

**PARENTHOOD AND MENTAL ILLNESS:
A SOCIOLOGICAL JOURNEY THROUGH
SILENCED
EXPERIENCES OF ILLNESS**



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DECLARATION OF ORIGINALITY

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution, and to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent for this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying subject to provisions of the Copyright Act 1968.

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ABSTRACT

This thesis examines the experiences of parents (both mothers and fathers) with mental illness. Following a tradition of sociology, this thesis is guided by the concepts of 'generosity' from Frank and 'stigma' from Goffman and 'risk' from Lupton. The thesis has gathered data from three sources. In-depth interviews with parents with mental illness are explored to gain an insight into their lived experiences of parenthood and mental illness. The national and state mental health policies on mental illness are analysed in order to assess their applicability to support services for parents with mental illness. The submissions to the Senate Select Committee Inquiry on Mental Health (2006) are also analysed to gain further information about the experiences of parents with mental illness based on a small number of submissions relating to their perspectives.

Analysis of the data collected and assimilated in this thesis provides a clear picture of the troubled terrain faced by parents with mental illness. The narratives from the interviews reveal stories of long-term mental health issues for parents with mental illness whose parenting role is largely unsupported. Analysis of this data provides a greater understanding of how parents negotiate their parenting role within the context of socially prescribed notions, limited agency, and limited capacity due to a lack of support services for parents with mental illness. Analysis of mental health policies highlights the disparity between policy and practice. Whilst national mental health policies are now in place, parenthood continues to be overlooked through the continued medicalisation of people with mental illness, and policies that operate under an individualist and economic rationalist discourse.

The motivation for this research was to elicit increased understanding and insight into how parental mental illness affects experiences of parenthood. This thesis focuses upon lived experience, social processes, and social policies relating to parents with mental illness. The specific contribution of this research to the sociology of mental health is that it documents for the first time parenthood as lived by parents with mental illness. Finally, it offers theories as to how the gaps in policies and services can be filled to support the 'silent' parents whose parenthood is so often unacknowledged the lack of attention paid to their mental illness.

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Part I

Setting the Scene

CHAPTER 1: OVERVIEW OF THESIS

1.1 Introduction

Parenthood is a common life experience that offers people, including people with mental illness, an opportunity, among other things, to develop and enhance their capacity to deal with life challenges. Parenting, therefore, can be a normalising life experience for people with mental illness. Parents with mental illness may, at times, have been defined by their diagnosis, either as a patient or as a disabled person. This can result in a loss of opportunity to take on certain roles based on the social perception of their capacity to function (Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedl, 2001). Dominant ideologies and discourses, along with societal definitions of ‘a good parent’, prevail. It follows that to be a good enough parent one must be able to feel secure in one’s parenthood, and one’s relation to one’s child. So secure that while one is careful in what one does in relation to one’s child, one is not over-anxious about it and does not feel guilty about not being a good enough parent (Bettelheim, 1987, p. 13). Such expectations can lead to parents with mental illness being considered ‘the other’ or a ‘not good enough parent’ (Smith, 2004).

This thesis is an extension of my professional work in the health field, during which I observed that parents with mental illness do not conform to the stereotype of deviant parents who set out to fail the societal notion of ‘good enough parent’ but are parents who at times need additional support to maintain their parental status. The aim of this thesis is to begin to shape understandings about how parents with mental illness experience parenthood. Therefore, questions as what is a ‘good enough parent’, who defines what is ‘good enough’, and who is able to reach this position are explored. Parents with mental illness juggle their identities, that of parent and patient, and, “like the rest of us, live quietly and unremarkably in the daily struggle of living. There is no great moment to the illness or the life” (Kleinman, 1988, p. 87). Parents with mental illness have similar aspirations of joy in the wonder of their children and hope for their future, and experience similar struggles in the enormity of life as a parent.

This thesis differs in its approach to previous research studies. Most of what has been learnt in Australia about parents with mental illness is medically driven, addressing

the experiences of mothers in institutional settings, who, in the main, have severe mental illness and multiple life stressors. This research incorporates the experiences of mothers and fathers with mental illness living in non-institutional settings. Non-institutionalised parents are largely invisible and under-researched (Bassett, Lampe, & Lloyd, 1999; Maybery & Reupert, 2006; Thomas & Kalucy, 2003; Thomas & Kalucy, 2002). The study also deals with issues related to medicalisation of mental illness, which prevails in Australian society.

Data were gathered from a variety of sources. These included in-depth interviews with parents with mental illness, national mental health policy, submissions to the Senate Select Committee Inquiry on Mental Health¹ (2006), and, lastly, field notes. The data from the in-depth interviews provides an overview of the lived experiences of parents with mental illness in a field where the number of parents with mental illness, while anecdotally reported to be growing, can only be estimated (Farrell, Handley, Hanke, Hazelton, & Josephs, 1999). In Australia, research suggests, “One in five . . . adults will experience a mental illness at some time in their life” (ABS, 2006), while other research has found that between 29% and 35% of mental health services’ clients are female parents of dependent children under the age of 18 (Cowling, 1999; Thomas & Kalucy, 2003). That this is an estimate only, is due to the failure of mental health services in Australia to collect routine information from patients about whether or not they are parents (Seeman & Gopfert, 2004). This situation is true not only for Australia but also for many other countries, so globally, the issues faced by parents with mental illness remain a ‘silent’ or hidden problem (Fudge & Mason, 2004). Various surveys and audits in the United States and in Britain suggest that at least 20% and in some cases up to 50% of adults known to mental health services have children (Falkov, 1998).

This thesis will discuss the embedded paradox experienced by parents who balance the need for services and the desire to seek appropriate help weighed against the wish to remain invisible and thereby limit the stigmatised positioning and isolation of families who live with mental illness. The analysis of the narratives brings forth

¹ The Senate Select Committee on Mental Health was appointed on 8 March 2005, to inquire into and report on the provision of mental health services in Australia by 6 October, 2005. During the writing of this thesis, a further Senate Select Committee on Mental Health was established on 28 March, 2007, to improve mental health services in Australia, with reference to the National Action Plan on Mental Health. The Committee is due to report by 30 June, 2008.

stories of mental illness from parents who live quietly in the community, some with severe mental illness and some who have times when they feel better or worse.

1.2 Thesis outline

The structure of the thesis reflects the interplay of theoretical concepts, and lived realities which are of equal importance. This thesis is divided into four sections, which address theory and method; policy and government; the experiences of the parents who were interviewed; and lastly, a discussion and concluding comments. Part I contextualises the study and considers the theoretical discourses that have shaped the thesis. This chapter, Chapter 1, has introduced the thesis and its contents. Chapter 2 sets the scene by introducing the theories, discourses, and ideologies that shape our understandings not only of parenthood but also of mental health and mental illness. Chapter 3 introduces the research process and describes the methodology, collection and analysis of the data from the interviews.

Part II places the reality of the lived experiences of parents with mental illness within the framework of the policy aspirations for mental health services in Australia. Chapter 4 provides an analysis of national and state mental health policies in Australia. This chapter covers the development of mental health policy from a solely state level concern to an issue of federal importance. It contemplates mental health policy development and how principles embedded within the service provision are determined by these policies. The chapter also points out the lack of attention given to supportive community interventions and highlights opportunities where this could have been facilitated. In Chapter 5 data, from the Senate Select Committee Inquiry on Mental Health (2006) is analysed. In excess of 500 submissions were received by the Senate Inquiry during the twelve month process. A review and analysis of the submissions that were identified relating to parenting and mental illness are discussed.

Part III builds on the foundations provided in Part I, and integrates the data gathered from all the various sources. Chapters 6, 7, 8, and 9 are derived from the interview data. Chapter 6 provides an overview of the parents who participated in the research. Analysis of the narratives provides an understanding of how they lived their lives each day. Chapter 7 discusses the concept of ‘a good enough parent’ and what this entails. Chapter 8 provides an insight into parents’ experiences of the mental

health system and the negotiation of agency. It also discusses the parents' experiences of support services. Chapter 9 discusses parenthood, and mental illness. To provide a balanced picture of the experiences of parenthood, both mothers and fathers were incorporated into the study. Differences in experiences were often based on their role as a working parent and this is discussed during this chapter.

Part IV brings together the earlier three sections and synthesises the data analysis from the various sources to provide a comprehensive picture of the lived experiences of parents with mental illness in Australia. Chapter 10 critically discusses the potential impact, brought to light in this study, of the developments in theoretical knowledge in the field of parental mental illness. This final chapter offers some concluding thoughts about directions for the future.

CHAPTER 2: PARENTHOOD AND MENTAL ILLNESS: KEY CONCEPTUAL AND THEORETICAL ISSUES

2.1 Introduction

This chapter sets the scene for what lies ahead in this thesis. It provides an introduction to the theories, discourses, and ideologies that shape our understandings not only of parenthood but also of mental health and mental illness. Each concept is defined and discussed in relation to the social construction of parenthood. These linked concepts introduce the concepts of how understandings of the nature of parenthood and mental health are underpinned by policy and sustained through societal understandings and discourses. This chapter introduces the concepts of stigma and risk which are evident in parenthood and mental health debates. These discussions will continue throughout this thesis in order to challenge commonly held notions and beliefs about the capacity of people with mental illness to be parents.

2.2 Parenthood - biological, social, and ideological constructs

Before identifying the different lenses through which mental health (and illness) is viewed, it is important to consider how the dominant trajectories affect concepts of parenthood. The traditional societal discourse of parenthood is related to the biological connection between parent and child. This discourse ensures that parents operate within an unspoken, yet clear understanding of what 'parenting' or 'parenthood' is and what it should be like. Within such paradigms there are clear expectations related to the roles and responsibilities of a parent defined by genes and associated with biological ties. The term 'parent' serves as a label that summarises a bundle of expectations, rights, and obligations. Parent implies the biological relationship of an adult to a child, or defines expectations related to the care and protection that an adult provides for a child (Smith, 1999). As Kendziora and O'Leary (1998, p. 176) suggest, parenting includes "playing, disciplining, teaching, caring for physical needs, and establishing a pleasant emotional environment." The status of 'parent', as shown above, continues to be defined as biological, based on procreation and symbolised by blood. It is difficult to find a different and broader definition of parenthood. It can also be argued that because

they appear to stem from biology, the dominant discourses and notions of parenthood are also associated with the medical discourse just as childbirth has largely become a medically observed procedure.

The role of parent appears to be taken-for-granted. It is expected that parents will live in a traditional family unit of mother and father, and even if one parent were to become sick, the entrenched belief appears to be that another parent will be at home and able to care for children. This could explain why there is limited data about the complex needs of families who live through mental illness (and the possible risks for their children) (Bassett et al., 1999; Bond & Burns, 1998; Nicholson & Biebel, 2002). Existing research into the concerns of parents with mental illness is limited. The research that is available falls into three main areas: outcomes for children of parents with a mental illness (Maybery, Ling, Szakacs, & Reupert, 2005); effects of mental illness on mothers (Peden, Reyens, Hall, & Grant, 2004); and deficits in parenting due to mental illness, which, in turn, focuses attention on child protection issues (Cousins, 2004). The word 'parenthood' is used throughout this thesis in an attempt to broaden the understanding of experiences of parents with mental illness to include that of fathers (Evenson, Rhodes, Feigenbaum, & Solly, 2007).

Social models of parenthood could offer analysis of this area from the standpoint of parents with mental illness; however, research representing the views of parents is largely inaccessible. This thesis provides stories that will attempt to offer alternatives to traditional and ideologically held beliefs about parents with mental illness. Therefore, whilst traditional notions of parenthood may be challenged, many characteristics and qualities deemed by society to be attached to contemporary notions of parenthood remain. As Hill (1996, p. 65) suggests, "The role of parent can be seen as a composite of many different role enactments (by one and the same person) involving elements of commitment, hierarchy, and the capacity to accurately interpret the child's action."

The mental illness of a family member is a challenge to the functioning of a family more than most other issues (Muhlbauer, 2002; Yun-Hee Jeon, 2004). This is because mental illness is often protracted or even lifelong (Royal College of Psychiatrists, 2002). The identification of parents with mental illness is complex because most mental health systems in Australia make no attempt to identify or record the

parental status of a patient (Seeman & Gopfert, 2004). Clearly, the culture within the mental health system is one that ignores the importance of parenthood for clients with mental health problems.

Failure to recognise the importance of parenthood has the potential to negatively affect the mental health of many parents (Thomas & Kalucy, 2003). This is primarily due to concerns about possible systemic responses to any disclosure, such as the removal of their children from their care (Finke, 2004). The most updated estimate of the population of parents living with mental illness in Australia was provided by Maybery, Reupert, Patrick, Goodyear and Crase in 2005. They estimated that between 21.73 per cent and 23.52 per cent of children in Australia (Victoria) were living in households where at least one parent had a mental illness.

The lack of recognition and value given to supporting positive parenthood can be seen to result in the continued failure of mental health systems to provide support services (Nicholson & Biebel, 2002). In fact, only recently has evidence emerged to indicate any awareness of the presence of children within the lives of parents with mental illness (Bassett et al., 1999; Maybery & Reupert, 2006). Organisational responses to parents with mental illness only come into effect when parents are identified as a risk to their children, or where child abuse has been identified or is reported for investigation (Nicholson, Sweeney, & Geller, 1998b).

A growing body of literature on the effects of parental mental illness on children is also contributing to the risk discourse which links parental mental illness with adverse outcomes for children (Camden-Pratt, 2006; Leverton, 2003; McConnell Gladstone, Boydell & McKeever, 2006; Stern, Smith, & Sung Joon, 1999). The research also suggests that children of parents with mental illness (COPMI) may be at increased risk of problems at school, drug use, and poor social relationships, and may become isolated from their peers and other community members (Maybery et al., 2005).

Other adverse outcomes include the development of psychiatric disorders, cognitive, emotional, social and behavioural difficulties (Cogan, Riddell, & Mayes, 2005; Foster, O'Brien & McAllister 2005). Sands (1995) found that when parents are depressed, they become less emotionally involved with and less invested in their children. As a result,

the communication between parent and child diminishes, thereby creating risk to the child. More recently, Maybery and Reupert (2006, p. 57) argue:

Parental mental health places children at significant greater risk of having lower social, psychological and physical health compared with children from families not affected by parental mental illness with long term effects including social and occupational dysfunction. . . . Such children are often referred to as ‘hidden children’ because mental health professionals are often unaware that their patients are parents.

Whilst there is much discussion about parents with mental illness, even the sympathetic research from Camden-Pratt (2006, p. 217) identifies mothers with mental illness as responsible for bad relationships with their children:

It’s time to write new stories about mad mothers and their daughters. Having read this far, means you have immersed yourself in the pain. If you have, or have had, a mother who is mentally ill, then I know you will have been immersed in your own pain and hope that you have taken care of yourself.

Camden-Pratt (2006) is not alone in her view that parenthood and mental illness are not compatible. Other examples of such research findings can be seen in Mowbray, Oyserman and Ross (1995) and Oyserman, Mowbray, Meares, and Firminger (2000). This research upholds societal notions of mental illness, which result in the stigmatised positioning of parents. Not only that but much of the literature is specific to women who are biological mothers with a diagnosed mental illness requiring ongoing or regular psychiatric treatment. As a result the experiences of fathers appear to be ignored.

2.3 Mental health - sociology, definitions, and models

This study draws from the discipline of medical sociology. The sociological gaze is an important tool to use when rejecting taken-for-granted assumptions about health and illness. This approach is concerned with how symptoms become interpreted as illness, and how this influences personal experiences. Sociological inquiry in this study has allowed attention to be given to the personal illness narratives, which has brought understanding and insight to the experiences of parents with mental illness. The sociology of mental health and illness dates back to the 1930s (Faris & Dunham, 1939; Weinberg, 1967) and is based on research of the experiences of people with psychiatric disorders and the social conditions that shaped their lives (Mechanic, 1990). A short overview of this field, which has been hugely influenced by the

discourse of medicalisation and the dominance of psychiatric ideologies, is provided in order to place the study within a conceptual orientation.

Cook and Wright (1995) argue that increased interest in mental health services has assisted in changing notions of mental health services. Research has attempted to challenge the dominant medicalised paradigms about mental health away from individualistic 'blame' ridden approaches of the early models and brought attention to the social aspects of mental health issues within the general population, such as psychological distress, stress, coping, environmental and economic conditions. This discursive shift has also coincided with the development of mental health services from a predominantly institutionalised base to current models of community-based mental health care realised through the process of deinstitutionalisation (Brown, 1985; Grob, 1994). Thornicroft and Rose (2005, p. 23) provide a succinct overview of this process:

The recent history of mental health services can be seen in terms of three periods: the rise of the asylum; the decline of the asylum; and balancing community and hospital care. While the first two periods have been well documented, the third is still underway in most high income countries. In this stage, the main goal is to develop a balance of care offering treatment and care.

The process of deinstitutionalising mental health services in Australia has also contributed to the increase in the number of parents with mental illness. As Devlin and O'Brien (1999, p. 20) suggest:

Deinstitutionalisation and improvements in pharmacotherapy and psychotherapy have resulted in greater numbers of people with mental illnesses being able to lead more productive lives within the community. Normalization of lifestyle has resulted in greater potential for child-bearing, culminating in a corresponding growth in the number of children affected by parental mental illness.

