on leave during a period of low staffing. Her condition was unknown to this manager. In this particularly upsetting incident, she was phoned at home by the manager as she explains;

*I remember I just got out of bed, got the phone and she's like 'Jo why are you off sick again?' and I was like 'well I've been to the doctor I've got you a sickness note' and she's like 'well this just isn't good enough Jo' and just started like going off at me on the phone I said 'look I've got you a sickness certificate. I can't tell you any more' I can't even (stand)...cause I couldn't stand properly without wobbling over. Anyway she didn't give a shit about that she was really angry and she just kept telling me how 'it's just not good enough' and she was literally shouting it at me. I remember putting the phone down and just being really, really upset, one, because I felt so sick and two, because she rang me at home to tell me that and I was like, 'what the fuck?'.*

Although Jo later reported this incident to the human resources (HR) team, she felt that she was in a powerless position again. This time by being silenced when HR responded by saying “*oh well, she (the managers) not here to defend herself, we can't help you, (and) she's actually a friend of mine*”. Jo's attempt to gain some control by reporting the unprofessional behaviour of her manager resulted in the reinforcement of her isolation and the ongoing lack of support from the organisation. The fact that she was taking extended sick leave alerted her manager to concerns about her health. Jo was unable to explain and fearful of the response to disclosure of her illness; “*I can't tell you any more*”. Jo has had to engage in a variety of strategies including silencing and strategically disclosing in order to adapt to what she perceives as a hostile work environment. Non-disclosure and actively concealing her health status is an integral part of Jo's story. She was introduced to the dominant narrative regarding her condition with the message that she received from the occupational health team,

*The guy at the occupational health said to me 'do not tell your colleagues about this. Don't tell them about anything...because people will treat you differently'. He told me about this other guy who had issues with his blood...he was open about it and it just turned his life to shit from the response of the other nurses.*

It is clear that in order to maintain an acceptable social identity the risk to the social and personal self must be managed. Silence and secrecy perpetuate stigmatization and shame (Valle, Volpitta, & Connor, 2004) and leave dominant discourses around deviancy unchallenged. Jo was subject to the silencing practises of the organisation.

The strong message that she is unacceptable is reinforced when Jo experiences events with some of her colleagues. She hears other nurses' viewpoints about patients who also have hepatitis C. *"Like the nurses say, 'oh they can just wait for things', you know, like they see them as a lower patient ... like they've only got themselves to blame, that idea"*. What Jo understands here is a punitive blaming of patients for causing their own condition/illness and they are punished by being made to 'wait'. The tendency toward 'other blaming' means that people often respond to threats (for example the threat of contamination) by resorting to existing representations to protect themselves and the groups they identify with from fragmentation and negative association (Joffe, 1999). These patients are seen as 'lower' in the hierarchy of meaningful subject positioning. Through her experience Jo considers that she has some knowledge about how to treat people with the same condition ; *"I kind of know how they need to be treated, with respect at least...and some people are scared, especially if they start bleeding from somewhere or something...and they need understanding, not punishment"*. Witnessing some of her colleague's responses to other people with hepatitis C reinforces Jo's decision to not disclose her condition. She knows that she too will be treated in this way. This knowing compromises her ability to advocate for her patients, as advocacy may make others suspicious of her own condition. Being stigmatised is an experience that occurs in encounters with others or is perceived through interpretations of certain situations (Butt, 2008). As a result Jo has learnt to manage the risk of social rejection by deliberately and strategically employing silence in order to maintain her identity within various settings. Her silence in response to her colleague's unethical behaviour (punishing patients by making them wait) can be interpreted as being complicit with the behaviour and mirroring the dominant narrative of socially privileging certain health conditions. Jo becomes compromised in her nursing role by her need to remain hidden. To address the discomfort of this compromise Jo volunteers to work with these patients herself when possible.

The different meanings invested in categories of identity indicate the notion of legitimacy and social acceptability. Illness is a socially accepted category; one has a disease and is not responsible for being a victim of forces beyond their individual control. This is the case if the cause is not considered to be associated with an unhealthy lifestyle (Grytten & Måseide, 2005). The association of hepatitis C with intravenous drug use, infectiousness and chronicity means that it is a highly stigmatised disease (Harris, 2009). This unethical perspective of viewing people as being responsible and 'deviant' means that people who have ignored the moral prescriptions of society and fallen ill as a result, are now seen to be paying the consequences. Certain illnesses position people within a public narrative that is socially and morally defined (Lupton, 1994). Although there are other causes of hepatitis C than intravenous drug use, Jo was

again framed problematically within the deviant discourse of hepatitis C. The stigma of hepatitis C stigma is said to be pervasive in healthcare settings (Butt, 2008). Jo is aware of this dominant negative discourse that she resists participating in by keeping her health status hidden and employing silence to safeguard her sense of self. Jo avoids being positioned as someone who has not cared for herself and who now has consequences related to this self neglect.

When Jo became unwell at work she disclosed to a manager because as she felt she had little choice but to explain her circumstances. She considers this manager as supportive as she *“just lets me take an annual leave day”* when she has treatment. Taking an annual leave day is strategic. Sick leave, especially if it is within the extra allocation given by occupational health, would become noticeable to both the human resources and the occupational health team within the organisation. Here Jo has acted to reclaim some power as she explains; *“I’m never going to let that happen to me again (having to go to occupational health). If I feel sick I’d rather take an annual leave day than have to explain.”* Jo ensures she has some control over her work situation by manoeuvring so she does not have to discuss her personal health details with the occupational health team again. Other than this scenario of disclosure, Jo states *“I never discuss it with anyone”*.

The ongoing effect of Jo’s condition is fatigue which at times means that she has to take extended time off to rest and recover from work. Jo is also strategic in how she organises her time off as she needs considerable time to recover from shift work. She ensures she has accumulated time owing which enables her to take annual leave when required. This allows her to bypass official channels such as occupational health and ensures that she does not draw unnecessary attention to herself. At times, however, Jo does not have annual leave entitlement and her fatigue is noticed by her colleagues she explains that late nights are the cause.

Jo was informed by the occupational health team about the contexts she is unable to work in and this issue becomes salient when short staffing in the organisation requires nurses to be redeployed to other contexts such as the emergency department. Jo then has to manage this tension on her own. She acknowledges that this situation does cause *“unnecessary stress”*. Jo *“doesn’t want to have to explain”* and manages by asking other staff to cover this deployment even when it is *‘her turn’*. Here Jo is being strategic and an active agent.

### **The public and private face of disability**

Part of the secrecy and silence of non-disclosure in Jo’s story involves maintaining privacy in relation to her own medical treatment. Jo attends specialist appointments at the same location as

her work. Maintaining privacy around her health becomes problematic as she may see work colleagues when attending for specialist appointments. While waiting for her consultation there is a danger that people may see her, become curious and possibly discover her condition. There is a constant threat of detection in relation to her inappropriate biography (Harré 1983). *“I hate the fact that if I have to have an outpatient’s appointment or have to go into hospital the chances are I’ll bang into someone that I know and they’re always like, ‘why are you here?’”* Jo is very affected in this scenario when seeing medical staff in the same working environment. Consequently not risking being seen by colleagues would enable Jo to feel more in control of her personal information and mean that she does not have to explain herself. Having this control would also have a direct impact on how she sees herself staying well and in not being reminded of her condition.

*It would be good if you could see doctors outside of work, you know, like EAP, like you can go away from work and see those people. If they had doctors away from work who weren’t involved with the hospital instead of people that you see in the hallway or in the cafe, you know? I don’t even know if I’m making a big deal out of it but I feel like if I want to stay well it’s easier to not think about shit. Because if I see them it reminds me. It’s weird. And the bottom line is I never feel good about it. I don’t feel good about having it in my blood. I don’t know why, too many things that people say.*

Jo uses the personal pronoun ‘I’, an embodied ‘I’. She uses the term ‘it’ as a means to disassociate the condition from her personal embodied identity. Having ‘it’ in her blood is associated with negative comments from colleagues which ultimately affects how she feels about herself. In this way Jo’s identity becomes contaminated by feeling devalued by others and she works to separate and protect herself from being negatively positioned by her illness.

Hence, for Jo, ensuring that her condition is not discovered is a means of control and maintaining her sense of health. Disclosing her illness can mean revealing potentially discrediting information about herself, with the risk of losing acceptance and autonomy, which would affect not only Jo’s social identity but also her personal identity (Harré 1983). Charmaz (2002) states that people *“learn strategies to manage their bodies and their lives particularly after they suffer the sting of diminished moral status”* (p. 308). Jo has a constant personal struggle to sustain both her public and a private self.