In spite of advances in the sociology of mental health, sociologists have continued to reject defining labels for mental health issues (for example, Schumacher, Corrigan, & Dejong, 2003). This means that as medical sociologists, boundaries related to labels are rejected and work occurs within a field which rejects one true sociological perspective but, instead, allows for many. Sociologists are aware that certain assumptions are made about the causes of and responsibilities for mental illness in society. Concern is not focused on the medical interface, rather it centres on collective behaviour and the attribution of concerns about mental health that focus on explanations rooted in the general organisation of society. As Mechanic (1997, p. 92) suggests, "Health, as people view it, is truly a social concept". Inherent in any approach to research are a number of limitations. One that is notable in this field is

that the application of sociological inquiry into mental illness clashes with dominant medicalised models that explain mental illness and presume that there is always an identifiable cause.

2.4 Discourses - medicalisation and the sick role

The concepts discussed so far in this chapter are all reliant on the dominant Western view that illness is biological or accidental as opposed to notions from other cultures.

As Lester and Tritter (2005, p. 650) suggest:

The most frequently used framework for understanding mental health within the medical profession for the last 200 years has been a biomedical model of mental illness. This approach is based on a deficit model that presumes health problems primarily arise from within the 'patient'. The impairment of mental illness is consequently framed as a personal tragedy and 'cure' is equated with the removal of the impairment.

Prevailing medicalised notions of illness in Western societies identify and classify different types of illness as diseases. Under this discourse all illnesses are reliant on a doctor's interpretation of presenting symptoms which is viewed as objective. This reliance fails to address other issues related to the medical system, such as access to treatment or services. Our understandings of health and illness are therefore generated by dominant medicalised models, which work from a deficit orientation only treating people once they are sick. Indeed, many parents with mental illness will opt not to access mental health services due to their fear of systemic responses to assessment of their condition which often reduce them to a position of an agent with limited choices. The following section discusses the dominant medicalised discourse which prevails in the mental health system and mental health policies in Australia.

2.4.1 Medicalisation

The central theme when studying mental health and illness is that it cannot be understood simply by looking at biological phenomena and medical knowledge. The dominant medicalised discourse inherent in the concept of mental health forces actors to regulate their behaviour to fit the ideological notions assigned to their label as sick or as a 'patient'. Kleinman (1988, p. 16) suggests:

Clinicians sleuth for pathognomonic signs or the observable, tell-tale clues of symptomology, under this discourse the patient-professional interaction is organised as an interrogation. What is important is not what a patient thinks, but what they say.

The medicalised discourse is reliant on pathologising illness through a lens where symptoms that commonly co-occur are grouped together into syndromes; these are the diagnostic units of psychiatry. This conceptualisation is referred to as the medical model of mental illness (Frances, First, & Pincus, 2005). As Australian mental health policies are reliant on such medicalised notions of mental health and mental illness, the medical model, in the form of the DSM-IVR, is the dominant method of diagnosis in Australia for public and private mental health services. This thesis accessed parents receiving support from community organisations which were less reliant on the need for these rigid diagnostic criteria.

The dominant method of diagnosis is the DSM-IVR² which describes the symptoms³ and syndromes⁴ of mental illness and is considered to be the official diagnostic system in mental health. Under the DSM-IVR, mental illness is understood as a clinical behavioural or psychological syndrome that occurs in an individual associated with personal distress, disability, violation of social norms, increased risk of suffering or loss of freedom. Mental illness is deemed, under this discourse, to be diagnosable and considered a manifestation of a behavioural, psychological, or biological dysfunction. Each of the characteristics of a mental illness subjectively identified by the clinician will guide assessment. The clinician, therefore, works in a deficit-driven model seeking to prove behaviour is normal or abnormal, yet assessing the presentation of the patient through an abnormal gaze. The clinician's perceptions of normal and abnormal also need to be critiqued as the basis of their assumptions will shape their diagnosis.

A major limitation of the DSM-IVR is that it describes only symptoms and syndromes that have already been identified and includes the need to fit objective criteria specified in the DSM-IVR to a label that represents a mental health diagnosis. Under review, changes have been made to the DSM-IVR and it is argued that these changes

² First published in 1952 by the American Psychiatric Association. The current edition was published in 2000.

³ A symptom is defined as a feature, which is noticed (reported) by a patient/client, as opposed to features which are noticed by medical professionals, and categorised as signs of mental illness.

⁴ A syndrome is an association of several clinical features - signs or symptoms, which often occur together. The presence of one will alert the medical professional to the presence of others.

reflect advances in medical research and differing societal and cultural expectations. For instance, ‘homosexuality’ was removed as a diagnosable disorder to reflect changes in societal acceptance of normal and abnormal sexual preference. Again, there are issues related to the power of groups in their ability to challenge the exclusions and inclusions of criteria in the DSM-IVR. Furthermore, there are politically-driven discourses involved in inclusion/exclusion criteria as once included there is a need to provide services to support people labelled with a particular diagnosis.

The DSM-IVR involves five axes as shown in Table 1 below:

	Table 1: DSM-IVR Diagnostic Criteria	
Axis 1	Describes clinical symptoms	
Axis 2	Refers to long-standing conditions	Mental retardation, personality disorders
Axis 3	Refers to medical conditions	
Axis 4	Identifies psychosocial and environmental problems	Assesses background and functioning
Axis 5	Global Assessment of Functioning Scale (GAF)	Assesses functioning on a scale of 0-100 - with 100 being no functioning problems

The DSM-IVR requires judgments by a clinician to make an assessment on each of the five scales. Supporters of the DSM-IVR argue that this forces the clinician to consider a broad view of the patient’s life and social circumstances, thereby supporting its use. However, the fact that one particular aspect of an illness can be attributable at the level of diagnosis is problematic, as many people have multiple issues, which affect their functioning and ability to clearly explain their symptoms. Labelling one particular aspect as their diagnosis limits their ability to resolve other issues, which may severely affect their lives, for example, backgrounds of abuse, domestic violence, or alcohol and other drug issues. This was clearly seen in this study in the lives of parents with mental illness who juggled many daily problems. Following diagnosis the focus of services the parents received was determined by their illness as opposed to their struggles with daily living. Such an approach oversimplifies the lives of parents with mental illness and misrepresents their actual lived experiences.

Not every parent who took part in this study had come under the gaze of a DSM-IVR-driven diagnosis as they had not accessed mental health services or medical assistance. A diagnosis is dependent on assessment through statutory mental health services or a doctor who may make an assessment and then prescribe medication.

The DSM-IVR is also associated with acknowledged risks; a particular diagnostic criterion may then label and stigmatise the patient. Particularly relevant to this study is the risk discourse that places parents with mental illness under increased surveillance. A DSM-IVR diagnosis often leads clinicians to make interpretations of a patient's behaviour based on the medical diagnosis. Problems with assessment, for example, missing information, and misinformation, can lead to a misconception of the patient. Proper use of the DSM-IVR is reliant on the power held by the person making the diagnosis and their interaction with the patient. Issues of diagnosis can flow into treatment, which focuses on symptoms, and can potentially ignore other issues or concerns that may be affecting the patient's behaviour. Examples of diagnoses are presented in the narratives of the parents who participated in this study and are discussed more fully in Chapter 8.

2.4.2 *The sick role*

Associated with the medicalisation are expectations related to treatment. In relation to health (particularly mental health), Parsons (1951) describes this as conforming to the expectations of the 'sick role'. This expectation differentiates between the role of a sick person and the role of a healthy person. The sick role defines the motivation of the patient and is comprised of four components: (1) exemption from normal social responsibilities; (2) the privilege of not being held responsible for being sick; (3) the desire to get better; and (4) the obligation to find proper help and follow that advice. According to Parsons, illness is a social state and the recognition of illness is a legitimate social role, but conforming to this role is not a straightforward process as it involves a number of stages. Shilling (2002) argues that Parson's theories remain important in suggesting how society deals with illness. Each stage in health and illness is therefore saturated in social and cultural meanings and values. Parslow & Jorm (2000) supports these ideas in his belief that few aspects of health and illness can be considered 'objective', due to the attachment of beliefs and meanings inherent in interactions.

There are many limitations to notions of the 'sick role', particularly Parsons' oversight of the role of the medical professionals (or even institutions) in influencing the person in the sick role. Fahy & Smith (1998) argue that the 'sick role' does not address the place of culture, gender, sexuality, race, class, or chronic illness, such as chronic mental illness. The 'sick role' also fails according to Filc (2006) to be critical

of inequalities in the role of doctors as gatekeepers and agents of social control. There are also issues associated with the sick role in this thesis, in that parents did not have to have a medical diagnosis to participate. Application of Parsons' theory is also problematic in this thesis in relation to the long-term nature of mental illness, and whilst recovery and rehabilitation remains the goal of treatment, this is not always possible. The alternative is to find strategies that will accommodate the needs of long-term mentally ill people as opposed to requiring them to recover (Foster et al., 2005).

2.5 Stigma - labelling, deviance and risk

The power of the medical profession and the operation and legitimacy obtained through the medicalised discourse are particularly problematic for parents with mental illness. Notions that have been presented in this section rely on assessment, as it is not only integral to stigma, labelling, otherness and the sick role but also of major importance in commencing this process. One consequence of labelling according to Martin, Pescosolido, and Tuch (2000) is that clinicians who attach the label of mental illness to a person are less willing to interact with that person, therefore, creating problems in accurate assessment. Research links this type of rejection to the assessment of stigmatising responses such as labelling a person as 'dangerous' (for example, Link, Cullen, Frank, & Wozniak, 1987; Pescosolido, Monahan, Link, Stueve & Kikuzawa, 1999; Phelan, Bromet, & Link, 1998; Rogers & Pilgrim, 2001). Stigma often affects both the perceived and actual ability of individual to fulfill necessary cultural and economic roles in society.

2.5.1 Stigma

The concept of stigma can clearly be seen throughout this thesis. This is no surprise as "the stigmatization that surrounds mental illness is increasingly recognized as a central issue, if *not* the central issue, for the entire mental health field" (Hinshaw, 2005, p. 714). Stigma is evident in all of the narratives of the parents who took part in this research study, woven through their stories and daily lives. In the social science literature, the first reference to the association between stigma and health dates back to the 1880s; but it was not until the 1950s that Goffman began his work in psychiatric hospitals and developed a social theory of the connection between stigma and disease. As Karp (1996, p. 47) suggests:

Social scientists have studied how groups as diverse as divorced persons, those missing limbs, dwarfs, and the elderly manage information and adopt behavioural strategies that afford maximum protection of already tainted identities. Despite all the public education that has recently surrounded depression, sufferers know that they have a condition that is conventionally defined as mental illness. Thus, they fall into a category with a range of 'others' who have what Goffman terms 'blemishes of individual character'.

Goffman (1963) took the notion of stigma from medicalised discourses whereby patients are treated and labelled as part of their treatment. Within narratives gathered for this study, parents suggested that stigma led not only to being labelled as mentally ill but also to reducing their capacity to parent under societal notions of a 'good enough parent' (Boursnell, 2007).

Stigma, according to Goffman (1963), is the identification created by a social group for a person (or group of people) based on some physical, behavioral, or social trait perceived to deviate from group norms. Goffman's concern was with people who had certain characteristics and were accordingly discredited in the eyes of others. This describes the position of parents with mental illness. Goffman focuses on the relationship between an individual whose stigma is defined and those with the power to define the stigma. Goffman does not focus on the individual's unique characteristics.

According to Goffman (1963) there are three types of stigmatised individuals. Firstly, discredited stigma, where stigma takes a visible form, and people have to manage the tension caused by the visible blemish or deformity during social contacts with people who do not have a similar stigma or are deemed normal. Some people with visible stigma may choose, if possible, to physically remove these identifying characteristics. The second type of stigma is that of a stigma of character. In this situation, the stigma is not known or immediately perceivable by others as it is not visible. As a result, people with a discreditable stigma must manage their condition so that others do not discover their stigma (Phelan, Bromet & Link, 1998). Concealment of their stigma can be a continuing problem. This type of stigma is especially applicable to parents with mental illness as many live with a discreditable stigma, struggling to maintain a front of normality so people do not recognise their mental illness. The third type of stigma is that associated with collective social groups (Schulze & Angermeyer, 2003) and is less relevant to this thesis.

Many stigmatised individuals are forced to adopt long-term strategies to manage their stigma (Johnstone, 2001). This response has also been noted by Goffman (1963) who has suggested that people might choose to withdraw from society due to their stigmatised positions when they are not only identified as abnormal but also as deviant. It is the associations which link people with negative stereotypes and engender prejudiced attitudes that Goffman (1963) proposes results in acts of discriminatory behaviour towards them. Whilst such a leap does require significant oversimplification of categories, it also reflects dominant values and power structures in the society. For instance, it can be related to practices in mental health services to manage child protection and risk of harm procedures which must be enacted by mental health professionals when parents with mental illness access services. These issues are discussed in more detail in Chapter 3.

Herein lies one of the main criticisms of Goffman's theory. He understates the disparity in social attitudes towards the normal deviant and those who are significantly impaired. Obviously, there have been changes in the concept of stigma since Goffman first introduced his theory. This theory is applicable to discussions in this thesis as it highlights the trajectories faced by parents with mental illness if they deviate from ideal notions about parenthood (Gray, Robinson, & Seddon, 2007). Ultimately, some parents may fall victim to stigmatisation and become labelled as bad. This is not universal and parents' strategies may allow them to a varying degree to escape this marginalised position. Link and Phelan (2001, p. 367), for example, suggest that the way that individuals with mental illness interact and with whom may add important dimensions to the different approaches to understanding stigma. This argument is supported by Rusch, Angermeyer and Corrigan (2005) who argue that stigmatisation relates to access to social, economic, and political power and that this allows individuals to be identified as different and to have negative reactions and sanctions applied as a result.

Notwithstanding the issues with Goffman's theoretical standpoint and his oversimplification of categories, such as gender, and types of illness, the study of stigma remains pertinent to this thesis. The stigma of being a mentally ill parent not only provides a major barrier to recovery for people with mental illness but was also found by Ackerson (2003) to limit their capacity for parenthood. This socially constructed identification as a deviant parent lays the groundwork for subsequent

disqualification from parenthood by other normal parents - a group in which the stigmatised parent was originally included.

Stigma can potentially create internal impacts for parents with mental illness. For instance, they may expect to be rejected as 'a good enough parent' and subsequently stigmatised. They may internalise the stigma by modifying the expectations they had of parenthood prior to their own diagnosis (Bassett et al., 1999; Corrigan & Watson, 2002a). This aligns with other research, which has found that people with mental illness often accept negative societal discourses of mental illness and anticipate rejection from others (Nicholson et al., 1998a). In turn, this leads to anxious and withdrawn behavior, which compounds their rejection, resulting in further isolation, shame, and anxiety, again increasing rejection and leading them to inhabit the margins of society (Link & Phelan, 2001).

2.5.2 Labelling

Notions of stigma can often lead to lifelong problems that can be conceptualised as spoiled identity. This is directly related to the acceptance of an altered identity associated with labelling theory. The term 'label' is derived from the social labelling theory developed by Becker (1963) to explain how social groups can enact deviance by constructing rules that challenge societal discourses. Labelling theory suggests that deviance is caused by the person being negatively labelled as deviant, processing this label, and then acting in a way that maintains the deviant label. This stems from symbolic interactionist theory, which also suggests that the dominant group (for example, doctors or medical professionals) hold the power to decide who and what should be labelled deviant. They also decide what is acceptable, and, thereby, label people as 'other' than acceptable and, in this case, a 'not good enough parent' due to mental illness.

Various people have built on Becker's original theoretical standpoints. For example, Hinshaw (2005) suggests that for parents with mental illness the reality is firstly the diagnosis and then the gaze of services and assessment of parenting capacity. Busch and Redlich (2007) also note that a consequence of assessment is loss of parental status due to being labelled incapable because of symptoms of mental illness. These theories are useful in this thesis as the label of mental illness impacts on the social and cultural meanings of symptoms which play a role in the long-term custodial

status of parents with mental illness. As mental illness is also a highly politicised issue (Corrigan, Watson, Gracie, Slopen, Rasinski & Hall, 2005), the profile of mental illness is likely to increase and the attributes and behaviours linked to diagnosis further deemed socially desirable or undesirable. Rosenhan (1973) maintains any behaviour is then interpreted under an altered gaze where symptoms are associated with mental illness in accordance with expectations of that parent and the reactions or responses are likely to be affected. In his groundbreaking study, Rosenhan found that the social construction of disability hinges on assigning labels of deviance and thus constructing an 'other' even when there is no mental illness present.

Other older studies remain relevant, such as that of Scheff (1966), whose concern was that residual or episodic deviance is often named as a 'mental illness' (see also Pfohl, 1994). Consequently, people labelled as mentally ill tend to adopt the behaviours of the stereotypical mental patient as seen in the media (Heather, 2006). Scheff argued for the normalisation of mental illness suggesting that everybody expresses symptoms of mental illness at some point in their life; but the labels are more likely to be attached to those without power (Heather, 2006). Scheff's arguments have long been challenged on both theoretical and empirical grounds. For instance, Holstein (1993) notes that Scheff's views focus only on the deviant and not the moral entrepreneurs who attach labels. Gove (1980) also suggests that Scheff should not dismiss the influence of psychopathological variables on mental illness. There is some relevance in Scheff's position to this research study, as parents who participated and had economic funds to afford private mental health care were less likely to be labelled or to feel the effects that this might bring in terms of surveillance and assessment of parental capacity.