Jo’s treatment and experience by her employers reinforces the stigma of her condition and she distances herself from the primary marker of her identity as being someone with hepatitis C,

which incorporates the unacceptable. She refers to her illness as “*that*”. “*I don’t want to be ‘that’. I don’t want people to know about that, because it changes how they think (about me)*”. For Jo “*that*” is not “*me*”. Although Jo acknowledges her fatigue as ‘disabling’ she explains how she refers to her condition; “*I would just see it as something I have, that’s all*”. These discourses produce a mind/body split which enables Jo to enclose her illness so that it does not crowd out her identity entirely. This indicates that she does not give her illness the same importance that others would, if they were aware of it and she is disassociating herself from the deviant and stigmatised category and the identity producing practices of others (Goffman, 1963).

Jo’s story is about power – her story highlights the powerless positioning which in this case begins with the silencing of an individual within the wider organisation. Silencing may also contribute to Jo’s isolating experience of her illness. In contrast to Vicky’s story in chapter 4, there is no social support for Jo, no discussions of choices, of opportunities, of support, of rights. Rather there is an experience of Jo struggling to maintain her social position and using her own resources to prevent powerlessness from re-occurring in relation to being exposed by her employers and colleagues. Jo understands that she must also take responsibility for the stigma associated with her illness by not disclosing. Furthermore, she must endeavour to keep her condition hidden even when seeking treatment in her work environment.

Jo has an illness that has an assumption of personal and moral responsibility for the condition. Hepatitis C is associated with pollution, as being contaminated and contaminating, by being able to be transmitted from person to person through blood. This contaminating association is in conflict with dominant narratives of what makes a ‘good nurse’ as good nurses are connected to a high moral standing (Catlett & Lovan, 2011). Politics of difference serve the purpose of dividing society into opposing groups, that is, into ‘us’ and ‘them’. Where there is difference, there is the potential for institutionalised discrimination, the unfair or unequal treatment of individuals or groups inbuilt into the policies and practices of institutions and perpetuated at the personal, environmental and structural levels (Swain & French, 2008). Such discrimination is evident in Jo’s story.

Riro and Bella’s stories below also illustrate their experience of having stigmatised health conditions within a nursing context. As nursing professionals both participants facilitate the maintenance of ‘normal’ identities and resist being positioned as potential employment risks or as unsatisfactory employees. Both Bella and Riro can be understood to utilise Harré’s (1983) identity projects to maintain their social identities.

There are similarities in that both participants have initially been mindful of not disclosing their experience of mental illness, however at a later stage they choose to use their experiences to challenge and educate nursing colleagues. These participants' journeys are of self acceptance and advocacy. The presence of mental illness, a term which is medically based, and its social construction in terms of the negative conceptions of mental illness affect both Riro and Bella. Most psychiatric discourses embrace a traditional biological model that articulates mental illness as a medical disease involving neurological pathology located within the individual (Lewis, 2011). This perspective is more recently challenged by the biopsychosocial model which recognises that experiences are also influential and mediated by interactions between psychological and social factors (Penhale & Parker, 2008). Although there is a growing interest in social approaches to mental illness, there is no equivalent to the critical analysis outlined in the social model of disability and there is a complexity in the relationship between mental illness and disability (Wilson & Beresford, 2002). The experience of physical impairment compared to mental illness has both similarities and differences. Individuals, who fall into such categories, by self or expert definitions, may be linked by frustrating experiences of the mind and/or body, similar disabling structures, social responses and embodied acts of resistance in their wider social life (Parr & Butler, 1999).

Arguably, people experiencing mental illness or distress are also 'disabled' by the prejudice and discrimination that they encounter within society (Duggan & Cooper, 2002; Henderson, 2004). The recovery movement in mental health is similar to the social model of disability in that living a fulfilling life with mental health problems valued as part of that experience is dependent on civil rights and opportunities for inclusion. However many people who experience mental illness do not wish to be included in the disability model and do not want to take on the term 'disability' as one stigma is enough (Sayce, 2000). Where the models differ is that often recovery is still viewed as an individual recovery storyline.

**Riro's story: I try to look on the bright side of it all rather than the 'this is what I've got' because I don't believe that at all.**

Riro identifies her experience of panic attacks as a journey and a challenge, "*it (the experience of panic attacks) has impacted on my journey as a nurse, on my career and redirected me into other directions which I've taken up and enjoyed, you know, any job has up and down days*". Riro describes a story of the initial incidence, of what she now knows as a panic attack, which occurred after she had taken a homeopathic remedy. From that point the attacks "*started to get closer together*" and Riro's response was that she; "*stopped going to things, I stopped going out.*"



*All the things that we used to do I stopped doing*". This was a confusing and isolating time for her" *I didn't know what was happening and I didn't talk to anybody about it*". The fact that Riro said nothing to others is salient. She was already responding to dominant narratives that silence some experiences. Discussing fears and experiences of mental illness as opposed to physical illness is significantly different because of the associated stigma of mental illness. Riro experienced confusion in her nursing identity based on biomedical knowledge as she asked herself "*how could a nurse not know what this was?*"

Throughout Riro's dialogue there are clear cross roads in her journey where significant decisions are made. Her first crossroad is to determine what is happening to her and what she will do about it. At her lowest point during a prolonged panic attack which Riro described as a "*catalyst*", she clearly remembers thinking "*There are two options here, either I end and say goodbye, or I go and work on this*". Riro then chose to disclose her experience to her mother who she discovers had "*gone through a period of having a few panic attacks*" and who was able to direct Riro to self-help resources to assist her in the form of a book. This act of pursuing self-help resources aligns with research that indicates; "*Healthcare is very much an activity that takes place within people's private lives*" (Barnes & Prior, 2000, p.61). Support and advice from family and self-help treatments are initially used for health care needs prior to people seeking professional help. In this narrative it was always Riro's intention to avoid professional help.

### **Disability, knowledge and control**

In order for Riro to understand and control her condition, she began a period of "*work*", by reading and writing which took place over many years. The knowledge gained then gave Riro a sense of control which was crucial to her identifying as "*someone who lives with panic attacks*" and is not disabled. A disability for Riro would mean not being able to control her panic attacks. Her lack of control is related to her not having the "*confidence*" or "*skills*" to explain what she needs should her anxiety levels rise and not being able to implement the anxiety management techniques that she has learnt. These are skills that she has gained. She describes other people who have similar experiences but have not gained these skills as being in "*the disabling part of it*". Knowledge and control for Riro is about "*the difference between it (panic attacks) being disabling and not disabling*". A disability as described by Riro is not being able to do (things) and would be about being prevented from 'doing' and from having choices. A 'journey' metaphor is used to describe the experience of having her panic attacks and learning to understand and apply techniques that enable her to remain in control. This journey involves much work. Even though Riro acknowledges that she has made some choices that accommodate her anxiety levels, such as choosing her place of employment, she views these

choices as being good choices. As Riro states “*there are a lot of things I haven’t done that I could have done*” however she does not experience the choices she has made as being in response to barriers.

The journey is one in which Riro has been “*my own because of stigma*”. Being alone and isolated with her experience has affected her future decision to about support others who have similar experiences. The expectation of being judged by others at the time of her panic attacks had meant that Riro was initially fearful of others reactions to knowing she had panic attacks. She therefore chose to not disclose to anyone except her partner and her mother.

*I was fearful because ... I was thinking they’re all going to think I’m mad.  
And I was scared of that because I knew for me its panic attack, it’s not  
madness. It was a stigma that would be associated with it...they would see me  
as less than and I didn’t want that.*

The use of the term ‘*madness*’ suggests a perceived threat to individual agency and to the integrity and soundness of the self (Persson & Newman, 2006). Images of ‘*madness*’ within society make it clear that it is best avoided or denied and it becomes problematic to view oneself simultaneously as mad and as a valid person (Sayce, 2000). As a consequence of stigma, people who experience mental illness expect to be devalued (Markowitz, 1998). Scott and Wilson (2011), state “*mental illness crosses boundaries laden with concepts of rationality, autonomy, individuality and free will. People with mental illnesses are thus believed to threaten the security of the western self*” (p.46). Choices about whether to disclose a mental illness are made more complex by the relationship between clinical competence in nursing and mental illness. Furthermore there is little research available that explores the effects of mental illness on clinical practice (Kidd & Finlayson, 2010).

### Coping strategies: The avoidance of stigma

Riro was fearful that she would be labelled as mad, in itself a socially stigmatising label. She states “*how I managed it was by not telling people... I just kept it inside me. I hid it the whole time*”. As Loodin (2009) identifies, the relational order in her biography is changed. Now Riro participates in a field structured by a psychiatric ontology. She becomes aware of her condition within the framework of psychiatry and how this changes her social position and her biography. Riro also had a sense of letting others down, of “*the embarrassment of it all*” should her condition be known. As such she perceives that she is personally responsible for managing her illness. Dominant discourses of mental illness are framed in terms of individual pathology and making sense of experience outside of these dominant meanings can be difficult (Wilson & Beresford, 2002). Riro’s account aligns with Scott and Wilson’s (2011) work identifying people with mental illness as affected by a neoliberal responsibilisation which is the result of discourses which place the individual as self-disciplined and moral. As such it is Riro’s responsibility to manage her illness and maintain her recovery. The essence of neo-liberalism is self-governance through personal choice and personal autonomy which encourages individuals to take responsibility for making socially responsible choices. People are required to adopt self care in relation to their bodies, minds and conduct. The role of the state is seen as establishing the requisite conditions for the exercise of personal choice and responsibility (Henderson, 2005).

For Riro finding “*a way through it*”, without using medical intervention was important. Her choice was influenced by her nursing experience of not wanting “*to be drugged out of my head*” as she had perceived some people with mental illness experienced when she had nursed them. Riro explained that when labels are given people may “*Assume that they’re mad. Assume that they’re unemployable. Assume that they’re going off the deep end*”. According to modified labelling theory, stereotypes about the mentally ill become personally relevant for persons with mental illness. Riro is responding to discourses embedded with the societal understandings that are placed on those with mental illness. As such people protect themselves by not identifying with the stigmatised group (Bos, Kanner, Muris, Janssen & Mayer, 2009). By not positioning herself as being ‘*mentally ill*’ Riro perceives herself as sane and in control. By considering how people in her situation are positioned she strategically avoids that positioning. Riro states that “*...from day one I said to myself ‘I am not mentally ill’ and I thought ‘no, I’m not mentally ill, this is something that’s happening to me for whatever reason’*”.

There are public narratives (Somers, 1994), about being ‘*threateningly mad*’ or the ‘*worried well*’ that express the polarisation within categories of mental illness. This polarisation serves to

reinforce assumptions about a separate group of mad people who are a threat to society (Wilson & Beresford, 2002). Riro's intention is to avoid any category of 'illness'. Her construction and reshaping of her identity is linked to circulating discourses on mental illness, as well as, the social context in which her identity is expressed. Riro recognises that others may "*analyse*" and "*label*" her like an exhibit. She didn't want to be labelled "*that person*", which suggests an oppressive experience of being associated with that label. In a neoliberal environment attention is directed toward the private sector as the appropriate source of support for individuals experiencing mental distress with families identified as important sites of support for the distressed individual (Teghtsoonian, 2009). Riro's uncertainty about the extent of available support in the workplace forms part of her decision to not disclose her experience.

### **Concerns about stigma**

Later in her story, Riro notices a shift in her attitude and self confidence that impacts on her thinking about disclosure and stigma. "*There were barriers at first, but they were self imposed, a lot of the time, and me thinking that other people were going to impose them on me*". The barriers that she would be discriminated against she perceives are self imposed as opposed to 'actual' discrimination that she experienced. Riro has recognised the societal script of stigma and has managed to avoid the damage of being labelled as being mentally ill. With hindsight the salience of the fear she had experienced as being categorised and devalued is underestimated. Riro is now more confident about herself and more able to ask for assistance. "*If I get really stuck I just go to my colleagues and say hey look I'm really stuck here, I need a hand to move through this or whatever, so I do things like that*". She has come to use her experience to teach others about anxiety and panic attacks. This positive aspect has contributed to her nursing and her understanding of herself and others. "*I think it's a challenge, get up and get on with it. And when I say that I say it lightly but it hasn't always been easy but I will keep going that way rather than keep going backwards on it*". Riro's language echoes forward movement, that is, she gets up, she keeps going, she refuses to be stuck or to move backwards. This reshaping of Riro's view of her personal identity is congruent with Harré's (1983) framework of far-reaching personal identity projects that help to make the resolved state of identity more meaningful and rewarding for the individual.

Riro's story highlights her accomplishment through the difficult task of managing and understanding her panic attacks and the affect of this on her daily life and her nursing career. The task of integrating an acceptable social identity with a difficult and complex personal struggle is evident. This task involved negotiating a contested personal identity, that of someone perceived to be experiencing the effects of a mental illness. Riro actively sought knowledge in

order to assimilate this understanding into her response and hence into her identity, she now presents to the world an identity that incorporates the experience of her panic attacks. Riro's experience and acquired knowledge also affected her own understanding about how people with mental illness can be treated within the dominant medical narrative of mental illness. Her story is also an ongoing journey. Even now, she conducts self monitoring by noting her decisions and observing her triggers, being constantly mindful of controlling and managing her anxieties (Scott & Wilson, 2011). In this way, Riro has developed strategies focused on maintaining her well being and sense of self. Her story is about personal responsibility- the journey has been a personal one. Whilst she has predominantly been alone, she now shares her journey with others.

Riro has a condition that is associated with mental illness. There is a general perception that people with mental illness lack responsibility for their condition and when unwell need support at these times. Riro experiences her workplace as more supportive than Jo, and has been able to triumph over her disability through strategies that she has developed that enable her to maintain control. Her relative success in managing her illness means that she is able to provide advice and support to others, *"I can help because I know it, I understand it, you know, been there, got them, do them, get them and know how to manage it a lot better than what I used to be able to"*. Riro has been able to overcome and create a forum for advocating for others who experience anxiety and panic attacks. In this way Riro's journey is transformative and parallels the recovery paradigm of living well with her experience (Sayce, 2000). Her personal identity now incorporates a facet based on her experience of anxiety. This experience is now included as part of her social identity as she speaks to others of this experience. As Valle, Volpitta, and Connor (2004) identify *"a degree of self-acceptance is a crucial factor in making the decision to tell others"* (p.5). There is contrast here to Jo's story, in that Riro finds a voice to express her experience as opposed to the silencing of Jo's voice although both participants have initially used silence strategically as a protector.

Bella's story below follows a comparable trajectory to Riro's. Bella also has an experience of mental illness and has negotiated the associated stigma and navigated selective disclosure. In addition, Bella is reflective of how her experience has contributed positively to her nursing practice yet she is concerned that there are barriers to participation in nursing for people who have similar experiences as herself.

**Bella's Story: fit and proper doesn't include being mentally ill.**

Bella is a nurse who has a history of mental illness, *"I had post natal depression and I think I actually had post natal psychosis and I had an entire conversation for myself as a human being from that point on"*. Bella has also had a previous back injury *"lying down for eight months in a single bed in my sitting room was horrific"* as well as further periods of depression. Her story is a journey that progressed from a lack of acceptance toward self acceptance, critical reflection and increasing self-advocacy. Bella would present as a person who according to Harré (1983) *"appropriates and transforms culturally defined identity resources"* (p.256).

**Being 'outed'**

Bella acknowledges that, *"Post natal depression was not something that was recognised in those days (the 1970's)"*, so there was no 'diagnosis' for what she was experiencing at that time. For Bella her attempt to share her experience with her family met with the response to *'get on with it'*. She states, *"I didn't disclose because I didn't see any point in it"* and also *"... it was actually nobody else's fucking business"*. Bella considers her experience of depression is her business and a private matter. She considers herself a private person *"I don't tell anybody much at all, I could be in the secret service. That's my mother's way of being"*. This relates to Charmaz (2002) identifying that, *"Secrets and silences may reflect lifelong patterns"* (p.37).