Whilst labelling theory has relevance in explaining how people may come to perceive themselves due to illness, Link et al., (1999) have highlighted problematic aspects of the assignment of labels by suggesting that labels are negative in that they depict deficits. This is especially true as labels may also become the defining characteristic of the parent as the label becomes the focus of any intervention (Devlin & O'Brien, 1999). Labelling, according to McDermott (1993), is also believed to be detrimental to self-esteem and self-concept.

Another important deficit of labelling theory is that it reduces the categorisation of people to the use of binaries. Being labelled as 'abnormal', through the introduction

of an 'other', constructs subjectivity and, for example, places parents with mental illness as oppositional to other parents. Accordingly, to speak of a parent with mental illness is to acknowledge the existence of parents who do not have mental illness. The result is the dichotomy of 'them' and 'us'; parents with mental illness, the undesirable half of a binary pair who are 'othered', often devalued, subjected to deviant status, and believed to be incapable to maintaining their status as a parent. As these subjectivities are constructed by mental health policies that embrace these binaries; Sands, Koppelman and Solomon (2004) suggest that parents with mental illness are frequently denied the right to participate in the lives of their children, especially if they are removed from their care. In spite of the growing awareness of mental illness in the community and new optimism about reduced stigmatisation of parents with mental illness, parents continue to be blamed for their illness. Labelling also subjugates children to the position of a child of a parent with mental illness (e.g., COPMI) (Manderson & McCune, 2004).

The continued use of labels ensures that, once discovered, parents with mental illness are inscribed with value-laden texts. If parents are able to maintain a hidden status, they continue to be viewed as acceptable, whereas once their mental illness becomes known they ultimately become 'other' and this 'other', as a parent with mental illness, often becomes related to deviance (Singleton, 2007). As a result, parents with mental illness cease to be perceived as real people or 'good enough parents' (Foster et al., 2005). Rather, their deficits are diagnosed and labelled, and they are treated accordingly.

2.5.3 *Deviance*

Under the discourses that dominate our understandings of parenthood, those who fail to fulfill ideal notions and who become labelled as 'not good enough' also feel the constraints imposed on their parenthood capacity through punitive measures of societal surveillance and are likely to be viewed as deviant (Sands, Koppelman & Solomon, 2004). It is generally accepted that deviance is socially constructed and determined by the judgments of others often in a more powerful position. Once labelled 'deviant', a person is predestined to the consequences of the label (Rusch et al., 2005). In this study, examples of public labelling will be discussed by some parents, for example those were investigated by DoCS, and through the court process were labelled as bad parents. This concurs with Knutsson (1977, p. 10), who argues

that “the deviant's social situation is changed, as is their self-image because the negative label has a destructive impact on the individual who has conceived his or her self as ‘deviant’; s/he has become what people said and will act accordingly to the new status as ‘deviant’.”

Deviance as a concept is multi-dimensional; for example, Sacco (1992), proposes three ways in which negative labels alter a person's behaviour. Firstly, when a label is assigned, patterns of social interaction are changed. Secondly, labelling people as ‘deviant’ pushes them into the periphery or margins and into the company of others in a similar subculture. Lastly, the individual who has acquired the classification of ‘deviant’ gradually conforms to societal expectations, resulting in a “self-fulfilling prophecy” (Sacco, 1992, p. 84). These notions of parents with mental illness as deviant are rejected in this thesis; however, the medical discourse and many medical professions adopt such views when working with mentally ill people. Analysis of the narratives of the parents who participated in this study illuminates this issue in detail.

2.5.4 Foucault

The parents could then be described by Foucault (1967) as ‘conscripted’ into pathological identities which are a feature of dominant medicalised discourses. Such positioning according to Foucault involves the use of power to impose meanings on people, and in turn, to apply sanctions, such as exclusion or for mental health clients even enforced treatments. Foucault suggests that these processes are played out in interactions; for example, between family members and, importantly, between family members and the professionals and within wider regimes of power and knowledge. Therefore, according to Dallos and Hamilton-Brown (2000) the formation of a deviant identity can be seen not simply as a one-way but rather a two-way process.

Furthermore, Foucault (1979) developed concepts and critiques of the medicalised discourses inherent in mental health treatment. According to Foucault, the clinical gaze located in hospital-based medicine is characterised by an emphasis on clinical observation. Foucault suggests that a patient is expected to ‘confess’ during treatment as the doctors are able to exert power over patients, reducing them to compliant, ‘docile’ bodies. The creation of the power relationship between

professional and patient marginalises the patient's claim to 'authenticity' in the face of 'expert' knowledge, which takes precedence over their experience of embodiment. Under the medicalised discourse, doctors or medical professionals are afforded power. Foucault (1979, p. 93) suggests that power is everywhere, not because it embraces everything, but because it comes from everywhere: "Power is not an institution, nor a structure, nor a possession. It is the name we give to beliefs and meanings. It is a complex strategic situation in a particular society."

The growth of psychiatry and pharmacology according to Foucault (1979), regulates the behaviour of people with mental illness. For instance, advances in the pharmaceutical maintenance of mental disorders allow doctors to not only distribute the label of mental illness, but also claim success for the treatment, recovery, and rehabilitation of people with mental illness. Consequently, Foucault argues that those who fail to comply with their medication regime are often labelled as deviant.

The medicalised discourse is reliant on individuals being held responsible for their illness and the associated blaming. It does not account for different positioning of people and their access to power and agency to make decisions about their mental wellbeing. The dominant discourses inherent in treatment are, therefore, juxtaposed to the developing public health responses to mental health and illness. Indeed, current mental health policies embrace the concepts of public health (or population health approach to mental illness) through adoption of prevention and early intervention approaches to treatment (Moran, 2006). Furthermore, Skidmore, Warne and Stark (2004) argue that as a consequence there appears to be a huge chasm between rhetoric and the reality of clinical services, which continue to be embedded in blaming individuals for their illness, for example, non-compliance with medication, lack of awareness about symptoms etc. There are a myriad of issues to be addressed within the dominant medical model of mental health and illness, including risks associated with the diagnosis of mental illness and the resulting process of labelling and stigma. Theoretical or idealised alternatives to the medical model can be seen in social approaches inherent in the population health approach to mental health policy, for example, the growth of social ecological models, which take a broader view of the person's social circumstances (for example, Daub, 2006; Lester & Tritter, 2005; Simon, 2006). The inclusion of such approaches and their effects are discussed within the data analysis of the mental health policies in Chapter 3.

2.5.5 Risk

The issue of risk appears frequently in this thesis. The concept is discussed in the parents' narratives during Chapter 7. However, there remains limited research addressing parental mental illness (Mowbray, Schwartz, Bybee, Spang, Rueda-Riedle & Oyserman, 2000; Nicholson & Biebel, 2002; Repetti, Taylor & Seeman, 2002). Mostly this is because until recently people with acute and/or severe mental illness would have had their capacity to become a parent regulated through their institutionalisation. Due to deinstitutionalisation, this issue has become more relevant; arguably, there are attempts to continue to provide social control over parenthood. However, Montgomery, Tompkins, Forchuk and French (2006) suggest that doing 'motherwork' and seeking help can be challenging for parents with mental illness. Failure to seek treatment is justified because this would put their capacity to parent under surveillance. Whether through choice or mandate, clinicians working within the mental health sector who support parents with mental illness become agents of the state by promoting individualistic responsibility for illness, through their assessment of risk and by reporting on parenting capacity⁵ (Navarro, 1979). Devlin and O'Brien (1999, p. 20) suggest that parents with mental illness should be viewed with caution because they present "increased risks [to their children which] can be attributed to variables such as genetic factors, the stress caused by the parental mental illness, disruption to parenting (e.g. through hospitalisation), and dysfunctional temperament or personality traits". The concept of risk has been evident throughout this study and seen in the powerful position adopted by government services called upon to assess the capacity of parents with mental illness to be parents. However, this strong support for parents with mental illness presenting a risk to their children is not evidenced in the data on child deaths in New South Wales (NSW Department of Health, 2007).

Discussions about the reasons why risk has become so prominent in contemporary social analysis are prevalent in contemporary society (for example Beck, 1992; Lupton, 1999 amongst others). Lupton (1999) suggests that the social understandings

⁵ In New South Wales, mental health professionals are under mandate as child protection reporters (Children and Young Persons Care and Protection Act, 1998). Many parents with mental illness are deemed to be a risk to their children; when clients access mental health services, clinicians will often send a report about client's status for DoCS to investigate. If a patient is known to be a parent (for example, on admission to mental health treatment, whether community-based or in-patient treatment), reports are always made to DoCS.

of risk have changed from medieval times, when risk was thought of simply in terms of fate or fortune, to the present day. Six main categories of risk are identified, which appear to predominate in the concerns of individuals and institutions in Western societies. These include: environmental risks, lifestyle risks, medical risks, interpersonal risks, economic risks, and criminal risks. Lupton offers a critical approach to other theoretical standpoints on the analysis of risk. Lupton (1999) suggests there are significant commonalities between all approaches to risk. Firstly, that risk is a pervasive political and cultural concept that influences social life in Western society. Secondly, that risk has become a central aspect of human subjectivity. Thirdly, that there is an acceptance that risk can be managed through human intervention. This third suggestion implies that risk is associated with notions of choice and responsibility, and, therefore, attached to blame. Lupton also pays attention to the relationship between risk and subjectivity. She suggests that an important question to address is: How do parents construct risk knowledges in their everyday lives? She observes that they may deal with risk in one way in public but that this may differ from how they approach risk within their own home. This argument is in contrast to other sociological explanations of risk that focus on risk in public arenas and often neglect the private domain of the home.

Lupton's categories of risk, noted above, are highly relevant to this thesis as they are indicative of the sociocultural, political and economic environments in which mental illness has acquired meaning (Lupton, 2003). These risks also have an important ontological status in our understandings of parenthood and mental illness as there is a heightened sensitivity to risk now evident that has developed through a more reflexive approach to the world (Lupton, 2003, pp. 14-15). Factors that contribute to increased risk for society and increased societal surveillance of people with mental illness can be attributed to the process of deinstitutionalisation of psychiatric care and the move to community care (Scheyett, 2006).

The distinction between parents with and parents without mental illness, defined by labels and hidden from society, creates a binary concept of 'otherness'. Whilst this applies, as noted earlier, to the concept of deviance, in the mental health field, 'otherness' describes ways in which mental health service users have been perceived, especially since deinstitutionalisation, as 'not normal' or different to societal expectations of a 'normal' or 'good enough parent'. Lupton (1999) contends

that the concept of 'other' is necessary for the development of self and that the 'other' is always conceived in terms of danger or risk which leads people to feel a sense of uncertainty. Since risk always involves uncertainty, it may be considered as one form of the 'other'. The implications of such an argument, for the analysis of the data in this study, are numerous. An example of the notion of 'other' in relation to parents with mental illness occurs when parents are considered risky or a threat to their children. This is because the 'other' status is culturally linked to the marginalisation of an individual by the dominant group.

The medical model of the risk discourse strongly influences parenthood experiences when risky parents (such as those with mental illness) are subject to an ongoing normalising gaze (Foucault, 1991). Thus the extent to which parents feel they have power and control over their experience of parenthood, and are able to develop a confident capacity to negotiate the restrictive imperatives of surveillance of their parenthood, as well as the multitude of other expectations made of parents, vary with social, economic and demographic positioning. Lupton's use of Foucauldian theory is useful because it assumes that social phenomena, such as mental illness, exist as complex and variable socio-cultural constructs. Foucauldian theorising is able to make sense of, rather than exclude, ongoing debates over the meaning and significance of mental illness (Paterson & Stark, 2001).

The 'risk meanings and strategies' which parents reflexively develop "are attempts to tame uncertainty, but often have the paradoxical effect of increasing anxiety about risk through the intensity of their focus and concerns" (Lupton, 2003, p. 13). These paradoxical effects include emotional alienation, obsessive concerns with avoiding risk, feelings of failure and inadequacy at not being a 'good enough parent', the stress of too much choice, negotiating the vagaries of economic rationalism in service resourcing, over-medicalisation and disempowerment (Lupton, 1999).

2.6 Parenthood, mental illness and employment

Discussions about work, mental illness, and parenthood need to be viewed within discussions about identity. Mental illness often causes biographical changes to people's lives especially in terms of employment or work. There is however, limited literature specifically addressing whether or not employment can mitigate the effect of the mental illness and provide a continued sense of self (or identity) for parents. It is acknowledged that work can be positive to many people's lives however, according to Bryson, Warner-Smith, Brown, and Fray (2007) it requires constant negotiation. It is unclear whether or not work may assist in countering the psychological aspects of loss of self due to mental illness (Schwefel, 1986). An issue of maintaining employment whilst living with mental illness is that treatment for mental health may cause disruptions to the working life of the person. Desire to continue to maintain the mask of normality through employment or professional identity may also interfere with family life and relationships.

Many mentally ill parents reject or deny the need to reconstruct their sense of self (Bury, 1991; Milliken & Northcott, 2003). The extent to which parents strive for normality is difficult to understand for those not placed under the stigma of mental illness. Within the context of living a marginalised and stigmatised life, this may be worth the risk. Waghorn and Lloyd (2005) found that in some cases, the workplace and organisational culture may be hostile to some types of mental illnesses especially where symptoms are not hidden. Therefore, a tactic adopted by many people is to remain silent about their illness. The pervasive ideological and stigmatising notions that question their capacity to work often override the person's desire to gain workplace support. Employers tend to remain skeptical about the capacity of a person with mental illness to contribute to the workplace. Clearly, mental illness deeply affects 'the self' because of the meanings given to the illness and the consequences of mental illness, such as disruption to employment and potential to limit career options.

2.7 Illness experience - narratives, and generosity

To seize the opportunities offered by illness, we must live illness actively; we must think about it and talk about it, and some, like me, must write about it. Through thinking, talking and writing we can begin, as individuals and as a society, to accept illness fully. Only then can we learn that it is nothing special. Being ill is just another way of living, but by the time we have lived through illness we are living differently.

Because illness can lead us to live differently, accepting it is neither easy nor self-evident. (Frank, 2002, p. 3)

Frank's work on generosity is a useful concept in which to place the need for increased understanding about the needs of parents with mental illness. Frank argues that a few moments of time and engagement can critically affect a person's journey through illness. Frank (2004, p. 14) provides an evocative metaphor of 'The Tunnel', referring to the tunnel-like space people with mental illness often experience. The concept of generosity is utilised in this study to explain how parents experienced the mental health system and what they felt was lacking in their care, such as empathy or knowledge about the specific issues they were facing when accessing inpatient treatment. Chapter 5 will discuss these issues more fully.

2.7.1 Narratives

The parents' own stories included descriptions of their daily lives as parents with mental illness and provide rich and valuable insight into their experiences. Whilst criticism about the use of narratives in qualitative research has been reviewed by Tovey & Manson (2004) I am not suggesting that the experience of all parents are the same as it is acknowledged that they are not a homogeneous group so it is therefore acknowledged that their experiences do not allow for statistical generalisability. In spite of this critical view of the use of narratives given the sensitivity of the issues under investigation the use of this framework has been significant. For example, Rosenfeld (2006, p. 64) suggests that such an approach is important, "After years of being ignored by a medical sociology stressing the sick role, stigma and the medical encounter, the illness experience has finally come of age." Illness narratives reflect patients' underlying understandings of their illness as well as their efforts to position themselves within a specific social situation (Kleinman, 1988). In this section, the work of Kleinman and Frank will be introduced as they address the importance of narratives in medical encounters.

In his early work on the importance of narratives, Kleinman (1988) discussed how physical forms of 'illness' often accompany powerful narratives, which shape the personal illness experience. Any condition can be experienced by different people in a myriad of ways; influencing the personal assimilation of this experience is the reaction of family, friends, and physicians. This influence is important in shaping the identity and the narratives gathered whilst a person is ill.

Kleinman (1988) first developed the term 'narrative' to refer to interpretive notions about episodes of sickness and treatment that are employed by those engaged in the clinical process. Importantly, both carers and patients utilise explanatory models extensively. Kleinman (1988) provides a particularly useful example of the contribution of narratives in furthering the development of knowledge about the illness experience. He suggests that narratives empower patients to embed themselves within the milieu of their medical encounter in order to reclaim, absorb, and make sense of their experience. In turn, patients as people can reject stories retold by clinicians and developed into scientific knowledge, for example, through case reports that depict a person dislocated from their illness and removed from its context in their lives. Kleinman's illness narrative can further our understanding of illness and treatment systems to incorporate the impact these have on the person's life. Thus, the person becomes central to the experience. In this light, Kleinman provides space for the experiences of parents with mental illness to be explored. He would suggest that not only is a parent a schizophrenic or a person diagnosed with bipolar affective disorder but they are also greater than the sum of their illness, and, accordingly, need to be understood within the surroundings of their lives as a parent.