Bella is adamant about her position in relation to disclosure as follows; *"My attitude towards being revealed, outted, known as someone with a mental health disorder, depression even, I didn't want to have that label. Because that's not who I was"*. She refutes the label of having a mental health disorder for the benefit of both her social and personal identity. Bella perceives that there is an alternative self with an unacceptable biography that she does not want to be mistaken for (Harré 1983). She also uses the language of queer identity, being *"outted"* as someone with a mental illness. Disclosure of mental illness is similar to the disclosure of homosexuality as it is often a partial and gradual process rather than a one-off or discrete event (Irvine, 2011). The narratives of disabled people, with non-visible impairments who use the language of 'coming out' parallels and borrows from the discourses of queer people even though the language can have different meanings. Coming out is not a one off decision but a series of risks in different situations (Sayce, 2000). Being outted is different to coming out, being outted means not having control over information and not having choices. The discourses Bella is drawing from are concerned with emerging identities and how experience can have a transformative effect on an individual's identity.

Perception persists that people with nonvisible impairments prefer to ‘pass’, passing means deliberate concealment (Samuels, 2003). This is a strategy that avoids stigma and keeps people safe from the unknown responses of others. ‘Covering’ requires minimizing the significance of impairments so that the extent of the impairment is not known and the person presents themselves as fitting the ‘norm’ of being ‘able’ (Myers, 2004). Leary (1999) posits that the ability and act of passing calls into question the way categories of identity cross, overlap, assemble, and deconstruct one another, testing the basis of identity politics, supporting the idea that identities are fluid, multiple, and conditional. Samuels (2003) supports the claim that disability and sexual ‘preference’ are both social labels and that nondisabled and heterosexuality, are always already presumed. This presumption in relation to disability, positions people as ‘able’ or ‘well’. There are also parallels between same- sex desire and impairment as deviance from the ‘norm’ (Myers, 2004; Shakespeare, 1999). Both disabled and queer people know their deviance from the norm to be beyond their control and both are aware of societal pressures to put others at ease with their difference. Disclosure is not only an individual act but it is political. There is an acknowledged coming out process for gay men and lesbian women that is similar in language use as the coming out process for disabled people. It is however significantly different in that coming out is primarily portrayed as the process of revealing one’s impairment *to* others, rather than as an act of self-acceptance (Samuels 2003). There is an assumption that disabled people do not have to go through a process of self-acceptance. This is not always the case as demonstrated by Bella and Riro’s stories where their journeys have included self acceptance in relation to their experience. Bella’s process of ‘coming out’ meant that she (re)defined disability for herself.

*So if I think about having had post natal depression as a disability, I don't suppose I see it as a disability now, with hindsight of thirty three years behind me, because it has expanded who I am in the world and it has never been a barrier in my practice.*

For Bella the experience of being ‘*expanded*’ is an important link to her humanity and how she sees herself as a nurse. The term ‘*disability*’ is incongruent with this expansiveness, as a disability is perceived to be a ‘*barrier*’. This example suggests this viewpoint has developed over time, ‘*with hindsight*’, as Bella was more aware of the stigmatising effect of her illness in the past. Temporal distancing in this way becomes a form of safety, disability is no longer part of her identity, and it belongs in the past.

### **Impairment and disclosure decisions**

Disclosure of a person's impairment is often perceived as being essential if a person's individual need for support and accommodation is to be met. However, evidence from the participants suggests the fear of exclusion from within the nursing profession acts as a barrier to disclosure. Decisions about disclosure are influenced by the perception of whether the information is positive or negative, acceptable or non-acceptable. Disclosure decisions are therefore based on dominant societal and cultural discourses of acceptability (Fishbein & Laird, 1979). Explanations for non-disclosure also include a reluctance to assume a disability identity and the assumption of unacceptability that accompanies this label. Negotiating disclosures includes complexities that are beyond those of whether a person tells or not and includes when and how the telling occurs (Zitzelsberger, 2008). The impact for people who experience impairments that position them in unacceptable social groupings means that they may also have to negotiate complex identity projects. Disclosure involves a multi-faceted positionality (Myers, 2004).

Joyce, McMillan and Hazelton (2009) suggest that when nurses discuss their mental health they have experienced their workplace as an unsupportive and negative environment. As such, nurses are amongst the most unsupportive and discriminatory professions when it comes to accepting colleagues with mental illness (Kidd, 2008; Kidd & Finlayson, 2010). Literature indicates that disclosure is frequently 'partial', firstly in that only select people may be told and secondly that the person may choose to limit the amount of information that is disclosed (Brunner, 2007). All of the participant's stories explore disclosure and how this is negotiated. Tessa regrets having no choice around disclosure, Vicky is open about her story, Mary and Lonnie selectively disclose to management and some colleagues. For Jo disclosure is a threatening event and she is highly selective of whom she discloses to as she protects the knowing of her condition. For Bella and Riro, the journey to disclosure has been a significant part of their story that is linked to self acceptance, and increasingly to political acts and advocacy. As Myers (2004) states "*coming out with illness can be liberating—a move from a “resistance identity” of defensiveness stemming from a devalued sense of self, to a project identity where one proactively constructs a new identity that redefines position in society*" (p.268).

Bella's process of public disclosure began when "*they asked me to talk to the student body about post natal depression and so I did ...and I cried my entire way through it. It was really quite a powerful thing to have done*". Bella was invited to talk as her experience was perceived as significant enough to share with others, so that they may learn and therefore the context



presented safety in disclosure. She is aware of reclaiming her experience and the power inherent in the action of telling. Bella recognises that this moment of ‘telling’ was congruent with her (re)thinking of her experience of illness as a positive experience that she could use to challenge stigmatisers. *“I had got to the point where I had wanted to champion mental health and mental illness and how people are in the world and how our lives determine who we are to a large degree”*. As she had become involved with supporting others who had mental illness experience, Bella moved this aspect of her life from being private to being public and in doing so moved toward acceptance of her experience of mental illness.

Her attitude about being ‘revealed’ was an attitude from her past, from ‘then’, about who Bella ‘was’. ‘Now’ her experience is different,

*I don’t talk about it (depression) at work particularly much (now), and that’s about I suppose that it’s common, it’s been normalised, it’s normalised for me. It’s not a drama if someone says to me look I’m feeling really bad today.*

Bella’s language suggests that previously her condition was ‘abnormal’ and there may have been a ‘drama’ associated with feeling ‘bad’. Part of the process of telling has led to the ‘normalising’ of her experience. Bella’s narrative demonstrates a restorying of her experience and an identity project that has led to an identity transformation by developing acceptance of a stigmatised identity (Harré, 1983). Previous to this Bella spent many years avoiding disclosure and like Riro, circumvented the need for disclosure.

### **Becoming an advocate and enabling others**

Bella reflects on who she was *“I was a strong girl, I was a strong person and even now I don’t see myself as disabled”*. Her image of herself continues to be congruent with her perception of herself prior to her experience of depression. Her sense of herself as being strong, able and socially desirable has an unproblematic continuity at this point in time. Her journey to self acceptance now enables her to support others who have similar experiences. Bella’s experience has had a profound effect on how she views the worlds of mental and physical illness and wellness and how she now uses this experience. *“...the impact on my (nursing) practice was that I had more humanity... having had those experiences to me (has) expanded me as a human being and as a nurse”*.

Bella’s story focuses on her own experience in terms of her illness and also on people she has been involved with in her work. Her experience has meant that her awareness of the impact of mental illness for nurses as a whole is significant. *“I would talk about various topics around mental illness and I would have people come to me”*. When this occurred Bella’s advice was

always “*I say to people ‘Now you be careful who it is that you speak to’*”. Being careful means being thoughtful of the need for protection from judgement and discrimination from others by only disclosing to trusted people. On an individual level, Bella is mindful to ensure people are protected from stigma and discrimination and that non-disclosure is also part of that protection. As an activist Bella sees there are also political discourses that concern her. She identifies the need to discuss the experience of mental illness amongst nurses in order to raise their awareness. This action is similar to Riro who works with other nurses who are having similar experiences to support them to gain knowledge and understanding of their anxiety and panic attacks.

### **Fit and proper: Power agencies and discrimination**

Nurses are governed by legislation. The Nurses Act (1977) referred to the terms ‘fit and proper’ reflected in professional nursing discourses that referred to the character and bearing of nurses at that time. The term ‘fit and proper’ was never clearly defined, but related to the concept of suitability to practice rather than competence to practice, which is the focus of today’s legislation the Health Practitioners Competence Assurance (HPCA) Act (2003). The Nursing Council of New Zealand (NCNZ) has defined competence as “*the combination of skills, knowledge, attitudes, values and abilities that underpin effective performance as a nurse*” (NCNZ, 2009). Mandatory reporting is required under the HPCA Act if a nurse is unable to perform the functions required for the scope of practice of nursing due to a mental or physical condition (NCNZ, n.d.). The Health Committee of the Nursing Council has a supportive role in recognising whether the nurse is unwell or not. To comply with the HPCA Act (2003) when nurses apply for their Annual Practicing Certificate they must identify if they have any physical or mental condition that affects their ability to complete their role. Whilst this may be the case it is acknowledged that the notion of competency and how it is measured is not unproblematic. Regardless of this established continuing competence framework (CCF) “*it is important to note that the indicators in the CCF cannot guarantee that a nurse is safe to practise on any given day*” (NCNZ, 2010, p.78).

Bella has become politically aware of the potential stigma and discrimination for nurses with mental illness. She considers the NCNZ, the regulatory body for nursing, has a responsibility to develop an awareness of attitudes towards nurses with a mental illness.

*I think it will require a shift in society’s opinion and Nursing Council’s opinion around mental illness for people to feel safe enough to disclose that they’ve had a mental illness or a mental health event or a mental disorder.*

As a nurse, Bella describes her wariness in disclosing her illness to NCNZ as they potentially reflect discriminatory attitudes of society as a whole. She explains,

*That 'fit and proper' stuff is a really, really interesting conversation, it's like who determines what's fit and proper? Show me a definition of fit and proper, there isn't one. But fit and proper is determined by who holds the power and the people in power are people chosen by government so it depends on their practice ethic and their own life experience. When I think about fit and proper I think about people who wear twin sets and pearls, walk straight, live the life, they're definitely heterosexual single women who pray alot... however they don't reflect society and society is broad and the people we deal with and work with are broad.*

The underlying governing discourse is that nurses need to be monitored to prevent harm occurring and that risks need to be guarded against as much as possible. Research supports the view that preferred meanings evident in discourses on nurses with mental illness suggest that having a psychiatric diagnosis is not conducive to safe or competent nursing practice (Joyce, McMillan & Hazelton, 2009). In this study, only one of the seven participants notified NCNZ of their impairment. The other participants did not consider their impairments affected their ability to complete their role. The common response from participants was that NCNZ did not 'need' to know.

Bella links her experience of stigma with the legitimising power of a structured organisation such as the NCNZ and the governing discourses in regard to who can be a nurse. Literature on stigma from both medical sociologists and social psychologist has emphasised the operation of stigma at an individual level and less attention has been given to the social structure (Green, 2009). Parker and Aggleton (2003) link their analysis of stigma to social groups in society whereby dominant groups decide who is devalued. They posit that "*in our view, stigma plays a key role in producing and reproducing relations of power and control*" (p.16). Although the notion of the fit and proper nurse is an outdated concept this does not mean it is without influence in nursing culture.

Bella gives an example of other discourses in nursing that she finds disturbing:

*At this conference that we had recently there was this conversation about... 'and who are we letting in to the (nursing) programmes these days?' So I said 'well what you are talking about is the path that is set for people, the good daughters in the world and ...if that's the **only** path then there's no place for me here ... because we don't fit'.*

She recognises the sub- text of her own experience. She does not see herself as a 'good daughter', nor does she 'fit'. Having an experience of mental illness for Bella is messy. It is not the path that is set and it is not an experience that 'good daughters' have. Bella directly challenges the circulation of oppressive power by questioning assumptions perpetuated by the dominant culture. Bella does not see herself or her experience reflected by a regulatory body of nursing who she perceives permits a narrow criterion for entry. She further recognises that there are potentially serious consequences for her and others who share an experience of mental illness. "Because when I come along to be nursed, those people don't suit me, those people look down their nose at me and those people make judgements about my life that they have no right to make". Bella rejects the socially dominant voice that makes negative judgements of her or others with mental illness. In asserting agency, those who refuse to be silent, who speak back at the dominant discourse, engage in acts that are "disproportionately powerful and disruptive" (Sedgwick, 1990, p. 78). Her concerns raise the issue that although the terminology of legislation in relation to fitness has changed, there is still a dominant discourse about suitability within nursing circles.

Bella's story is one of transition through both life and health events. She considers her positioning with regard to her family and her nursing role, and shows how the development of her thinking about what her illness is links to the sharing of her story with others. Bella is concerned that there is an abuse of power and a judgement that is made about people's lives, including her own, by NCNZ and the nursing profession.

### **Summary**

Both Riro and Bella describe a personal experience of illness that was alarming. They found it a frightening experience to negotiate the embodied affects, for Riro of anxiety, and for Bella of depression, as they viewed their social status altering as a result of stigma. Riro and Bella have negotiated their way through to a socially constructed sense of self, which had a biography they sought to avoid (Harré, 1983). They have both developed a sense of personal identity that incorporates their experiences of illness as positive and meaningful. Both participants' identity projects can be perceived as contested and dynamic as they negotiate multiple and often

conflicting identities. Their perception of themselves and their places in the social world has altered in response to their experience of illness. Both participants have created meaning out of their experiences and constructed their identity as being able and valid nurses who share their experiences with others in order to assist them. Riro and Bella have become politicized through their experience of impairment.

Jo, Riro and Bella have negotiated identity projects which involved the requisition of a social identity that secures a position among other people that is considered respectable. Stigmatised categories of health conditions can result in the person being silenced and can challenge a sense of self worth and self. Control of personal information becomes salient for people with invisible impairments, both in terms of keeping impairment hidden, strategically disclosing private information and avoiding stigma. The participants' stories in this chapter illustrate that they are active and strategic about disclosure of their impairments in their work environment and that disclosure and sense of self are intertwined. The stories in this chapter have illustrated a journey for some to acceptance and a raised consciousness in regards to the power agencies in nursing and their influence.

Identity formation influenced by (re)positioning, corporeality, temporality, stigma, in/visibility and power have pervaded the narratives of the participants in the preceding chapters. In chapter seven how these narratives contribute to progressing understanding of acquired impairment and disability in nursing is discussed.

## Chapter Seven: Telling stories of disability

*For clinicians to empathically recognise and clinically respond to disability in their patients, they may need to begin by recognising and responding to disability within themselves and within their own ranks, rather than continuing to uphold impossible ideals of health and normalcy.*  
(Garden, 2010.p.71).

*What is New Zealand doing about the health of our nursing workforce and, on a collegial level, what are we doing?* (Poole, 2011.p.1).

### Introduction

The initial aim and focus of the research was to address the lack of attention given to disabled nurses by exploring the experience of registered nurses who have impairments and who may have experienced disability during the course of their careers. What this research has shown is the experience of nurses who have impairments in disabling environments and the difficulties of negotiating identity formation within contexts which uphold an oppressive and discriminatory perspective of disability. The dominant cultural and social scripts apparent in the nursing context which relate to normalcy and health further problematise the way impairment and disability is conceptualised and spoken about. Despite this the nurses have negotiated a continuity of their professional identity and sustained participation in the nursing profession.

This final chapter provides an overview of the research aims and reviews the key findings of the study. The contribution of the methodology to research is briefly mentioned and the chapter concludes with recommendations for practice, suggestions for further research and outlines the limitations of the study.

### Review of the findings

The participants in this study demonstrated a range of subject positions with regard to their experience of acquired impairment. Tessa wanted things to be different, wanted people not to know about her MS. Vicky let people know about her accident so that she could be supported to rehabilitate. Mary and Lonnie accepted that their experiences of pain and fatigue were just how things were and they got on with it. Jo kept her illness hidden. Riro and Bella negotiated stigma and disclosure eventually gaining self-acceptance and provide support to other nurses with similar experiences.

In keeping with an abductive approach each story has been highlighted individually. In chapter four, positioning theory was used to explore how the participants were linguistically positioned in relation to a disabled identity. The negotiation, resistance and response to negative and positive positioning as disabled was explored in Tessa's story as her experience became over-determined by her impairment forcing her to (re) negotiate her social position in the workplace. Vicky did not identify as disabled, instead she viewed her head injury as an inconvenience to be overcome. Following her accident Vicky was eventually able to return to nursing because she was supported by state mechanisms and rehabilitative medical services. The narratives of participants reproduced in chapter five indicated that corporeality, space and time also dynamically affected identity formation suggesting that positioning theory was not just a linguistic, spoken phenomena. Mary and Lonnie's narratives demonstrated the nuanced and flexible aspects of identity formation as their identities shift and change by being positioned within certain narratives that are spatially and temporally located. In chapter six identity projects that involved the acquisition of a social identity that secures a position among other people that is considered respectable were explored. Jo, Riro and Bella's stories illustrated that they are active and strategic about disclosure of their impairments in their work environment discussing their identity projects in the face of highly stigmatised categories of health conditions that challenge their sense of self and self worth. The participants' stories evidence dominant social and cultural scripts about disability apparent in the context of nursing that overlap and influence each other in particular ways.