Both Kleinman and Frank provide models through which to understand illness that are transferable to the study of mental illness. Kleinman (1988) suggests that there are five models of illness to support the development of non-professional explanations of illness; however, none is fixed, and they are all fluid and able to integrate different dimensions of the personal experience. These focus on: (1) the cause of the condition; (2) the timing and mode of onset of the symptoms; (3) the diagnostic processes involved; (4) the history and severity of the illness; and (5) the appropriate treatment for the condition.

Frank (1995) provides a personal model developed through his own treatment journey. He views the illness journey in three narratives: the restitution narrative, the chaos narrative, and the quest narrative. He does not see any one narrative as standing alone, but suggests that the three co-exist, often in relation to the same illness. Each narrative is subject to different discourses and each requires a different type of attention when engaging with the person experiencing the narrative journey: "Stories are not material to be analysed; they are relationships to be entered" (Frank, 1995, p. 200). The use of Frank's narrative typologies have allowed for an analytical framework to be applied to the analysis of the data.

The restitution narrative, where illness is seen as transitory, describes the wishes of the person for their body to regain its former self - before illness. In the restitution narrative, the person orientates their story from the perspective of the diagnosis and treatment. It is a position where they are often disempowered, as the clinicians and treatment are dominant.

The restitution narrative dominates the stories of most people . . . particularly those who are recently ill and least often the chronically ill. Anyone who is sick wants to be healthy again. . . . Restitution stories can be told prospectively, retrospectively and institutionally. (Frank, 1995, p. 77)

Some people whose illnesses fail to follow the form of restitution narrative or who themselves refuse to package their illness narratives in this form are found deficient and may be marginalised along with attention to their illness.

The chaos narrative is the opposite of restitution. People who become engaged with this narrative cannot imagine life ever changing, or the illness dissipating. At this stage, the person cannot engage in self-reflection and does not necessarily have the skills to tell his or her story.

In the chaos narrative, consciousness has given up the struggle for sovereignty over its own experience. When such a struggle can be told, then there is some distance from the chaos; some part of the teller has emerged. . . . In stories told out of the deepest chaos, no sense of sequence redeems suffering as orderly, and no self finds purpose in suffering. (Frank, 1995, p. 105)

Frank suggests that this stage of the chaos narrative almost becomes an anti-narrative. The chaos narrative describes a point where the patient is out of control on a journey that is without understanding or an endpoint.

Lastly, the quest narrative is one that is told through a body that has learnt to communicate the experience.

The quest narrative recognizes ill people as responsible moral agents whose primary action is witness; its stories are necessary to restore the moral agency that other stories sacrifice. (Frank, 1995, p. 135)

Quest narratives describe the experience of pain, a person's hopes and fears, and their sense or lack of sense of the meaning of suffering and even the possibility of death. Quest narratives are complex, showing the multiple dimensions of the illness experience, and allow the person to share their knowledge. At this stage in the journey, the illness is incorporated into the identity of the person; it is no longer

something that they are struggling to reconcile but becomes valuable to them and also of value to others. In the narratives gathered for this study, parents with mental illness occupied different parts of Frank's narrative journey. Their stories also told of their experiences with mental health professionals, which were less than positive. These experiences nest well within Frank's concept of medical generosity - or lack of it.

2.7.2 Generosity

Frank (2004) suggests that there is a dire need for increased generosity to be shown to patients through their illness journeys. This concept of 'generosity' explains some of what the parents identified as lacking in mental health service care; for example, time to talk, time to explain their feelings, and time to be heard. Frank sees the concept of medical generosity as the ability to bring "grace to welcome those who suffer" (Frank, 2004, p. 1). It is essential that this "generosity begins in welcome: a hospitality that offers whatever the host has that would meet the need of the guest" (p. 2).

Frank theorises that a lack of generosity creates two problems. Firstly, that many people are left feeling unhappy with how they are treated, and secondly, that many medical professionals are left feeling estranged from the reasons that motivated them to practice medicine. One of the critiques of Frank's theory may be that the world is seen through a philosophical lense which could lead to an idealistic view on the patient experience. Furthermore, whilst Frank bases his work firstly on his own experiences it must be acknowledged that his position within the medical system may have been affected by his previous position and accumulated knowledge about systemic issues. Frank did however add to his work through further larger studies about patient experience and as a result the concept of 'generosity' utilised in this study was one of the contemporary theoretical trajectories derived during further research. Notwithstanding the need to be specific about patient experience Frank does provide a sophisticated phenomenological model that does not just take their experience literally but allows for significant exploration of the issues presented in the narratives (Tovey & Manson, 2004).

Both of these issues are clearly relevant to the narratives provided by the parents in this study who were mostly disillusioned with mental health services. This aspect is discussed in more depth in Chapter 5. As will be seen later, the parents' narratives

also provide evidence of generosity towards mental health service professionals and the recognition that such professionals operate within an ideological value-laden system with the result that they are over-stretched and badly treated. Experienced case managers often move on, opting out of the mental health systems that are deeply embedded in a less than generous environment.

2.8 Implications of the literature for this study

Parenthood and mental illness are both socially constructed and driven by biological determinism. Little literature focuses on parents with mental illness and their experiences but the limited literature that this study can draw from is entirely specific to the issues of mothers as primary carers. Furthermore, empirical research findings indicate increased levels of risk for the children of parents with mental illness including psychological, cognitive, emotional, social and behavioural difficulties however; these studies are also limited to women with long term acute psychiatric conditions.

This chapter brings a sociological analysis of the issue of mental health and illness, and in doing so, does not require medicalisation or diagnosis of parents as patients. This analysis suggests that the medicalisation of mental illness and subsequent studies of parents with mental illness does not provide adequate explanations for the experiences and daily lives of parents. In part the deficiencies identified in the literature can account for the rigidity of treatment systems and their exclusion of parents to the detriment of their parenthood. Whilst mental health is referred to as a homogeneous group of illnesses this thesis accepts that parents experiences may be different but the sociological perspective contests the positioning of parents as patients. Therefore, the use of the concepts of stigma and risk allow for the exploration of their experiences. This standpoint will be explored in this thesis through parents' experiences of their occupation of a position on the margins which at times are paradoxical as they both require and reject treatment and support. This juxtaposed position of visibility and invisibility is supported by the theories outlined of risk and stigma as it allows the parents to access support and treatment when they determine their need is great as opposed to the imposition of rigid treatment structures and systems.

Added to this perspective the Foucauldian analysis of the position of parents with mental illness allows suggestions about power, risk and deviance in terms of concepts of achieving expectations of 'good enough parent' to be challenged. Lastly, Franks theoretical positions also discussed have been utilized in a novel way to provide frameworks for understanding how parents reflect on their experiences. The concept of generosity brought forward by Frank provides understanding about the needs and requirements of parents. The phenomenological approach suggested by Frank is useful for exploration of this study as it allows for an understanding of the world view of the person being interviewed. This standpoint is significant as it allows for everyone around the mentally ill to understand the world from their perspective, and in doing so; meet the deficits required to support their parenthood.

In spite of the plethora of literature covered in this chapter there are significant exclusions when attempting to explain the role of parents with mental illness. This can be explained by rejection of literature that is based on medicalised diagnosis and positioning of parents as patients. As a result there is only a small body of literature applicable and accordingly it is the aim of this study to further knowledge about the experiences and lives of parents with mental illness.

2.9 Chapter summary

This chapter has provided an overview of the theoretical context within which the thesis is placed. These theoretical trajectories have been discussed as they underpin this study and have, therefore, been set against the background of the terrain occupied by parents with mental illness. Issues have begun to be apparent in the position of the parents under the medicalised discourse, whereby their power as a parent is reduced and their capacity to realise their full potential in terms of parenthood is already challenged when their private family world clashes with societal notions of 'good enough parent' and a public position is adopted determining capacity to parent.

The following chapter, Chapter 3, provides information about the methodological pathways followed during this study. Particular attention was paid to utilising a non-judgmental and appropriate methodological paradigm to ensure that the silent parents would be able to find their voice and provide some light into their hidden

worlds. The guiding philosophy utilised in both the fieldwork and the writing of this thesis is that of providing a 'generous' witness to the stories of parents with mental illness who live their lives largely unwitnessed.

CHAPTER 3: RESEARCHING PARENTS WITH MENTAL ILLNESS

3.1 Introduction

This study investigates the lived experiences of parents with mental illness. A variety of methods has been used to gather and collate the data. These include analysis of mental health policies in Australia, analysis of submissions to the Senate Select Committee Inquiry on Mental Health 2005/06, in-depth interviews, and field notes recorded in a research diary. The fieldwork took place during 2006 and 2007. Media reports/discussions and debates during this time were also useful in understanding how they influence public understanding about parents with mental illness.

The main research methods and sources of data for this study are:

- Analysis of national and state mental health policies in Australia.
- Analysis of submissions to the Senate Select Committee Inquiry on Mental Health in 2005/06.
- 15 in-depth interviews with mothers and fathers with mental illness.

3.2 Methodology

The objective in undertaking this thesis was to learn how parents with mental illness live their everyday lives. This thinking resulted from both professional experience and academic enquiry. Whilst working at the clinical interface (since 2002 in Australia), I observed that services for parents with mental illness are limited because of policy and budget restriction. The argument within local mental health services was that neither adult mental health services nor children and young people's mental health services were funded to work with parents. In order to understand this, an analysis of mental health policies in Australia was undertaken. It was timely that during the tenure of this thesis a select committee inquiry into mental health services in Australia was conducted. The submissions to this inquiry were available for public viewing. This, in turn, enabled further investigation into a larger body of national data that could be analysed to identify any relevant themes.

I read widely about research methods within health contexts to find the most appropriate approach for this research (for example, Mellis, Williams, & Xuan, 2001; Minichiello, Sullivan, Greenwood, & Axford, 1999). In preparation for this study, I was also committed to a number of considerations: sensitivity to the issue under investigation, the stigma of mental illness, and the sense of self of the parents who subsequently participated in the interviews. This investigation also considered how parents with mental illness negotiate the social expectations and ideological notions of their roles.

Health services research is also broader than traditional clinical research, which directly focuses on patients in relation to their treatment and care. Health services research investigates the outcome of medical interventions from social, psychological, physical, and economic perspectives. (Bowling, 2002, p. 7)

This research project falls under the umbrella of qualitative research. This method focuses on accessing and describing personal experiences and interpreting the meanings people ascribe to experiences in specific settings (Polgar & Thomas, 1991). The specific methods utilized during the interviews was that of life histories, in order to allow the parents to interpret their experiences about mental health, events in their lives and about how mental illness issues affected their daily lives (Plummer, 2001). This narrative approach allowed for the ‘personal documentation’ from the parents about their lives in their own words which was deemed to be the richest and most appropriate approach as it provided space for the parents to tell their stories “from a full subjective view as possible, not the naïve delusion that one has trapped the bedrock of truth” (Plummer, 2001, p.20). Furthermore, this particular methodological approach enabled me to assist the parents to reconstruct and interpret their whole lives, and to reflect on their experiences (Frank, 1995; Atkinson, 1998). During this process parents were very open to the real risks that their mental illness created for their children thereby showing how useful this approach was for the research as there is little data on the experiences of parents with mental illness. This rich data gathered during the interviews became part of this research project and was subsequently subjected to narrative analysis. These and other issues were incorporated into the ethics approval application for this research study and are discussed below.

3.3 Ethical issues and protocols

Ethics approval was sought and provided for this research by the Human Research Ethics Committee, The University of Newcastle, Australia. The consumer movement has demonstrated the importance of listening to people who have illness experiences in order to ensure that their voices are heard in mental health research (Epstein & Olsen, 1998). A qualitative research method, chosen for this study, supports this aim. Ethical issues, considered when selecting participants, were associated with the sensitive nature of being labelled as having mental illness whilst still confirming their experience of mental illness. The ethical protocols involved designing a process that would support the collection of detailed data from in-depth conversations, and would protect the vulnerability of participants.

Part of the ethics process was to ensure that if any issues arose for participants during the interview, they would be provided with support. Accordingly, negotiations with non-government mental health service providers and mental health support groups ensured that any ethical dilemma concerning the participants could be resolved. In order to be mindful of the power relationship between myself and the parents the interviews were framed as an opportunity for them to share their experiences of mental health and illness (Jones, 2004). In this way the parents were given a voice and thus an opportunity to address their marginalised position which is at the heart of the narrative approach utilized in this research project. The quality of the relationship between the storyteller and the researcher is significant, as it has bearing on specific interaction that occurs during the telling. From this experience, I became aware that, if the storytellers recognise the researchers' genuine interest in their stories, then the storytellers are more likely to be open and honest, it was from this position of respect that I undertook the interviews (Wicks & Whiteford, 2003).

Issues of both confidentiality and anonymity were also considered in the design of the study. While participants were, of course, not anonymous to me, their identities are not disclosed and pseudonyms are used throughout the thesis. Furthermore, there was no collection of any identifying data, such as address, date of birth, ethnicity, etc. During the application process for ethics approval, issues related to child protection concerns were addressed with the understanding that these might arise during fieldwork. Procedures for dealing with any issues or incidents were

explained to potential participants along with the researcher's responsibility for reporting any concerns about safety. The research protocols were also designed to allow me to access support and supervision for any issues of concern that arose during the interviews. This strategy reflects comments by Beale, Cole, Hillege, McMaster and Nagy (2004, p. 141) who suggest that "because the qualitative research interview can also be therapeutic in nature . . . the emotional engagement of participants, the emotional response of researchers and the possibility of over identification by researchers" need to be acknowledged. A rigorous safety protocol was also adopted which incorporated plans for debriefing following interviews; however there were no situations which required utilisation of this plan.

House (as cited in Beale et al., 2004, pp. 141-2) outlines a number of ethical qualities and standards, which were incorporated into my research practice:

The three basic ethical principles in qualitative field studies are mutual respect, non-coercion and non-manipulation and support for democratic values. Mutual respect involves opening our perspectives to understanding the point of view of others and providing a rationale for our actions. Non-coercion ensures that participants freely consent to their participation. Non-manipulation highlights the importance of informing participations fully about the purpose of the study and research procedures.

Given the sensitivity of conducting research with vulnerable people, issues related to emotions involved in the interviews were also considered and incorporated into the research protocols. The choice of research methodology meant that participants had a great deal of control over what was discussed, what they chose to disclose, and what remained unspoken. A few participants did become tearful during the interview for brief moments, but they did not appear to be too upset to continue and declined the opportunity to terminate the interviews. All of these situations had been considered in the methodological planning for this research similar to suggestions provided by Beale, et al., (2004) who stress the importance of preparation especially when interviewing vulnerable people. However, follow up with the referring organisations was not required for any of the parents as there were no concerns about their safety or that of their children. There were times after the interviews, however, when I required debriefing and reflection on the stories to which I had borne witness. Engaging in such process was important as Foster et al., (2005) explain that a reflexive orientation is important when undertaking qualitative research.

The data collection process therefore, was undertaken with significant sensitivity due to the traumatic nature of some of the narratives which were provided during the lengthy interviews. In this light, the virtue of qualitative research as a choice for this thesis was significant due to “its flexibility and openness . . . enabled questions to be asked about the personal context of health and illness, the meanings of health, illness and disease . . . and their lived experiences of these constructs” (Robertson & Lyons, 2003, p.415). Furthermore, as Bradley, Curry and Devers (2007) suggest qualitative research can improve the description and explanation of complex, real-world phenomena such as parental mental illness which is useful in the field of health services research.

3.4 Liaison with non-government organisations

Due to the geographical area chosen for this study, only a limited number of agencies had the potential to recruit participants for the research. Most of the mental health organisations were located in the city area.⁶ Letters were sent to all the organisations, support services, and groups⁷ in the area that work with adults who have mental health issues.

3.5 Recruitment of interviewees

The major challenge of the research was to access the largely inaccessible group of mental health consumers who exist on the margins, but who are known to be parents with valuable stories to tell. These parents do not often access statutory mental health services although they may be known to other agencies (for example DoCS). Eventually, the fifteen participants were recruited through non-government mental health organisations or community support groups that referred parents to the study. The processes by which recruitment was achieved had a significant bearing on the parents decisions to participate in the research. Recruiters in the support agencies, in particular those also providing care to the parents, were aware that the parents should not feel vulnerable and coerced by the recruitment process. It was also important that parents did not feel pressured to make a decision quickly about their participation. However, the personal relationships the support agency workers had

⁶ The research area was made up of City and Shire (local government areas) with mental units located in each area - Unit 1 and Unit 2.

⁷ See Appendix 1 for a list of these organisations.

with the study participants and individualising the recruitment approach to them may have assisted recruitment and enabled the parents to have power over the process.

The timing and method of approach also had important implications for the success of recruitment. Consideration of the parents' situations before presenting research information ensured that requests for participation were not made when a parent was in a particularly vulnerable position. Careful consideration was given to the content of information sheets, with excessive jargon avoided where possible. If interested the parents were given written information together with verbal information from their support agency workers to support this process. All potential participants were therefore provided with information about the research project, including the expectations of participation, and also offered an opportunity to ask questions about the study prior to agreeing to participate.

Inclusion criteria for this research were people who believed they had a mental illness and who were either mothers or fathers living in the geographic research area. The term 'parent' incorporated a broad definition and included people who had permanent, substantial, or minimum care of children aged 0-18 years. This research was also designed to include grandparents who may have been carers and who met the criteria as set out above.