### **Disabled identity negotiations**

A key theme that emerged in the participants' stories is that their identities are not stable categories but are dynamically affected by the exchange of thoughts and ideas and the contexts within which the participants are situated. The stories demonstrate the different ways identities are picked up and enacted by exploring the influences of dominant discourses within the nursing context. There was a predominant view that disability was associated with a loss of control, a loss of ability and a severity of experience. What became salient in the stories was that overall the accounts suggested that the participants' sense of identity, in relation to how they think about and imagine themselves, demonstrated that they do not see themselves as disabled. Nurses interviewed did not claim an identity based on their impairment or how they are viewed because of their impairment.

Nevertheless the participants had a range of experiences of being positioned as disabled. The participants rejected a description of themselves as disabled and resisted and negotiated the formation of a disabled identity and the negative meanings attached to this. Predominantly

awareness of the self was based on a notion of what the participants feel themselves to be, not what others suggest they should be. The rejection of a disabled identity is the rejection of a discursive positioning as disabled. Participants gave accounts of themselves in comparison to what they imagine disability to be, these accounts discussed an increased severity or constraint associated with being disabled that they did not accept for themselves. Participants were drawing from social and cultural scripts of disability and distancing themselves from being part of a disabled and marginalised group.

### **Language and identity**

Participants rejected the language of disability along with identity characteristics that were perceived as negative. Tessa, Vicky and Mary used the term limitations to describe their impairments, Lonnie referred to deficits and Jo, Bella and Riro named their impairments using the medical diagnoses associated with their condition. All of these terms are medically influenced. Connotations of disability were seen as negative and severely limiting and therefore did not apply to them. There was evidence in this study that the word 'disability' was viewed as deficit-based, as associated with the idea that something is lacking or abnormal and as such this thinking is reflective of the biomedical model of disability. The biomedical model of disability has provided the prevailing framework for thinking about disabled people within a nursing context and as shown in this study it continues to be prominent in shaping the language and the thinking of people with and without impairments. The discourses that routinely border disability are largely forged by the dominant biomedical notions, which outline disability as a personal deficit, rather than as a form of social positioning. This biomedical narrative is shown in this study to be powerful in the way it shapes the participants identities and sense of self. It was also apparent that the terminology of disability was not only used but also understood by the participants in terms of the biomedical discourse of disability.

Disability is clearly understood as something a person has - there was no discussion of disability according to the social model perspective incorporating discrimination or of understanding rights to reasonable accommodation. As Watson (2002) identifies being disabled is not about celebrating difference or diversity. Identity is about defining disability in a person's own terms, using their own terms of reference. The participants suggested that they wanted to be incorporated within the conventional and ordinary working to counteract any form of difference that they perceived to be unbecoming. The participants interviewed for this research downplayed the importance of their impairments in order to be assimilated and to see themselves and been seen by others as normal through declining to allow disability to direct their lives. Each participant speaks to the difficulty of negotiating assumptions of deficit-and the



accompanying lowered expectations-that circulate within the discourses of disability. What is evidenced in this study is that the nurses have a wide range of impairments and experiences and that an understanding of disability becomes problematic when the definition becomes negative and narrow because then the definition is more likely to be rejected.

### **The influence of medical discourses**

Understanding impairment as biomedical is evidenced in this study and commensurate with the nursing context being dominated and influenced by biomedical discourses. Biomedical discourses of disability vary considerably from the way disability is experienced and theorised by disability rights activists and academics in disability studies. The participants used their nursing and medical knowledge to claim a diagnosis, explore treatments and understand their experiences. Tessa used her knowledge to get a referral in order to receive her diagnosis; Mary and Riro use their knowledge to source alternative treatments. The participants interpret themselves through a biomedical lens and valuing their knowledge about their bodies and the control this provides them. This perspective is not a social perspective which would include understanding socially imposed barriers and prompting a rights based point of view on employment. A social perspective would also provide a critique of the underlying power relations and discourses that advantage some groups over others. There is a tension in that biomedical discourses evident here are both empowering and disempowering simultaneously. Medical knowledge was drawn upon to give some participants a position of power and control however this same medical knowledge can also situate individuals who are perceived as belonging to marginalised groups within powerless positions. The biomedical perspective entraps the participants into an individual experience of impairment and is the platform for their active negotiations to avoid undesirable categories. Nursing's professional attention to restoring norms of health and ability can make it difficult for the participants to identify themselves and represent to others their own impairments and differences. The nursing culture evident in these stories demonstrates nurses as predominantly socialised into understanding pathologised, individualised biomedical discourses of disease and impairment. With this understanding evident disabled nurses are hidden within the nursing population.

### **Barriers and opportunities**

The purpose of the social model was to provide a structural analysis of disability and to challenge the biomedical model (Oliver, 1983). In doing so social barriers could be identified and addressed to enable participation of a marginalised group. The participants in this study met with physical and attitudinal barriers and negotiate these predominantly in isolation. They did not appear to have a critical consciousness with regard to encountering discrimination or have a concept of a right to accommodation in order to be able to work. When accommodation was

made as in Lonnie's story, by provision of equipment, this was unexpected and she was very grateful. Tessa struggled with colleagues who overcompensated for her and over determined her identity as disabled. What the participants experienced and accepted was an understanding that their impairments were theirs alone to manage. There is evidence in the stories of institutional structures that are oppressive and continue to produce social inequalities, such as in Jo's encounters with the practices of occupational health and human resources personnel. There does not appear to be a critical consciousness portrayed within the context of nursing of discrimination in relation to the social model of disability or of employer's willingness to provide equality of opportunity.

Despite individual differences in lived experiences all participants described the decision to disclose or not disclose their impairment as an ongoing tension of their professional lives. All participants have disclosed their status as a nurse with an impairment to different people in various work situations and with varying responses. The choice to disclose is significantly influenced by how the participant views their impairment, and how this is understood and spoken about, or not, by colleagues within the wider organisation. The location and context that the nurses work in is medically influenced to the extent that the environment assumes that people are non-disabled. It is because of this assumption that the participants are then manoeuvred into positions from which they have to make choices about disclosure. An environment that is inclusive of difference means that there is a critical consciousness in regards to such assumptions and that difference is evidenced as valued.

The idealised image of the professional nurse is one in which 'do-ability' is present and verified yearly by a declaration that states the nurse is able to perform the functions necessary to practicing nursing and is not unable to due to any physical or mental condition. The tension for the participants was to negotiate the overriding non-disabled environment and this resulted in most of the participants changing employment positions in order to find environments and attitudes in managers and colleagues that supported their continuation in the profession. Changing employment was a common theme in order to enable participants to continue working. Employment was changed or adapted because of the expected bodily performance required and also because of attitudes that did not enable participants to contribute.

One of the tensions that arise through the participants' acceptance of a disabling environment is that this environment marginalises not only the participants but also the disabled clients that they serve. The consequence of upholding medical discourses about disability is the continuation of harmful social practices that stigmatize and marginalize those labelled as

disabled. What occurs for these participants is that their knowledge about their experience of impairment is incorporated into their practice as they work alongside people with similar experiences of impairment on a one to one basis. These actions with clients are unspoken advocacies that all of the participants mentioned. Lonnie explained how she always ensures the right amount of pain relief for clients who have the same condition. Tessa described her ability to be nuanced in her assessment processes because she has learnt to be more empathetic in her practice. For some participants these actions are covert and not visible, for others, such as Riro and Bella, actions have become visible as they support colleagues who have similar experiences.

When asked what they would recommend nursing learns from their experience, the majority of participants suggested that an increased understanding of their individual impairment was required. Understanding the nature of their impairments, arthritis, anxiety, depression, they thought would lead to an increased acceptance for them from their colleagues and within nursing. The participants perceived that it is because others do not understand their experiences that they experience the struggles for acceptance that they do. Understanding can best be achieved through listening to people's stories. The action that each of these nurses took in participating in this research enables their experiences in nursing to become visible and their stories to be told. In this way these nurses' experiences are no longer hidden.