The term 'mental illness' was used in the broadest possible sense and included people who had a diagnosed psychiatric disability (under DSM-IVR) and also people who did not have an identified diagnosis but were engaged with non-government services providing support for people with mental illness and therefore considered mentally ill. People who wished to participate were receiving support from a number of sources including community services or support groups. It is not known how many comparable parents manage without such support. The decision that parents did not need to have a medical diagnosis to participate in this research was a commitment to support the reclamation of parents' identities from medicalised labels such as 'schizophrenic' or 'bipolar' and to see them as parents with valid, interesting and significant contributions to make to our knowledge and understandings about their lives. The prevalence of parental mental illness and the numbers of parents with mental illness is only estimated; as noted earlier as there is no national data on the population of parents with mental illness.

Once the community agency had identified a potential participant, contact was made and details of the study were outlined. It was made clear that participation was voluntary, with no penalty for withdrawal or non-participation. The process of negotiation was flexible in an attempt to support each individual parent's ability to participate. For instance, one mother wanted to be a part of this study but as she had two acute inpatient admissions, it took over six months before we were able to arrange a time for an interview.

The interviews usually took place in the home of the participant, as they were most comfortable in their own surroundings. At the beginning of each interview, the participant signed the consent form and again discussed issues of consent and their right to terminate the interview. Recruitment was ongoing throughout 2006, through a process of purposive sampling. This was meant to continue until a point of saturation was achieved (Strauss & Corbin, 1998) that is the point when the interviews are not revealing any new information. However, recruitment for this sensitive population was necessarily slow, and at the end of 2006, no further referrals were received and all avenues of finding more potential participants appeared to have been exhausted. However, when the first round of interview data had been analysed, a second phase of recruitment took place in 2007.

3.6 Data collection

The methods of data collection included in-depth interviews with fifteen parents with mental illness, observations, and field notes, analysis of Commonwealth and State mental health policies, and of submissions to the Senate Select Committee Inquiry on Mental Health (2006).

3.6.1 Interviews

Interviews with ten parents with mental illness took place between January and September 2006. A second phase of five interviews took place during 2007.

The interviews followed an interview guide. Questions were open-ended, thus allowing the participant to determine the direction and content of the interview (Boeree, 1998), and to elicit authentic information about the participants. The aim was to gather good quality data by establishing rapport with participants, avoiding

taking control, using effective listening skills, and by first asking a general question using non-specific language. Thus, the first question was: “Tell me a little bit about you and your family.”

The interview guide was not prescriptive, but a checklist included the issues shown in Table 2. The interviews however, did not always start with a prescribed question, but rather allowed the parent to introduce their family and begin their story where they thought it was important to do so.

Table 2: Summary of Interview Guide

Theme	Sub themes
Introduction	Universal introduction and general discussion to put participants at ease.
History of mental illness	When was it first diagnosed? Family history of mental illness
Experiences of parenthood	Challenges Barriers due to mental illness Experience of being a parent Acknowledgment of parenthood
Experiences of mental health services	Treatment Experience of inpatient care Experience of community care and support Private or public mental health service comparison Experience of incorporation of role of parent into service provision
Support	Type of support received for parenting What support would have helped you? What support would help? How can services support parents with mental illness?
Risk/concerns	Concerns about being a parent with mental illness What difficulties have you had? What would you like to change? What can't you change?
Advice for other parents	What would you say to other parents with mental illness?

The interviews were conducted in conversational style led by the data as it emerged from the interviews, and proved to be observational and reflective. Whilst not always easy and sometimes very emotional, the interviews were valuable in terms of not only collecting narratives but also documenting valuable personal experiences (Beale

et al., 2004). This form of qualitative methodology was chosen for this phase of the data collection process because of:

. . . its flexibility and openness to explorations of particular themes and issues. Further, such methods enable questions to be asked about the personal context of health and illness, the meanings of health, illness, and disease for individuals and their lived experiences of these constructs. (Robertson & Lyons, 2003, p. 415)

Interviews lasted between 1 and 3 hours; most took about 1 hour to record but there was significant time spent with the parents both before and after the interviews. The interviews were audio-tape recorded, with the consent of the participants, and transcribed verbatim to enable a complete and accurate transcript to be obtained (Grbich, 1999). Pseudonyms were given to the participants' transcripts to protect their anonymity. Only the supervisors and I had access to the interview transcripts. A research notebook was used to record additional observations and reflections about the context of the interviewees and their families. As Frank (2004, p. 7) suggests "how to hear the stories - neither to decode them nor to admire them but to make them part of our own practices of generosity - does require reflection."

The practice of generosity to the parents was, therefore part of the practice both before and after each interview. Reflections on the interview were recorded in the field notes along with other remarks as well - after conversations with professionals, service providers, or other people involved in the mental health field. Some friends talked about their experiences of mental illness, particularly post-natal depression. They were generous with their discussions about how it had affected their lives and that of their families. Information was also harnessed from incidental conversations - of which there were quite a few - with research participants after the interviews. Field notes also allowed reflections to be added about media articles or programs that had been seen or read at the time.

The research was also driven by a commitment to do the 'right thing' with the narratives. Frank (2002, p. 16) summarises this approach:

There has been less discussion about what constitutes respect for stories in narrative analysis. Narrative analysis entails extensive ethical obligations. The researcher who solicits people's stories does not simply collect data but assents to enter into relationships with the respondent and become a part of that person's on-going struggle toward a moral life.

During the process of gathering data, professional education in the form of seminars, conferences, and other training courses relevant to mental health and parenting also

deepened my knowledge and understanding of mental illness. These were informative not only in gathering information from overseas that was relevant and transferable to an understanding of what was happening in Australia but also anecdotes from others who were working in areas related to the focus of the study.

One of the difficulties in both the commitment to this study and undertaking the research within the geographical area in which I live, was the possibility of chance meetings with research participants. On numerous occasions, these encounters involved opportunities for participants to update their stories and to provide additional information about changes in their circumstances since their interviews. While this was not an expected part of the research process, it was decided that these conversations were a legitimate part of the research process and duly recorded in field notes. Whilst the unsolicited nature of the conversations was sometimes difficult, they continued to be enriching experiences and the interest and interaction could not be rejected without damaging the respectful relationship which I had built up.

3.7 Data analysis

I drew on qualitative methodological literature to assess practical approaches to qualitative data analysis (as suggested by Bradley, Curry & Devers, 2007) prior to beginning the challenging process of moving from descriptive summaries to interpretive analysis for all of the data sources utilised in this thesis. This involved the use of thematic content analysis and exploring associations and connections within each of the data sets.

In terms of ensuring and building reliability in this study multiple stages of interpretations allowed patterns to emerge. The emerging data was discussed with supervisors who made suggestions on the interpretations to provide a valid interpretive process similar to that suggested by Koch (2006). Further information is now provided on the process for each data set.

3.7.1 *Analysis of mental health policies*

The methodology for the analysis of the mental health policies was similar to that described above. The process however also required assembling all of the national

policies relevant to mental health service provision. The policies were reviewed historically to also provide an overview of the development of mental health services in Australia. The policy analysis was an essential source of information used to nest the experiences of the parents within a framework of expectations about mental health services. The national and state mental health policies set a benchmark for how mental health services should operate or what they should aspire to. Policies were sourced according to their relevance and use within mental health services and also for their significance in guiding the development of mental health services in Australia. Subsequent to this process each policy was critically analysed for its significance to parenthood and mental illness or its potential to provide support to this population.

3.7.2 Analysis of Senate Inquiry submissions

The submissions to the Senate Select Committee Inquiry on Mental Health provided a national data source and were available to the public for viewing. The 560 submissions provided a national snapshot of attitudes and opinions of mental health services. A relatively small percentage, which pertained to family issues, highlighted issues faced by families living with mental illness (Appendix 4 contains a diagram of the procedure for analysis).

Analysis of the 560 submissions made to the Inquiry identified a small number (13) that specifically mentioned parents with mental illness. Firstly, the submissions were filtered so that those relating to family issues were considered for their relevance to parents with mental illness. Many of the submissions were related to either families supporting children with mental illness (both young children and adult children) or to a lack of family support of an adult person with mental illness. These submissions did not relate to the specific experiences of a parent with mental illness. Thirteen submissions were finally obtained when a key word strategy was applied which specifically allowed for the identification of only those submissions which contained the terms 'parent' (parents, parenting, and parenthood) and 'mental illness' (mental health, mental ill health, and mental disorder).

3.7.3 *Narrative data analysis*

Thematic content analysis was used to make sense of both the data from the interview transcripts and the policy analysis. It involved reading the narratives and establishing a set of categories, which identified the themes, before applying a coding frame to each transcript (Broom, 2001). The use of a thematic analysis allowed for the identification of all data that related to classified patterns and major themes. The identified themes were expounded so discussions that fitted under specific categories could be identified and placed alongside the corresponding ideas⁸. As a result, the themes that emerged from the participants' stories have been pieced together to form a comprehensive picture of their collective experience (Leininger, 1985; Silverman, 1993) “each increasing the resonance of others like it” (Frank, 2004, p.7). However, the stories do not “stand alone” (Tovey & Manson, 2004, p.237) but rather allow for subjective analysis of the experience of the parents. Accordingly, the interview transcripts were read and re-read, and notes were made, which, in turn, assisted the thinking, analysis of the data, and development of this thesis. Both the impact of the narratives and their authenticity was also considered during the significant process of the analysis (Tovey & Manson, 2004). Only parts of the narratives are presented in the following chapters, as entire narratives would have made this thesis far too unwieldy.

3.8 Strengths and limitations of the methodology

The size of the sample restricted to fifteen parents with mental illness may be seen as a limitation in terms of generalizing from this research. However the research was not intended to represent the views of all parents with mental illness but rather through its in depth interviewing to elicit perspectives about the daily lives and issues facing parents with mental illness and their experiences of mental health services. Furthermore, similar arguments about restrictive data could be applied to the submissions to the Senate Inquiry as this type of inquiry generates particular types of submissions which may not always provide a generalisable view of the population. However, the combination of the data sources with the policy analysis provides a wide picture of a marginalised group of society.

⁸ For a list of the codes used in the analysis - see appendix 2.

The methodology of this thesis may also be raised as a limitation in terms of the generalisability of this study to other populations. However, if different methods had been elected which would have allowed for epidemiological data to be gathered it is feared that the difficult and hidden populations of parents with mental illness would not have participated in this study or would have been excluded from participation due to the rigour of implementing epidemiological methodologies. One of the drawbacks with qualitative data is that it is not easily reducible to numbers (Brown & Lloyd, 2001). Whilst, in principle there is no limit on sample size in qualitative research, time and resource constraints make large samples impractical, or also in this case merely accessing the hidden population of parents with mental illness was difficult. This could lead to the criticism that the data lacks generalisability and is unreproducible, as it is specific to the research location (Brown & Lloyd, 2001). However, the strength of this data is that whilst it provides a small detailed sample it also provides an in-depth explanation of the lives of the parents in this study and allows me to raise issues worthy of consideration to all services operating in similar environments (Grbich, 1999). The purpose and orientation of the methodologies utilised in this study were therefore driven by a need to examine understand the lives of the parents. The results whilst not statistically generalisable, do allow for theory to be generated and new information about the lives of parents with mental illness to be elicited. Hence 'theoretical generalisation' is possible from this study given certain remits and attention to over generalisation based on the group of parents who participated in this study (Atkinson, 1997).

A further limitation for consideration in this study is specific to the parents who participated in the research. The research was undertaken in a specific geographic area which was predominantly Anglo-Saxon and Australian populations and therefore provided limited opportunity to incorporate the views of different cultures into the research, although two of the parents do identify with a different cultural heritage. However, the mix of socioeconomic groups in the area and the parents who participated are representative of different population groups. This diversity has therefore provided some interesting data. Further limitations could be argued in the gender mix of the sample of the parents; however this is representative of the number of men who access mental health services in general. Furthermore, the fact that both mothers and fathers with mental illness are represented is also significant and not found in many other studies.

Lastly, there could have been limitations in this research due to my influence as a researcher. At the heart of the critical analysis in this thesis is the desire to normalize mental illness. This reflects the dilemma of the researcher having to integrate one's own discourse into the work whilst also being aware of how you may influence the research or provide bias. This was always addressed through support and reflection before, and after interviews.

3.9 Chapter summary

This chapter has outlined the methodologies used in this study. It has also highlighted the nature of this research, which has been, an emotional journey and an exhilarating experience of discovery. The research process sought to be generous - respectful of the participants' experiences and narratives, and inclusive of information available to provide a context within the discourse of mental health policies and service provision in Australia.

The next chapter, Chapter 4, provides a historical overview of the development of mental health services in Australia. This is an important precursor to the development of mental health policies in Australia, with historical issues largely driving and determining the landscape on which policies have been developed.

Part II

Mental Health Systems in Australia: Where is Parenthood?

CHAPTER 4: ANALYSIS OF NATIONAL AND STATE MENTAL HEALTH POLICIES

4.1 Introduction

This chapter shifts attention to the public policy content of parenthood and the question of what role, if any, governments play in regulating parenthood and specifically parenthood for parents with mental illness. After briefly reviewing the progression of policy approaches in Australia, it will explicitly discuss the public regulatory role in the parenting practices of parents with mental illness. An analysis of relevant policies is provided which includes federal, state (e.g., NSW Department of Health), and area health policies (e.g., Northern Sydney Central Coast Area Health Service (NSCCAHS) mental health policies).

The role of the state regarding parents with mental illness is analysed through current mental health policies in operation. Despite factors that appear to justify a public role in regulating parents with mental illness, the policy field remains problematic. Parenting regulation must have associated economic support to provide services. Consideration is given to whether policy enables or denies access to mental health services, including the provision of flexible pathways into care. This chapter also considers how parents can potentially shape policy to make it more applicable to their situations. Whilst issues of concern and risk are raised in the literature, making parents with mental illness a public concern is not possible as there is, in fact, little policy framework to support these families. Public control of parents with mental illness does not appear to be widely debated and, therefore, remains a largely private concern, relying on families to become carers (Heaton, 1999). Yet, there is a larger sociological issue embedded in the controversy and conflict within this economic rationalist discourse as to whose responsibility it is to support parents and intervene in the private business of raising families.

This chapter concludes by discussing the complexities involved in policy support parents with mental illness receive. For example, it discusses the justification for intervention in the lives of parents with mental illness, and the subsequent control of parenthood through the regulatory options inherent within the legal system.

Next, attention is given to a historical overview which will provide background to the development of mental health policy in Australia.

4.2 Morality underlying mental health policies

The first documented evidence about mental health services in Australia dates back to the early days of colonisation. This can be seen in the replication of the British system of mental institutions on the Australian population. There have been mental health services in NSW since 1805 when a member of the first fleet was declared to be 'a lunatic' but the first 'lunatic asylum' was not opened until 1811. As Meadows and Singh (2001, p. 52) note, "The colonies imported both the architecture and the system of treatment - mortal treatment that emphasised moral values and humane care." Garton (1988) in *Medicine and Madness* wrote about mental health services in New South Wales (NSW) between 1880 and 1940 which provides a history of both mental illness and the development of asylums. Garton argues that a historical analysis provides the basis for differentiating between policy and practice involved in treating people labelled as mentally ill. Other leading scholars, Lewis (1988) in *Managing Madness* and Matthews (1984), also provide a historical view of the development of mental health policies and services in Australia.

Inherent in these early developments of mental health services were clear distinctions between 'mad' people and normal people. These were embedded within ideologies that supported the need for the protection of normal people and the exclusion of the 'mad' through state intervention and regulation. Normal people were provided safety from the mad people through exclusion and incarceration enacted through mental health legislation. During the 1840s, there were changes to the mental health legislation: "the incapacitation of long-term inmates of mental institutions was in fact a powerful effect of the asylum. Such incapacitation - its possibilities and its limits - was the product of law as well as social policy" (Coleborne & MacKinnon, 2003, p. 24). Echoes of many of these changes are arguably inherent in service issues today. Meadows and Singh (2001, p. 53), for example, note, "Asylums were not a high priority in government spending. A period of neglect would be interrupted at some point by public revelations about poor conditions, then an official inquiry would take place and something would usually be done to remedy the situation." The discourse surrounding approaches to the treatment of people with serious mental illness supported institutionalised hospital

care and removal from the community (Brown, 1985; Grob, 1994). The overwhelming paradigm of service provision was that of ‘moral treatment’ and the subjugation of madness; it also included misogyny (Busfield, 1996).

The justification for the treatment of people with mental illness has, therefore, developed through marginalisation and has been based on the belief that: “Public provision of custodial care existed from the outset in the Australian colonies because it was always accepted that law-abiding citizens had to be protected from the possible violence and unseemly behaviour of people who were then seen as lunatic” (Meadows & Singh, 2001, p. 425).

Although Australia was federated in 1901, the continuing relationship with the British Empire meant that the mental health systems continued to be greatly influenced and affected by British and European issues. For instance, Crichton (1990, p. 32) notes, “In the decades prior to and following World War I, the development of mental health services was seriously affected by a shortage of funds.” This trend continued throughout the years of the Great Depression and World War II. It was not until the mid-1950s, that a national inquiry into mental health services (Stoller & Arcsott, 1955) found that long-term neglect significantly affected Australian mental health services in comparison to those overseas (Hazelton & Clinton, 2004).

Significant shifts in mental health services can be seen with the introduction and development of psychotropic medications from the 1970s onwards. This period is commonly known as a period of deinstitutionalisation, and was a global change in service provision. It was during this period that the dominant methods of social control moved from asylum to medication as the method of patient management. The development of more effective drugs enabled people to be sustained longer without supervision and allowed for the transfer of long-term acute patients to the community along with a transfer of responsibility from the state to the individual.

Generally, the system of mental health care and treatment in Australia has been based on the medicalised model of mental health care. Mental health care features power and control by those in dominant positions and loss of agency for those determined as being mentally ill. Whilst internment was a prominent method of treatment in the past, it continues to be seen as a threat. This brief historical overview, therefore, sets the scene for the continued neglect and inadequate

funding which appears to be embedded in the development of mental health services in Australia.

It was during this period that the need for a mental health policy became more urgent in order to overcome the transition to community care. Policy was needed partly to normalise mental illness and encourage people to accept the long-term psychiatrically ill populations into their communities; but it was also needed to direct the focus of services (Knapp, Funk, Curran, Prince, Grigg, & McDaid, 2006). Policy was the rhetoric that was meant to have formed the framework, which would underpin the resources needed to support the population of long-term mentally ill now living within society. One of the major faults and contentions within this area, however, has continued to be the lack of allocated funding to support policies.

4.3 Background to mental health policy in Australia

Mental health policy is an important tool that can improve the mental wellbeing of society. Since the mental health of Australians is both a national health priority area (*National Mental Health Policy, 2003-2008*) (Australian Health Ministers, 2003) and a major public health issue it is significant. There is a plethora of literature addressing the outcomes of mental health policy including the need for improvement to mental health services (Hickie, Groom, McGorry, Davenport & Luscombe, 2005; Jones, Baggot & Allsop, 2004; Rickwood, 2004). Literature also addresses equity issues in mental health policy, such as social and economic deprivation, which is well known to be a barrier to societal participation (Gillies, 2005; Williams & Doessel, 2006). Other issues, such as diagnosis, gender, education, geographic location etc., are known to impact on people's mental wellbeing (Browne & Courtney, 2007; Coker, Smith, Thompson, McKeowan, Bethea, & Davis, 2002; Stickley, 2006).

Mental health policy is described by the World Health Organization (WHO) (2004a, p.2) as "an organised set of values, principles, and objectives for improving mental health and reducing the burden of mental disorders in a population." The mental health of populations and societies is influenced by numerous macrosocial and macroeconomic factors, many of which lie outside the health sector. The direction of government policies, actions, and programs resulting from policy can have positive and negative effects on the mental health and illness of citizens. For instance, it is important to consider the social and physical environments where people live

alongside mental health policy development. The World Health Organization, (2000, p.1-19) suggests that any mental health policy should, therefore, incorporate three components:

1. **Improving the health of the population.** This includes objectives for improving the mental health of the population. Outcome or process indicators are often used.
2. **Responding to people's expectations.** This includes respect for people accessing services and a client-focused practice.
3. **Providing financial protection against the cost of ill-health.** This includes, for example, equity in resource distribution between geographical regions; availability of psychiatric drugs; equity and distribution of mental health services; appropriate budget for the provision of mental health services.

There were various factors, such as global shifts to deinstitutionalisation and increased use of psychotropic medication that, led to major calls for reform of mental health services in Australia following the process of deinstitutionalisation. This dissatisfaction with services partly resulted in the Richmond Report (Richmond, 1983), the Barclay Report (Barclay, 1988), and the Report of the National Inquiry into the Human Rights of People with Mental Illness - Burdekin Report (HREOC, 1993). Nevertheless, in spite of this plethora of inquiries, consumer satisfaction with mental health services continues to be questioned. Most recently, the Senate Select Committee Inquiry on Mental Health in Australia (2006) has provided another pivotal opportunity to encourage changes to mental health services. Each significant report is now considered alongside the policies or strategies that were developed to respond to issues raised. Due to the political process of policy developments there are significant ideological struggles embedded within each report that undoubtedly influence the outcomes and create barriers to progression of service improvement. Mental health policy is greatly affected by variable political ideologies and competes against other health priorities for priority and funding.

4.4 Deinstitutionalisation - The Richmond Report (1983)

Deinstitutionalisation refers to the policy of the reduction of hospitalised care and increased community-supported living for people with long-term mental illnesses. Deinstitutionalisation was driven by several assumptions. Firstly, that people with

mental illness would have an improved quality of life living in the community and would be admitted to psychiatric care only when required. Secondly, that long-term institutionalisation was permanently disabling (Brown, 1985). Research supported deinstitutionalisation, showing that people with mental illness preferred to live in the community (Mechanic, 2007; Priebe, Hoffman, Iserman & Kaiser, 2002) and that social integration significantly increased levels of functioning (Hobbs, Newton, Tennant, Rosen & Tribe, 2002; Pilisuk, 2001; Ware, Hopper, Tugenberg, Dickey & Fisher, 2007; Yanos, 2007) if mentally ill people were provided with an adequate level of care. Secondly, deinstitutionalisation was supported on the grounds that people with a mental illness should be integrated into communities thereby normalising their lives and allowing for increased societal participation.

O'Brien (2006) suggests that Australia, like many other countries in the British Commonwealth, inherited a system of mental health care steeped in the history of the asylum as the locus of care. Due to the pervasiveness of this discourse, people with mental illness were viewed as different and 'other', to be excluded from the mainstream of society. There appears to be a critical lack of work involved in addressing the social position of people with mental illness. These processes share the label 'deinstitutionalisation', but it is far from clear what the meaning of that term is beyond a simple definition of asylum closure. It is argued that deinstitutionalisation is neither a success, nor a failure, but is a concept dependent on the lens of analysis. There are two competing arguments in relation to deinstitutionalisation. Firstly, that it was a response to social pressure for reform caused by human rights issues for people who had been confined in asylums for long periods of time. Secondly, that it was a neoliberal government policy of economic rationalism with the aim of reducing financial burdens on state resources. Perhaps both these discourses coincided and shared the one goal: to reduce the hospitalisation of people with mental illness. Horsfall, Cleary, Walter and Malins, (2007, p. 8) suggest:

The closing of hospitals and the shutting down of beds can be deemed positive achievements by state governments and area health service managers, but consumers, families, and concerned citizenry may see this as lost beds, and a failure to provide adequate facilities for people who live with a mental illness.

The Richmond Report (1983) was undertaken during this intermediary period, which coincided with advancements in psychotropic medication for mental illness. This provided an opportunity for people, who had previously been considered too acutely unwell to be medicated and live in supported semi-independence in the community.

Therefore, the shift in mental health care from hospital to community service provision was arguably assisted by the drug revolution. Following the Richmond Report, practical service developments were undertaken flowing on from the realignment of state mental health policies (NSW Department of Health, 1985a; NSW Department of Health, 1985b). The Richmond Report did assist with the progress of deinstitutionalisation. Supporters of the Richmond Report also argue that it advocated the introduction of new policies and systems that reduced stigma and incorporated community mental health provision. On a global scale, Australia was one of many countries implementing deinstitutionalisation mirroring a shift towards community mental health care. The impact of the Report was definitely a reduction in specialist mental health nurses who had provided services in the inpatient units. The Report also signalled the start of a reduction of inpatient and long-term mental health care facilities for people with chronic mental health issues.

Community care has raised many issues, especially for parents who live with mental illness and their families. People who had previously been institutionalised and had their opportunity of parenthood negated now had the chance to have relationships and experience parenthood. The Richmond Report focused on individuals with mental illness, driving an individualised focus on mental illness - forcing families to accept the care and responsibility of their relatives with long-term psychiatric issues. There was no focus on family support within the policy shift from institutionalisation and public responsibility for mental health to a private community and family care issue. The Mental Health Council of Australia (MHCA) (2006, p. 7) argues:

When Australia's psychiatric asylums began closing down some 40 years ago, the promised investment in mental health services to provide both clinical and non-clinical support to enable people to live well in the community failed to materialize. The absence of these services goes a long way in explaining Australia's current mental health crisis.

4.5 Commonwealth mental health policies - development of National Mental Health Policy (1992)

Commonwealth collaboration in mental health policy took a long time to develop, it was not until the first *National Mental Health Policy* (NMHP) (1992) was introduced that new directions and structures of mental health services were seen (Australian Health Ministers, 1992). The NMHP established the importance of mental health on the government agenda. It was accompanied by the *First National Mental Health*

Strategy (NMHS) which was “designed to improve the health outcomes for individuals and the community over the period 1992-1998” (1992, p.2). Once enacted, these policies forced many changes to psychiatric services (Australian Health Ministers, 1998; Australian Health Ministers, 1995). According to Whiteford and Buckingham (2005), it was critical that the “changes that followed the introduction of the Mental Health Strategy needed to address the legacy of 30 years of deinstitutionalization. This resulted in a decrease in psychiatric beds decrease from 30 000 to about 8 000, with limited development of community services, and a doubling of Australia’s population”. Those who are more critical argue that it was merely a redistribution of funding (Bachrach, 1996).

The *NMHP* aimed to provide expanded community services delivered by community mental health teams, backed up by specialist mental health facilities, when required, to people with mental illness living in the community. Secondly, the policy drove the relocation of acute psychiatric care from psychiatric hospitals into annexed general public hospitals, thereby accomplishing a reduction in the capacity of psychiatric hospitals. Whilst the *NMHP* was economically driven, it did also aim to reduce human rights abuses and improve the quality of mental health services.

The *NMHS* primarily addressed and processed deinstitutionalisation. Its essence was to ensure services operated in the community through interdisciplinary teams who would provide a wide skill range and, therefore, were better equipped to deal with the complexities presented by people with mental illness than previous treatment models, which predominately utilised psychiatric nurses. Both of these founding policies were a starting point for changes to service provision.

Subsequent to the first *NMHP*, the government implemented a further two 5-year mental health strategies (1993-1998 - Australian Health Minister, 1998; 2003-2008 - Australian Health Ministers, 2003) which continued to focus on increased societal participation of people with mental illness. These strategies included attempts to increase consumer participation in the development of mental health services. These strategies aspired to a broader approach to mental health from a population-based health promotion and disease prevention model. They believed there should be universal access to basic health care: the provision of high quality basic services; equitable financing; the provision of a mixed public/private service delivery and financing system; increased accountability for allocation of resources; and increased

efficiency of services (Grbich, 1999). In principle, this could have been the framework in which supportive services might have been provided.

Arguably, the changes were progressed under the philosophy of economic rationalism and should be viewed as economically driven. As a result of this philosophy the quality of services subsequently provided were impacted by inadequate and limited funding (Webster, 1995). A further issue with the NMHS was that mental health services continued to be focused around hospitals (Morrall & Hazelton, 2000). There were also limited opportunities to address dissatisfaction with services until 1996, evidence of dissatisfaction across the mental health sector from service users who continued to experience poor quality of services was found (Quirk & Lelliot, 2001).

However, ethos of the NMHP was positive and there was a shift from provider to consumer-oriented services inherent in the philosophy towards mental health treatment.

4.5.1 National Inquiry into the Human Rights of People with Mental Illness - The Burdekin Report (1983)

In 1993, the Human Rights and Equal Opportunity Commission (HREOC) undertook their own review of mental health services in the report: *Report of the National Inquiry into the Human Rights of People with Mental Illness*. This report is known as the Burdekin Report. The report detailed continued systematic neglect⁹ of mental health services. The Burdekin Report detailed human rights issues including widespread suffering, systematic discrimination, and denial of rights to services to which people were entitled (HROEC, 1993, p. 908).

The Burdekin Report recommended improvements to mental health services and the need for more focused mental health policy. The Report contends that funding of community care was inadequate, and coordination of mental health service was poor. The Report found people had been abandoned through the closure of psychiatric institutions and the ‘mainstreaming’ of services to the community. The Report documented the effects of deinstitutionalisation, including significant barriers

⁹ Neglect detailed in the report included overt abuse within institutions, and covert neglect in the community.

to accessing mental health services, marginalisation and disempowerment of people attempting to use such services.

The Burdekin Report highlighted the role of non-government organisations (NGOs) in mental health care. While NGOs were providing extended services to meet the needs of people living in the community, they were drastically underfunded. The Report provided detailed information about the long-term mentally ill being labelled as ‘un-treatable’ or difficult to manage within community mental health services. The Report also suggests that these issues were partly attributable to the savings from deinstitutionalisation not being invested in community mental health services. However, most of the recommendations failed to be translated into policy - although some were integrated into the *Second National Mental Health Strategy*.

One of the main issues to emerge from the Burdekin Report that is relevant to the lives of parents with mental illness was the marginalisation of people with mental illness living in the community. The Report suggested that marginalisation was partly due to limited community awareness of mental illness and a desperate need for public education. This issue was omitted from the *NMHP* and *NMHS*. Therefore, community ignorance about the needs of citizens with mental illness resulted in limited integration into the community and lack of support resulting in both marginalisation and isolation. Whilst not reporting on the needs of parents with mental illness, there is mention of the needs of vulnerable groups,¹⁰ but parents were not classed as vulnerable populations. Vulnerable populations were found to be least likely to be accessing services due to limited understandings and lack of adequate specialist service provision in meeting their needs. Families and carers were inadequately resourced and unsupported. There were recommendations for improvements in services for women; specialist services were virtually absent or ill-prepared to deal with their specific needs. It is apparent that the medicalised discourse of mental health services created significant barriers to access, further disempowering people attempting to use services.

The Burdekin Report challenged the government to introduction the practice of early intervention, which could provide support for families, and indeed parents with

¹⁰ Vulnerable groups were defined as children and adolescents, elderly people, homeless people, women, Aboriginal and Torres Strait Islanders, people from non-English speaking backgrounds, people with disabilities, people in rural and isolated areas, forensic patients and prisoners.

mental illness. Early intervention could have been a proactive move in empowering people to take action to support the mentally ill. It could also have begun to alleviate the stigma and address the marginalisation faced by parents with mental illness but the evidence presented in the next chapters supports the argument that this has not happened.

4.5.2 *The Second National Mental Health Strategy (1998-2003)*

The priority of the *Second National Mental Health Strategy* (SNMHS) was improvement of services for people with serious mental illness. The philosophy was to extend the work of the first *NMHP*. The *SNMHS* paid attention to the targeted or vulnerable populations.¹¹ Therefore, “the second national mental health plan while continuing the imperatives of the first plan in respect of serious and psychotic disorders also explicitly mandates for a broadening of the range of disorders being treated” (Meadows & Singh, 2001, p. 218). Depression was targetted, offering an opportunity for many parents for whom depression was a major issue access to services (Australian Health Ministers Conference, 1992). The *SNMHS* also prioritised promotion and prevention of mental health as new principles for action, the development of partnerships between government and non-government service providers, and effectiveness of services and interventions.

It was from this point in time that parents and families (without being named) had an opportunity to access support. Literature shows that groups warranting attention for selective preventative measures are the children of parents with mental illness, and children who may have been abused and neglected as a result of a parent’s illness (Royal College of Psychiatrists, 2002; Sands, 2004; Smith, 2004). The introduction of promotion and prevention was a proactive move towards capacity building in communities as it provides an opportunity to normalise notions about mental illness and, therein, create potential for parents with mental illness to feel included in their community. Alongside this shift in policy, there was an increasing focus on recovery

¹¹ This was slightly different to the vulnerable groups identified in the First National Mental Health Strategy whilst again including children and adolescents, older people, people with mental illness; it also included people with intellectual disability or problems with drug and alcohol misuse (also known as *dual diagnosis*), forensic populations, and people with severe personality disorders.

and rehabilitation, often delivered through increased partnerships between agencies in service delivery.¹² According to Rickwood (2004, p.1):

Recovery is a major principle of the National Mental Health Plan 2003-2008 where it is stated that 'a recovery orientation' should drive service delivery. Recovery is therefore, a foundation of current mental health policy. . . . Recovery was not a term that was used in the First or Second Mental Health Plans, its intent was evident in the emphasis on mental health promotion within the Second Plan.

The main concern of the *SNMHS* appears to be improving the quality of mental health services through agreements on service delivery and clinical practice standards. An additional move was the establishment of consumer participation opportunities. The *SNMHS* did make significant progress in challenging the medicalised ideology of mental health services. The introduction of primary prevention models was also a positive outcome, and whilst the policy continued to focus on populations 'at risk' (Henderson, 2007) there was a broader health focus. This primarily ensured population driven developments such as parenting programs, for example the *Positive Parenting Program* (PPP), and *Families First* strategy. Although neither of these programs were developed through mental health policy, many parents with mental illness are able to access them for support.

4.5.3 The Australian Network for Promotion, Prevention, and Early Intervention (Auseinet)

The *SNMHS* introduced programs that focused on mental health promotion. This shift in focus is reflective of a wider health strategy towards population health and health promotion principles. Within mental health, there was a growth of specifically focused mental health promotion principles, and the government funded the Australian Network for Promotion, Prevention, and Early Intervention: Auseinet (actually under the first phase of the *NMHS*). Again, in a political move, the Auseinet program was launched in 1997 shortly before the *SNMHS*. In keeping with the culture of the *SNMHP*, Auseinet provides structural support for mental health promotion and illness prevention activities mostly through development of literature and programs.