The participant's narrated stories of successful competent knowledgeable nurses who have developed skills and experience that contribute to the practice of the nursing profession in a variety of roles. Despite the tensions apparent between individual and societal responsibilities the participants continue to negotiate their nursing careers and continue successfully in the nursing profession. The diverse nature of the nursing role and the varied areas in which nursing knowledge is used has enabled participants to create pathways of nursing practice for themselves. There is an opportunity to have these stories told and the role that nurses with impairments take acknowledged in nursing. Within an ageing nursing demographic there will be an increase in nurses acquiring impairments and it is vital that nurses with impairments are actively recruited and retained. In order to do this employing nursing organisations must demonstrate a willingness to promote equality and diversity and challenge the non-disabled norms and assumptions present within their culture. There are also wider implications for addressing the experience of disabled nurses, setting a precedent within nursing can be an initiative that includes support for all health professionals with impairments and also how disabled people experience health care settings.

### **Combined methodology**

The methodology employed in this research is a combination of narrative methodology and Somers' (1994) four interrelated dimensions of narrativity comprising ontological, public, and conceptual and meta-narratives. An abductive strategy is also employed based on a constructivist view of social reality (Blaikie, 2000; 2007; 2010). The abductive research strategy produces accounts of social life by drawing on the concepts and meanings used by social actors and the activities in which they engage (Blaikie, 2007; Douglas, 1996). Abductive research explores the specificity of individual stories in terms of language, meaning and context as opposed to creating general themes that cut across transcripts (Blaikie, 2007; 2010). The narrative methodology and abductive approach provides a unique contribution to the academic discipline of nursing and disability studies. An innovative methodology such as this enables presentation of stories of participants that would not otherwise be told in the ways that they are. A wider viewpoint is employed that means the research is not only a description of a lived experience but brings together consideration of factors that influence the nursing context and hence the participants experiences.

### **Recommendations for practice**

The recommendations for practice cover both policy and practice areas. Different conceptual models such as the biomedical and social model of disability point to different understandings of where the responsibility for the 'problem' lies and different prescriptions for action. In New Zealand organisations are obliged to provide an inclusive environment as stated within The New Zealand Disability Strategy (2001). The strategy is in turn underpinned by the social model of disability and by The United Nations Convention on the Rights of Persons with Disabilities. Implementation of the Convention means that the Government and people of New Zealand must ensure to disabled people the full realisation of human rights and fundamental freedoms on an equal basis and without discrimination on the basis of impairment. Article 27 of the Convention deals specifically with work and employment and includes provision that disabled person are protected from discrimination and have rights to reasonable accommodation. Hence State funded employing organisations are bound by legislation to provide a non-disabling, inclusive environment and have obligations to ensure inclusive citizenship of disabled people by providing equal access to employment. In order to address this obligation policy needs to reflect a positive attitude to embracing diversity and difference through challenging a medicalized individualised model of disability. As nurses with impairments are predominantly hidden within the nursing workforce policies that evidence an understanding of the tensions evident in disclosure need to be implemented.

NCNZ operates in accordance with the Health Practitioner Competency Assurance Act 2003 and protects the public by ensuring health practitioners are fit to practise. The Nursing Council Health Committee supports nurses who are unwell to recover and return to work and encourages nurses to take responsibility for their own health. This perspective again echoes a model of individual responsibility as opposed to social responsibility. The NCNZ asks what New Zealand is doing about the health of the nursing workforce and what colleagues are doing (Poole, 2011). Whilst NCNZ acknowledge that employers have a role in ensuring nurses are well enough to work, as the regulatory body for nurses in New Zealand they can also support employers to understand their obligations from a rights based perspective. NCNZ is able to demonstrate a willingness to promote equality legislation that sets a standard and precedent for embracing the diversity of the nursing workforce by ensuring that NCNZ policy includes a social perspective of impairment and disability.

Professional development for registered nurses is required in order to examine the cultural scripts of disability and the tensions between the medically influenced context of nursing and the impact for disabled people. Professional development that focuses more on the role of advocacy within nursing and assessment of barriers as opposed to functional assessment is required.

Nursing education: Undergraduate nursing education has an opportunity to portray a range of nursing role models to undergraduate students which includes those of nurses with impairments. A key way to extend positive attitudes is to profile a range of different individuals who are contributing to the nursing profession. Positive recruitment strategies to encourage people with different abilities to enter nursing are also required. It is important that the distinction between individual and societal models of disability is made apparent and a critical consciousness lens is applied to an understanding of the experience of disability in undergraduate nursing. Working alongside Faculty who have expertise in disability to contribute to the integration of disability-related content and related issues in nursing curricula is important.

### **Limitations of the study**

Research limitations specific to this study include the limited number of research participants, the lack of transferability of results and the context specific nature of the findings. Qualitative research is concerned with ascertaining depth as opposed to breadth of understanding. This research focuses on a detailed account provided by a limited number of participants and as such may draw attention to potential issues for larger contextually similar populations but transferability of results is not possible. The interview schedule ultimately shaped the stories that are told in the end. There were specific areas that I did not address such as research questions that reflect the relationship between disability and discrimination.

### **Further research**

This research has illuminated several areas for further investigation which include:

- Providing a social policy analysis of the implementation of disability policy within employing organisations in nursing.
- Considering how human resource departments within organisations who employ nurses support those nurses with impairments.
- Further documenting the contribution that nurses with impairments make to the nursing profession.
- Exploring the attitudes within the NCNZ with regard to employer responsibility to support nurses who are assessed by the Health Committee.
- Investigating the practices within the Nursing Council Health Committee in relation to the assessment of nurses with impairment.
- Exploring attitudes of undergraduate nursing students to disabled people and the effects on undergraduate and registered nurses practice from exposure to nurses who have impairments acting as role models.

Of particular interest is that it should also be possible to develop nursing research with the active involvement of disabled people in setting the research agenda, agreeing to the methods of enquiry, writing the report and deciding upon the appropriate channels of representation and language for dissemination of research the findings.

## **Conclusion**

In this chapter I have drawn together some of the analysis and the wider cultural and societal discourses that have emerged from the participants stories. The discourse and the analysis of these narratives serve to support the recommendations for practice and for further research.

These research findings will now be disseminated within the academic, nursing and disability fields. The stories of the participants will hopefully create dialogue and reflection and challenge the nursing profession to examine and address the cultural scripts that influence nurses. My intention in conducting this research was to bring to light the experiences of nurses with impairments in the nursing workforce and my belief that nursing can move to positively embracing diversity is mirrored in the words of the following participant:

*There is opportunity within nursing, it's about creating it, and it's about just changing the way things have always been done so that it can be done differently (Mary).*

## **Appendices**

Appendix 1 – Email Advertisement

Appendix 2 – Participant Information Sheet

Appendix 3 – Participant Consent Form

Appendix 4 – Interview Guide

Appendix 5 – Ethics Approval



## **Appendix 1 – Email Advertisement**

Kia Ora

Please pass this on to your networks.

A qualitative research study exploring the experiences of registered nurses who are disabled.  
Call for participants.

Are you a registered nurse who has a physical, sensory, neurological, psychiatric, or any other impairment; which is permanent, intermittent or temporary and has developed during your nursing career?

You are invited to participate in a qualitative research study exploring the experiences of registered nurses who have become disabled.

I am a registered nurse wanting to interview you about how your impairment impacts upon your nursing practice particularly in relation to any barriers or opportunities that you experience. This research is in fulfilment of a Masters of Philosophy at Massey University and has been approved by the Central Regional Ethics Committee.

If you would like to discuss this study in confidence and receive an information sheet please contact me:

Juliana Korzon  
Postgraduate Lecturer  
Whitireia Community Polytechnic  
Porirua 50910

Phone: 04 237 3100 ext 3223

Email: [juliana.korzon@whitireia.ac.nz](mailto:juliana.korzon@whitireia.ac.nz)

## Appendix 2 – Participant Information Sheet



**Massey University**  
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES  
Te Kura Pūkenga Tangata

Private Box 756  
Wellington 6140  
New Zealand  
T 64 4 801 5799  
F 64 4 801 2692  
www.massey.ac.nz

### Participant information sheet.

Dear

Fit to practice: What are the work experiences of registered nurses who become disabled?

Thank you for contacting me following my recent advertisement.

My name is Juliana Korzon and I am a 44 year old registered nurse currently employed in nursing education. I am of English and Polish descent and have been in New Zealand since 1988. I am doing a Master of Philosophy at Massey University, which involves a qualitative interview based project researching the work experiences of registered nurses who have become disabled.

The purpose of the research is to explore the experiences of registered nurses who have a work or non work related acquired impairment and to determine the barriers and facilitators that these nurses experience in their nursing practice. It is hoped that sharing the knowledge, experience and wisdom of participants will inform the wider nursing community and raise awareness of these barriers and facilitators. Between 5 and 10 registered nurses will be interviewed during the course of the next few months.

I am particularly keen to talk with nurses who are currently employed or have recently exited the health service whether experiencing issues in their employment or not in regards to disability. All stories will be partially transcribed and analysed using both thematic and narrative approaches. Tapes and interview transcripts will be kept in a secure environment only accessible to me.

The interview would ideally be conducted face to face at a time and place that is convenient to you. In recognition of your time and any costs incurred as a result of participating in this study a small koha of a \$20.00 voucher of your choice will be provided at the time of the interview.

The interview consists of me asking you about your story. The interview would be audio-tape recorded and would probably last about 60 to 90 minutes. I will ask questions to guide you (see the enclosed interview schedule) but you do not have to answer all questions and can stop the interview at any time. You will also have the opportunity to talk about topics related to this research that you consider to be important but which may not be covered in the interview schedule. I would like the opportunity to contact you after the interview for you to review the transcript and clarify points. At this time there will be an opportunity for you to debrief with me in relation to the interview and to add any additional information should you wish to do so.

You will be able to choose a pseudonym (a fictitious name), and this is the name which will appear in any documents relating to the research. Only you and I will know the name chosen for you. No material that can personally identify you will be used in this research. The results from your interview will initially be incorporated into my Masters thesis for Massey University. I also hope the work will result in publication of scholarly articles. Information may also be presented at workshops and conferences.

Fit to practice: What are the work experiences of registered nurses who become disabled?



I will discuss with you whether you wish to be kept informed about this sharing of information. There will be a period of time between the interview and publication of information.

**What are your rights if you are interested in participating?**

Your participation is voluntary. You are under no obligation to accept this invitation. If you decide to participate, you have the right:

- to decline to participate;
- to refuse to answer any particular questions;
- to withdraw from the study at any time without having to give a reason;
- to have a support person present at your interview;
- to terminate the interview at any time or request that the audio-tape be turned off for particular parts of the discussion
- to ask questions about the study at any time during participation;
- to provide information on the understanding that your name or any identifying details will not be used unless you give permission to the researcher;
- to be given access to a summary of the findings of the study when it is concluded.

As I am a registered health professional, should you disclose unsafe practice during the course of the interview then I am obliged to report this to the Nursing Council. If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact your professional organisation.

On the day of the interview I will bring the consent form with me so that I can check in person that you still wish to proceed. Please be reassured that if you change your mind and wish to pull out from the research at any time that this is perfectly acceptable and your right to do so.

The intent of this research is not therapeutic or counselling in nature. At the time of the interview I will check with you about support that is available to you in case participating in the research is any way distressing for you. Any concerns or complaints you may have about the research can be addressed to me or my supervisor who may be contacted on the address below.

If you are willing for me to contact you to arrange an interview please email or telephone me directly or complete the enclosed consent form and return it to me in the stamped addressed envelope provided. Upon receiving this I will contact you to arrange a date and time for the interview.

Thank you again for your expression of interest in this study. Please feel free to contact the researcher if you have any questions about this study

<b>Researcher:</b> Juliana Korzon Whitireia Community Polytechnic (04) 237 3100 ext 3223 E-Mail: <a href="mailto:Juliana.korzon@whitireia.ac.nz">Juliana.korzon@whitireia.ac.nz</a>	<b>Supervisor:</b> Dr Suzanne Phibbs Massey University Palmerston North (06) 356 9099 ext 2319 E-Mail: <a href="mailto:S.R.Phibbs@massey.ac.nz">S.R.Phibbs@massey.ac.nz</a>
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This study has been approved by the Central Regional Ethics Committee.

Fit to practice: What are the work experiences of registered nurses who become disabled?

## Appendix 3 – Participant Consent Form



**Massey University**  
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES  
Te Kura Pūkenga Tangata

Private Box 756  
Wellington 6140  
New Zealand  
T 64 4 801 5799  
F 64 4 801 2692  
www.massey.ac.nz

*Fit to practice: What are the work experiences of registered nurses who have become disabled?*

### PARTICIPANT CONSENT FORM

I have read and I understand the information sheet dated.....for volunteers taking part in the study designed to explore the work experiences of registered nurses who have become disabled. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time.

I have had time to consider whether to take part in the study.

I consent to my interview being audio taped. Yes ☐

No ☐

I wish/do not wish to have my recordings returned to me.

I.....(full name) hereby consent to take part in this study.

Signature:

Date:

Researcher: Juliana Korzon

Project role: Researcher

Project explained by: Juliana Korzon

Contact Phone Number: 027 289 8840

Signature:

Date:



## Appendix 4 – Interview Guide



**Massey University**  
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES  
Te Kura Pūkenga Tangata

Private Box 756  
Wellington 6140  
New Zealand  
T 64 4 801 5799  
F 64 4 801 2692  
www.massey.ac.nz

### ***Fit to practice: What are the experiences of registered nurses who have become disabled?***

#### Interview Guide

This is a guide only. I am also interested in any areas of this subject that you think are significant for you but which are not necessarily asked of you here.

- Tell me a little about yourself, how you came to be a nurse, and how you acquired your impairment?
- If you self identify as disabled, how did you come to an understanding of yourself as a disabled person? What factors or events facilitated this understanding?
- How has your impairment/condition influenced your work as a registered nurse? What kind of work did you do before you acquired your disability? What kind of work do you do now? How has it influenced your choice of work, hours that you work, the way that you practice (for example)
- Are you able to provide an example of a time when in practice your impairment has been an advantage and things have worked out well? (Having insight to what it is like to be ill, empathy, can offer special skills, advice from an old hand)
- Are you able to provide an example of a time when you have disclosed your impairment and people have been supportive?
- What barriers or opportunities do you see as a disabled nurse? (systemic barriers, attitudes, inflexible rosters/assignments, bullying, having to hide the



Te Kōwhiri  
Ki Pōwhiri

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disability, layout of workplace, nursing council review processes, insight, role modelling, alternative practices.)

- If you hide your impairment at work, what strategies do you employ in order to achieve this?
- What, if any, facilitators to practice do you see as a disabled nurse?  
(supportive people, equipment, workplace policy, etc)
- How has having this impairment/condition influenced the way you feel about nursing?
- What do you think could be done to facilitate practice for nurses with your impairment/condition who are disabled?
- Is there other information regarding these issues for you that you would like to discuss?

## Appendix 5 – Ethics Approval



Central Regional Ethics Committee  
Ministry of Health  
Level 2, 1-3 The Terrace  
PO Box 5013  
Wellington  
Phone: (04) 496 2400  
Fax: (04) 496 2191  
Email: [central\\_ethicscommittees@moh.govt.nz](mailto:central_ethicscommittees@moh.govt.nz)

8 November 2010

Ms Juliana Korzon  
Whitireia Community Polytechnic,  
Wineera Drive,  
Private Bag 50910,  
Porirua 5240

Dear Juliana Korzon

Re: Ethics ref: **CEN/10/07/025** (please quote in all correspondence)  
Study title: **Fit to Practice: Exploring the Work Experience of Registered Nurses who have become disabled during the Course of their Careers**

This study was given ethical approval by the Central Regional Ethics Committee on 1 September 2010. A list of members of the Committee is attached.

### Approved Documents

- Participant Information sheet, Version 6, 3 August 2010
- Interview Guide, Version 6, 3 August 2010
- Advertisement, Version 6, 3 August 2010

This approval is valid until 01/08/2011 provided that Annual Progress Reports are submitted (see below).

### Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

### Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by 1 September 2011. The Annual Report Form that should be used is available at

### Central Regional Ethics Committee 2010

Mrs Helen Walker (Chair)	Community representative
Dr Angela Ballantyne	Ethicist
Mr Paul Barnett	Lawyer
Ms Susan Corbett	Community representative
Mrs Gael Donoghue	Pharmacist / pharmacologist
Dr Diana Martin	Health researcher
Dr Lynne Pere	Health practitioner
Mr Karl Pulotu-Endemann	Consumer representative
Dr Dean Quinn	Health researcher
Ms Hillary Stace	Consumer representative
Assoc Prof Mark Weatherall	Biostatistician



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