¹² This began the need to develop formal partnership arrangements through policies, procedures, protocols and funding.

Whilst this growth in promotion and prevention was positive, it was reliant on individual responsibility for recovery.

As a policy outcome, Auseinet has the potential to assist parents with mental illness to feel assimilated into society as it has an awareness raising, networking, and information sharing role. It also provides a forum for the exchange of information with resources and information about parents with mental illness.

4.5.4 *The National Action Plan for Promotion, Prevention, and Early Intervention for Mental Health 2000 (PPEI)*

By 2000, the emphasis on the population health approach to mental health was significant enough for its incorporation into policy. Of significance in the *Promotion, Prevention, and Early Intervention Plan for Mental Health 2000 (PPEI)*, was the aim “to promote family cohesion” (Commonwealth of Australia, 2000, p. 49). This is, therefore, one of the few policies that directly name the need to support parents with mental health issues in order to reduce the “risks” associated with these families. The policy was delivered in two documents, the *Monograph 2000* which provided the theory, concepts and background information to the *Action Plan 2000* which provides the framework and actions for the policy (Commonwealth of Australia, 2000).

This policy was in addition to the *SNMHS* and the Auseinet providing further impetus to move towards promotion, prevention and early intervention of mental illness as outlined in the *SNMHS*. The *PPEI* continues to strive towards prevention, promotion, and early intervention with the potential to support parents with mental illness. The *PPEI* does mention parents, it also acknowledges that mental health problems in the young are predisposed by a range of factors not equally distributed in communities; therefore, children living with parents with mental illness need to be provided with increased services. The *PPEI* supports interventions that decrease risk and provide protection to children and those who have the potential to influence the mental health of children and young people. This would or could include providing support to parents with mental illness. Furthermore, the *PPEI* recognises the complex variables that influence risk and protective factors for families and the need to build the capacity of community-based services which are more able to respond to community needs and are often more trusted than statutory mental health services.

The substance of this policy was to enhance protective factors and reduce risk factors for people with mental illness. The framework supported intervention as early as possible to minimise the impact of the symptoms of mental health problems. Inherent in raising attention to resiliency, there appears to have also been an increased focus on risk (at the opposite end of the spectrum). This has created a two-edged sword for parents with mental illness. The focus on resilience pushed the need for interagency work across a remit of services.¹³ Parents with mental illness who participated in this research study, talked about the increased surveillance of this model of working and increased attention to the risks associated with their mental ill health. There have been very few programs supporting parents with mental illness; a one-year Parent Link Program (2004-2005) in the research area, failed to secure funding beyond the one-year trial project (Boursnell, Lee & Phelan, 2005). Other examples of programs which have continued to receive funding, albeit limited funding, are: Vicchamps Program (Victoria) and Early Intervention for Parents with Mental Illness Program in Bondi. The forthcoming chapters will also provide excerpts from the narratives of parents who have accessed support programs. This will place their experiences within the rhetoric and ideals of policy provision.

4.5.5 The NSW Select Committee on Mental Health, 2002

The NSW Select Committee on Mental Health conducted the first inquiry into mental health services in New South Wales. The report was based on evidence received from submissions and witnesses. The report outlines the disgraceful state of mental health services in NSW highlighting the limited changes in the 20 years since the Richmond Report (1983). The recommendations of the Select Committee identified the need for innovation within the mental health sector. There was limited impact from this inquiry as the more extensive federal Mental Health Council review of mental health services, *Out of Hospital, Out of Mind!* was released shortly after.

¹³ This included broader health sector, family and community services, education, workplaces, emergency services, correctional institutions, the sports, arts and business, as well as carers and consumer groups.

4.5.6 *Out of Hospital, Out of Mind! (2003)*

In 2002, the Mental Health Council of Australia (MHCA) reviewed the progress of mental health services across Australia since the introduction of the first NMHP. The review¹⁴ involved over 400 organisations and individuals. It uncovered a systemic lack of service development, but found no yearning to return to institutional care systems. Particularly problematic was lack of access to inpatient psychiatric care, which the review suggested was evidence of multifaceted systemic failure of care including inability to support clients due to limited resources. The result of this failure was marginalisation and stigma for not only people with mental illness but also their families who largely lived in the community without support. Concurring with the Burdekin Report, *Out of Hospital, Out of Mind!* found non-government services providing community services beyond their remit and without adequate funding. They also found the push for promotion, prevention, and early intervention was nothing more than rhetoric.

Out of Hospital, Out of Mind! recommended five solutions: investment, accountability, leadership, innovation, and research. These recommendations agree with findings of the other large-scale reports delivered over the preceding 20 years, such as those already outlined in this chapter. Hickie et al., (2005, p. 5) support this suggestion: “The current preoccupation with enhancing only the most resource intense and specialised domains of emergency and acute care may further delay the cost-effective community based and early intervention models.” Therefore, the report outlined that the continued failure to allocate sufficient funding would result in perpetuation of inadequate mental health services in Australia.

4.5.7 *The Third National Mental Health Plan (2003-2008)*

Following *Out of Hospital, Out of Mind!* came the *Third National Mental Health Plan (2003-2008)*. This current NMHP consists of four central themes which have been summarised in Table 3:

¹⁴ From August to December 2002.

Table 3	Themes from The Third National Mental Health Plan	
Priority areas	Priority themes	Adoption of a population health approach (framework)
Consumer rights - the need and right for parents with mental illness to be supported and recognised as parents by mental health services.	Promoting mental health and preventing mental health problems and mental illness.	Recognising that health and illness result from the complex interplay of biological, psychological, social, environmental, and economic factors at all levels.
Relationship between mental health services and the general health sector - the point at which supportive intervention could be given to parents.	Increasing/improving service responsiveness.	Recognises the importance of mental health issues across the lifespan, from infancy to old age, and across diverse groups within the population.
Linking mental health services with other sectors that could provide support for parents and their families.	Strengthening quality.	Recognises the contribution of physical health to mental wellbeing and the effect of mental health on physical health.
Promotion and Prevention which could educate and support parents and their children in their journeys through mental illness.	Fostering research, innovation, and sustainability.	
Research and Evaluation - such as this thesis which seeks to understand how parenthood is experienced by parents with mental illness.	Linking research and practice to provide best practice interventions in mental health.	

The summarised analysis provided in the table above shows that three main discourses are embedded in the latest NMHP. Firstly, the individual approach to mental health: ‘mutual obligation’ supported by social obligation through provision of services to those in greatest need. This contradicts moves to reduce the stigma and isolation of people living with mental illness. Prolonged lack of recognition contributes to a lack of support for policies to increase the participation of people with mental illness in society. This policy relies on the ideological focus of public/private dichotomies and discourses of ‘welfare dependence’. These dominant discourses do not accept the limitations or efforts of families of people with mental illness who are surviving in disabling social and physical environments.

Secondly, an increase consumer involvement in mental health services was given importance, whilst a feature of the earlier policy, progress had been limited. Jones, Baggot and Allsop (2004, p. 26) state: “Even groups that were in priority areas sometimes found it difficult to influence policy. Despite its status as an official government priority, groups in the mental health field saw a lack of public support as a barrier to influence.” Policy neglected to recognise barriers to consumer involvement in mental health. There is a need for policies that are based on the interests of people with mental illness as equal participants in society. If parents could be encouraged to participate, then policy would be able to focus attention on their needs, providing support and assistance to benefit their experiences of parenthood.

Thirdly, there was a focus on recovery and rehabilitation: “Recovery is a major principle of the National Mental Health Plan 2003-2008” (Australian Health Ministers, 2003). According to Rickwood (2004, p. 1), “Recovery orientation should drive service delivery . . . [it] is, therefore, a foundation of current mental health policy.” This philosophy reflected responsibility for mental health and illness on individuals and their families.

In addition to policy directions, there have been various national action plans to drive the implementation of policy. The latest of these plans, the *National Action Plan on Mental Health (2006-2011)*, was released in July 2006 (COAG, 2006). The Plan features 18 measures which, it suggests, will improve mental health services for people with mental illness, their families and carers through four strategies (pp. 2-4):

1. Increasing clinical and health services available in the community and providing new team work arrangements for psychiatrist, general practitioners, psychologists and mental health nurses
2. Providing new non-clinical and respite services for people with mental illness and their families and carers
3. Providing an increase in the mental health workforce
4. Providing new programs for community awareness.

In effect, this policy does not provide anything new, or any services that should not already have been provided under previous mental health policies and strategies. One of the potentials of this plan is the development of the Council of Australian Governments (COAG). The COAG model furthers collaboration between commonwealth, state and territory governments to include partnerships with non-

government mental health service providers. This group provides strategic collaboration and coordination of mental health policy direction in an attempt to improve services. Some have applauded the COAG approach, for instance, Martin (2006, p. 1446) who states:

The renewed focus on mental health in Australia through the discussion at the Council of Australian Governments (COAG) is to be applauded . . . with the explicit focus on PPEI - promotion of emotional wellbeing, prevention of mental illness and early intervention - this is also an opportune time for us to develop coherent strategies in prevention to stem the ever increasing burden of mental health problems.

A potential benefit of including non-government service providers is their access to consumer knowledge and opinions. This could address previous rhetoric about the need for consumers to be able to participate in shaping policy, as this in effect has continued to be only tokenistic. Conversely, a major criticism of COAG is that the Council only meets when a need arises as opposed to being a strategic incorporated policy-making body. This group is responsible for ensuring enactment of the NMHS and service development within communities.

4.5.8 *Not for Service: Experiences of Injustice and Despair in Mental Health Care in Australia (2005)*

Not for Service (2005) was released as a response to ongoing community criticism of experiences of care by the Mental Health Council of Australia (MHCA, 2005) and the Brain and Mind Research Institute (BMRI, University of Sydney), in association with HREOC. The report was consumer focused, documenting the reality of mental health by the people who had personal experiences of mental health services. The submissions detailed deficits in service delivery, including barriers to access to health services, the lack of respect, poor resources, and inadequate facilities when provided with care.

Not for Service outlined the continued burden on families living with long-term acute mental illnesses. It detailed adverse health, social and economic effects of poor mental health care, and stigmatisation. Most of the issues raised repeated data provided in the Burdekin Report (1983). *Not for Service* merely highlighted the lack of development, continued breakdown, and failure to provide basic medical and psychological health care. *Not for Service* evidenced increasing rates of suicide, rise in homelessness, marginalisation, and lack of employment for people with mental

illness, thus showing that deinstitutionalisation and integration into society was a failing philosophy.

Whilst this lack of advancement can be evidenced, it is weighed against examples of progress oriented towards preventative mental health service provision, for example, *beyondblue: the national depression* (2000), *Better Outcomes in Mental Health Initiative* (2001), and other promotion and prevention activities. However, there does not appear to be an equal allocation of service distribution between inpatient care and community-based services, both of which appear to be failing to meet the demand for services. The funding for services does not seem to account for increased population growth, longevity and diagnosis of mental illnesses affecting older people, or increased diagnosis of children and young people with intergenerational mental illnesses.

4.5.9 The Senate Select Committee on Mental Health (2005/2006)

In 2005, a Senate Select Committee on Mental Health was formed to address the ongoing crisis in the mental health system in Australia. The terms of reference for the Committee signified the magnitude of community concern over mental health services. There were over 500 submissions made to the Committee from various organisations, agencies, and private people. The submissions provide a rich, detailed description of the experiences of Australians who had contact with or accessed the mental health system, worked within the system, or vicariously experienced the services, or were interested in improving mental health services. For this study, the submissions were analysed for data regarding parents with mental illness and will be reviewed in Chapter 5. The Senate Select Committee on Mental Health released two reports, firstly, *A National Approach to Mental Health: From crisis to community* (Commonwealth of Australia, 2006a), which was followed by *A Final Report* (Commonwealth of Australia, 2006b).

4.6 State mental health policies - New South Wales

Policy development in New South Wales (NSW) is driven by the Centre for Mental Health. The government policy discourse embedded within mental health services reflects a risk discourse. This discourse prominently supports public control of people with acute mental illness as a strategy for reducing the number of critical incidents that have occurred in NSW associated with parents with mental illness (for example,

Tracking Tragedy Reports, 2003, 2004, 2005, 2007). The discourse is also apparent in the dominant risk practices of mental health services and Department of Community Services (DoCS) practices in NSW as evidenced by the narratives of the parents who participated in this research project. These dominant ideologies have serious consequences for parents with mental illness when accessing mental health services, as the policies reflect extensive social and legal consequences of identification as a parent with mental illness, such as possible loss of parental rights. Although there is a need to support parents with mental illness, the policy appears to favour increased surveillance and social control imposed on parents' lives. Government reports, for instance, note the correlation between mental illnesses, the prevalence of social problems and other issues, such as child abuse and parenting problems (e.g., Australian Institute of Health and Welfare (AIHW), 2000).

Ultimately, decisions made by mental health services and DoCS assume expertise in parenthood and make decisions about the public nature of parenthood. Rose (1992) discussed this concern about state influences and regulation of social and economic life in order to influence desired values about family and family life. Rose notes, "Expert discourses enable liberal governments to 'govern at a distance'" (p. 192). Murphy (2003, p. 437) continues this debate by suggesting "Expert discourses that identify certain practices as health, and therefore legitimate, and others as unhealthy, and therefore illegitimate, play a crucial role in such systems of domination."

In comparison to commonwealth mental health policies those enacted by each state at a micro level are more specific to any identified need of their local population. The main policies identified which impact on parenthood are listed in Table 4. The information provided in the table over page is an analysis of New South Wales Health Policies relevant to parents with mental illness. Each policy relevant to this thesis is listed with a summary of the key policy direction.

Table 4: New South Wales Health Policies

Policy:	Key policy direction:
Caring for Mental Health - A Framework for Mental Health Care in New South Wales	Introduced standard documentation for health assessment and triage activities, including national standards for mental health services.
Charter for Mental Health Care in New South Wales	15 key points to increase respect and service effectiveness for consumers of mental health services.
Identification of Risk of Harm (PD2006_003)	Directs staff to identify and report any concerns of risk of harm to children (under the Children and Young Persons Care and Protection Act, 2006).
Child Protection Issues for Mental Health Services - Risk of Harm Assessment Checklist	Directs assessment of women (and carers of children) to respond to risk factors associated with symptoms of mental illness.
NSW: A New Direction for Mental Health (2006)	Focuses on housing, community mental health service investment, promotion, prevention, and early intervention. Also provides pathways for easier access to services, and workforce development.
Interagency Action Plan for Better Mental Health (2006)	Focuses on improving ability of vulnerable families to increase the health and wellbeing of their children and highlights the need for increased liaison and communication between different agencies working with mental health clients. Covers discharge planning especially relevant to parents with mental illness.
NSW Integrated Perinatal and Infant Care Program	Provides support for the mental and physical health needs of mothers and their children during and after childbirth.
Statewide approach to measuring and responding to consumer perceptions and experiences of adult Mental Health Services (2006)	Directs increased consumer participation. Also sets the requirement for annual reports on mental health services.
Implementation of NSW Government Response to the Select Committee Inquiry into Mental Health Services in New South Wales (May 2007).	<p>Raises the following issues:</p> <ol style="list-style-type: none"> 1. Improving coordination of government agencies 2. Improving accountability for mental health services 3. New and enhanced funding 4. Improving supports to families and carers 5. Reforming key aspects of the Mental Health Act 6. Improving community support and participation 7. Enhancing services to priority population. <p>Success was reported in each area, suggesting, in fact that there was little work to be done to meet the recommendations.</p>

The main policies shown in the table above highlight state mental health services striving to increase collaboration between government services (for example, Health, DoCS and Housing). Furthermore, there is an acknowledgment in the policies of the issues and gaps in knowledge that can potentially occur between services. Furthermore, the Integrated Perinatal policy is a move towards reducing the potential for parents to become lost in systems and also a reflection of the commitment to a population health approach to state mental health services. Furthermore, it is apparent from the review of the NSW state mental health policies that there is an orientation towards easier access to information (for example providing annual reports on service performance). However, there continues to be a lack of consideration of the issues and barriers in accessing services for people with mental illness. For instance, service provision continues to rely on the hospital as the focus of service provision which creates barriers for people who may have a lower level of functioning due to their mental illness and fear social situations. However, the direction towards strengthening families resonates with the capacity building frameworks popular in health promotion and adopted by the population health approach to mental health (examples of this can be seen in the Action Plans and state directions for mental health).

4.7 Area mental health policies

The mental health policies in the area health service where this research was undertaken are procedural policy directives, which give process frameworks for clinicians working in the mental health services and guidelines to follow. These policies follow national policies but respond to the practice needs in the local area and reflect the needs of the clients in their local area. Table 6 which is shown over page is a micro level analysis of local area mental health policies which were relevant to the lives of the parents who participated in this thesis and are reflective of the mental health services provided to the local population. As indicated earlier in this thesis there is an acknowledgment in the area of the need to support parents with mental illness following the one-year Parent Link Project (2004-2005).

Table 5: Policy	Area Mental Health Policies Direction
Guidelines for Carer and/or Family Participation Partnership	This is a family-focused policy oriented towards increased carer participation but does not mention family and/or children. Carer and family are used as interchangeably to define people who caring or supporting a person with mental illness.
Commitment to Service	This is a guideline to area mental health service provision although there is no in-depth information on any service.
Children Visiting Unit 1 Clinic	Outlines contact with children of parents admitted to inpatient psychiatric facilities. Attempts to ensure visitation between children and parents - if there are staff to supervise and a place for a visit to take place.
Supporting Parents with Mental Health Problem/Disorder who are Clients of the Mental Health Services with children 0-17 years	Includes all community mental health teams with responsibility for responding to child protection concerns of their clients.
Minimum Contact with Mental Health Inpatient Families and/or Carers	Outlines a best practice framework for contact between young people in inpatient psychiatric care and their parents but does not cover parents' contact with their children (or young people who may be parents).
Dissemination of Mental Health Handbooks for Carers and Families.	Provides information to families about mental health services.

As shown in the Table 6, there are various policies that are applicable to services for parents with mental illness. There is evidence that these policies are having limited impact. Dean and Macmillan (2001, p. 357.), for example, found, "Parents with mental illness express concern that if they disclose their parenting status or, more important problems with parenting, treatment providers will file reports with children's protective services, thereby increasing the probability that they will lose their children." Fudge and Mason (2004) also found evidence of this suggesting that in order to protect their parental status, parents adopt a silence around their children thus resulting in the phenomena of 'hidden children'.

4.8 Non-government policy positions

Finally, there are also policies from organisations working with families with mental illness in the community which are also relevant. These policies are provided in this section.

4.8.1 *Consumer and Carer Participation Policy: A Framework for the Mental Health Sector (2001)*

This policy advocated support for parents with mental illness, suggesting that most parents with mental illness are able to live in the community with their families and children. This policy was developed as a guide for services involved working with consumers. The policy includes all levels of participation based on best practice for participation. This policy had wide consumer support because of its potential to increase their participation in mental health service delivery; however the update of opportunities for consumer participation with the population of parents with mental illness is problematic. Other studies suggest that whilst policies which encourage participation in mental health services are positive they remain largely rhetoric (Stacey & Herron, 2002).

4.8.2 *Principles and Actions for Services and People Working with Children of Parents with a Mental Illness Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA, 2004).*

Principles and Actions for Services and People Working with Children of Parents with a Mental Illness was generated through consultation between parents with mental illness and their families and service providers. This policy reviews the literature in the area of children of parents with mental illness, which mostly focused on the deficit effects for children of living with a mentally ill parent. It provides guidelines for intervention developed to build on the resilience of children of parents with mental illness. It is questionable as to how much influence this policy has had on government action in this area, as it has failed to be adopted at any local, state or national level.

4.8.3 *Family and community strategies*

There are no specific family-focused mental health strategies which is concerning. Yet, *Stronger Families and Communities Strategy 2000-2004* provides objectives consistent with those contained the NMHP and PPEI (also relevant is the National Evaluation Framework of the SFCS 2004-2008). The policy concentrates on early childhood issues and coordination of the National Agenda for Early Childhood. The

Stronger Families and Communities Strategy focuses on government concerns about the health, development, and wellbeing of Australian children, and provides limited financial resources to support services for children and young people. Whilst not focusing specifically on the needs of parents with mental illness, some of the parents discuss their experiences of support through this strategy in the forthcoming chapters. However, both of these policies may also position children of parents with mental illness as carers whilst continuing to fail to support the parents themselves (Heaton, 1999).

4.8.4 *Families First*

Families First is a prevention and early intervention strategy supporting parents of children 0-5 years. The philosophy of the policy is early intervention and collaboration between government agencies (NSW Health and Area Health Services, Community Services, Education and Training, Housing and Ageing, Disability and Home Care). It relies on government and non-government services working differently together and with communities to plan and develop more responsive and coordinated services.

4.8.5 *A Head Start for Australia: An Early Years Framework (NSW Commission for Children and Young People, 2004)*

Head Start for Australia is a policy developed by the NSW Commission for Children and Young People, the Commission for Children and Young People (Queensland) and the National Investment for the Early Years (NIFTeY). This policy is also based on early intervention philosophies, that helping children through a head start through the collaboration of all levels of government, businesses, families, even people without children.

4.9 The merging of parenthood and social policy

The review of the policy progress in this area in Australia suggests that families and friends of people with mental illnesses are expected to provide care and support for people with mental illness in the community. Jensen (2004, p. 33) suggests that “there has been limited examination of the mental health care system experiences of family caregivers . . . in many situations, family caregivers are essential to helping

their loved ones with severe mental illness to find their way through a maze of bureaucracies and health care personnel to access mental health care.” Family and/or support groups alongside NGOs appear to be providing services where statutory services are lacking; the narratives of the parents in this study provide evidence of this position which Heaton (1999) argues constructs them as carers.

The continued marginalisation of parents by mental health services is concerning given the discourse related to risk of children living with parents with mental illness (Devlin & O’Brien, 1999; Nicholson, Biebel, Hinden, Henry, & Stier, 2001; Nicholson et al., 1998b). Herein lies the contradictory juxtapositions becoming apparent that whilst parents are requiring support, which could be driven by policy, services are failing to see the need to ask parents whether children are in their care or to acknowledge their parenthood because it is not recognised as a policy matter.

For policy makers the issue of parenthood and mental health has become hidden and difficult to assess because no-one is sure of the magnitude of the issue, although anecdotal evidence and research studies suggests it is a significant problem. Due to this lack of awareness at policy level, there is no national data collection process that is able to provide accurate information on the incidence of mental health disorders or treatment occurring in people who have parental responsibilities. The situation is clearly inadequate but requires significant change to occur to bring to public attention.

A further issue with parents with mental illness is the public/private dichotomy inherent in this debate: Parenthood - who knows best? Rose (1999, p. 208) argues, “Parents are bound into the language and evaluations of expertise at the very moment they are assured of their freedom and autonomy.” Gillies (2005), who has critically examined the assumptions structuring policy discourses of support and inclusion in the United Kingdom, outlines an example of the development of policy incorporating the needs of parents. She has linked her findings to wider political and theoretical debates around professionalisation of child rearing and parenthood. She suggests that whilst families have long been a source of concern for politicians, in recent years [in the UK]; there has been a focus on parenting as a designated area of policy intervention. Furthermore, she argues that “the notion that parents must be ‘supported’ in their practice has sustained a variety of initiatives that aim to widen access to advice and guidance on child rearing” (Gillies, 2005, p. 71).

Therefore, whilst still needing more work to make policies equitable in the UK, there have been significant moves towards providing mental health policy support for families and parenting. This knowledge could usefully be transferred to assist Australian parents who live with mental illness. Gillies (2002, p.29) explains:

The placing of parenting at the centre of the government's policy agenda has been characterised by simple, causal theorizing that works to make the dynamics of power that operate within and between families. A more constructive approach would involve viewing parenting as an embedded, situated process, amenable to change only through social and material circumstances.

Policy is beneficial in binding society together, it provides pathways to care for people such as parents with mental illness, it can assist with overcoming marginalisation, isolation, and lack of social cohesion (Blank, 1990). Whilst parenthood is largely a private concern, the wellbeing of children falls under public scrutiny especially when children are at risk and their wellbeing becomes a state concern. Parents with mental illness need help, not abandonment, and the confidence borne through effective policy to access services without the fear of losing their children. Parents with mental illness must be able to have the ability to exercise their personal capacity rather than having it being curtailed and restricted by policy.

4.9.1 Issues with policy for parents with mental illness

Current mental health policies prioritise the accountability of services in terms of outcome and process indicators. These economic measures are deemed to gauge the effectiveness of programs and provide indicators on policy decisions. However, programs for parents with mental illness need to be long-term and are difficult to measure in terms of outcomes. As a result there are perceptions about the quality of the work undertaken and how it is facilitated especially when there is a deficit of measurable indicators. Intensive work supporting a few people to maintain parenthood and break intergenerational patterns of mental illness is not valued when placed against short-term work to greater numbers of people. The latter is more impressive to a government policy driven by economic rationalism.

Questions need to be asked about what effect short-term interventions have on people who live with long-term mental illness and their ability to parent and manage mental illness and parenthood. Meadows and Singh (2001, p. 53) state: "Widespread

social attitudes and values, which lived on from the nineteenth century, underlay the reluctance of governments to provide adequately on a continuing basis for psychiatric services . . . self help and individual responsibility for welfare and health care remained powerful values in Australian society.” The value for money approach to service provision incorporates the recovery paradigm dominant in policy but according to Pirkis, Burgess, Coombs, Clarke, Jones-Ellis and Dickson (2005) is linked to measurement of efficiency and economic outcomes. Herein lie the discourse values of individual responsibility and the public/private dichotomy of wanting parenthood to be a private issue but forcing it to be public through societal expectations of parenthood is also relevant.

Furthermore, policy impacts once again on service provision through the continued population health approach to mental health. This is also again outcome oriented, although driven by local/individual need, it reduces pressure to make national changes when as problems can be locally or regionally isolated.

4.10 Chapter summary

Deinstitutionalisation is partly responsible for the issues faced by parents with mental illness. Deinstitutionalisation and the reduction in the number of asylums has allowed people who would previously have been denied the opportunity, through institutional regulation, to engage in relationships and have children. Rickwood supports this position:

We can see that major and significant changes have been achieved. There has been a total shift in orientation and attitude from locking up and stigmatizing people with mental illness toward recognizing their rights and enabling their integration within communities . . . Australia is slowly, but surely moving toward a mental health service system that empowers and promotes the well-being of people with mental illness. (Rickwood, 2004, p.1)

Deinstitutionalisation did not consider the growth of the population of parents with mental illness nor the resulting impact on generations of children of parents with mental illness. Nor did it consider the intergenerational transmission, imagined or not, of mental health issues.

There is now a counter position and an increase in the numbers of inpatient beds. One argument suggests: “Contrary to popular belief, the overall number of acute beds in Australia increased by 6% over 1993-2002” (Whiteford & Buckingham, 2005, p.

3). This 'reinstitutionalisation', in effect, creates a threat to parenthood, as children are required to be separated from their parent if the parent requires inpatient mental health care. Limited places are available where parent and child can remain together.

The political discourse of mental illness is very important in the development and direction of mental health policy. Currently, the political discourse recognises individual responsibility for mental illness instead of viewing it as an issue which affects society as a whole. An alternative policy approach focusing on macro burdens of mental illness would allow for an understanding of all socially significant differences as socially generated, expressions of hierarchies of power and embedded institutional advantages. These positions continue to be perpetuated over time through policy, either consciously or not, to benefit or restrict people dependent on their social position and occupation within dominant groups (either class, gender, race or health). Thus, the barriers often created by policy, are experienced by people with mental illness in ways that continue to disable and marginalise them from participation in society.

In the case of parents with mental illness, there are significant gaps in policy because there is no specific policy that even acknowledges their particular issues. It is argued that reorientation of mental health policy could lead to a more sensitive, responsive, and individually affirming set of social and environmental arrangements which would reduce the disability experience of people with mental illness. It is interesting that the literature does not criticise policy for the provision of services to parents with mental illness, instead it highlights the lack of workforce capacity to respond to issues raised by parental mental illness (Maybery et al., 2005). Thus policy fails to address the process through which services are developed. In doing so, it limits the possibility of advocacy for an increase in funding to provide the services identified as needed.

There is without doubt a silent unacknowledged focus on parents with mental illness, although there has been a noticeable shift to recognising the needs of children of parents with mental illness (COPMI). Whilst there are a myriad of ways for parents with mental illness to connect to current policy concerns, there is virtually no explicit recognition of this. Even at service delivery level, parents with mental illness do not receive services specific to their needs. Moreover, there is no

specific reference to parents with mental illness. Rather, they fall outside the priorities and only appear as a potential focus within the broader field of mental health service delivery. Sufficient understanding of the long-term neglect of parents with mental illness can perhaps be viewed through research with the children of parents with mental illness. This brings new insights into the views of the experiences of adult COPMI into this arena. Disconnections ensure that the underlying causes of distress for parents with mental illness are neither sufficiently understood nor addressed. Policy could steer services towards the development of services suitable for parents with mental illness. For instance, if consumer consultants were utilised as suggested in policy then dialogue could be opened between consumers and the “inhospitable institutions” (Frank, 2004, p.133) which often compound the issues faced by parents with mental illness.

Chapter 5 provides a discussion of how the needs of parents with mental illness are overlooked and unacknowledged even by other people who suffer from long-term effects of mental illness. Through the submissions from the Senate Committee Inquiry a further data set is explored and analysed to deepen the understanding about the terrain of mental illness in Australia.

Chapter 5: Senate Select Committee Inquiry on Mental Health (2005/2006)

5.1 Introduction

The information presented in this chapter builds on the national overview of mental health services presented in the Chapter 4. This chapter brings together policy and practice through an exploration into an inquiry into mental health services in Australia which provide an overview of the issues presented nationally for parents with mental illness. In essence, the Senate Select Committee Inquiry on Mental Health (the Inquiry) generated public and professional debate over the application of mental health policies in practice. The submissions all “have an element of *testimony*, and the particular testimony of illness stories will be developed” through the utilisation of the data submitted to the Inquiry (Frank, 1995, p.18). This analysis links the discussions from the Chapter 4 about mental health policy with the reality of the implementation of policy into services and peoples’ experiences of those services. One submission to the Inquiry suggested that the mental health services were “not a failure of policy, it is a failure of implementation and delivery” (Submission 262 - Mental Health Council of Australia). Before discussion begins it must be acknowledged that as with any government inquiry that the nature of such inquiries often generates tension. Therefore, it is possible that submissions made to the inquiry only reflect a certain group of consumers or consumer organisations with specific interests leading to certain types of narratives.

5.2 Process and terms of reference of the Inquiry

As outlined in Chapter 4, mental health policy in Australia has developed over the last twenty years to provide a unified national approach to meeting the needs of mental health service consumers. It is apparent that whilst there is a plethora of policy approaches that should in essence ensure good quality mental health services, consumers, organisations, and agencies providing mental health services continue to be critical of the many gaps and issues in mental health services in Australia. This led to the Inquiry needing to investigate the state of mental health services. Wilson, a commentator on mental health policy and services, suggests:

Whilst Australian mental health policy is often depicted as world-leading for some time both those using and those providing services have claimed that the system is characterized by restricted access, variable quality, poor continuity of care, lack of support for recovery from illness and overt and covert human rights abuses. . . . The more that people who have never thought about mental health recognize these challenges, the more likely we are to reduce the stigma and the additional burdens it places on consumers and their families. (McGorry, 2005, p. 32)

5.2.1 *Process of the Inquiry*

Submissions to the Inquiry were open to anyone who had an issue that they wished to bring to the attention of the Committee which was formed to lead the Inquiry. Information was provided on how people could make submissions and how the information they presented would be treated. This included submissions that would be made public or information that so sensitive that it needed to be restricted to the Committee only. Following this process, public hearings were held all around Australia where people were called as witnesses to provide information to the Committee. Witnesses could be examined on the evidence that was being provided. All of the information that was heard during a hearing was recorded and transcripts were made. A long-term advocate for significant change to mental health services, McGorry comments:

The mental health arena contains an inherent reservoir of negative emotion constrained by silence. We need to build positive energy and momentum, and form an alliance for a new generation of sustained progress. (McGorry, 2005, p. 33)

5.2.2 *Terms of reference*

On the 8 March 2005, the Committee was formed to conduct a wide-ranging inquiry into mental health services in Australia. The terms of reference of the Inquiry can be found in Appendix 3. The Inquiry Committee was initially asked to report to the Senate by 6 October 2005. However, by 18 August 2005, a strong public response to the Committee's work led the Senate to extend the Committee's reporting deadline for an additional six-month period to 30 March 2006.

5.2.3 *General overview of the submissions*

This section provides an analysis of the 560 submissions made to the Inquiry. Many of the submissions outlined issues related to long-term, often acute mental illness. This

group of people had different issues to those of parents with mental illness. Part III of this thesis outlines the lives of the parents who were mostly living in the community with their families with limited support. This is different to the long term population of acutely mentally ill who often are not able to live independently and do not have the opportunity to form relationships and become parents.

Some of the submissions to the Inquiry highlighted the complexities of the lives of people with mental illness, for example they mentioned the impact of domestic and family violence on women's mental health, issues related to alcohol and other drug use and impact of mental illness on the lives of family members. Yet despite the specific focus on parents' issues none of these submissions addressed the issues associated with parenting children; nor did they mention whether the women had children. Again, this lack of specificity in the submissions failed to raise awareness about children and parenthood further silencing these families.

Many of the submissions were related to the need for provision of services for children, adolescents, and young people with mental illness. They addressed, mostly, the impacts on families and the stress caused by lack of service provision and accessibility of services able to meet their needs. There was a progression to a larger discussion with the submissions from parents still supporting adult children with mental illness.

Most of the submissions did not mention parents with mental illness. The main focus of the submissions, largely from organisations involved in the support of people caring for family members with mental illness, was on adult children or relatives (siblings) who had lifelong, prolonged, acute symptoms. These families represent the focus of mental health policies which aim to provide services to support these families.

5.3 Analysis of submissions on parents with mental illness

The data gathered in this section of the thesis provides an analysis of the submissions to the Inquiry relevant to the discourses associated with parents with mental illness. Names of people who submitted the evidence is provided as their submissions are a matter of public record. The selected submissions provide a national perspective on

the issue and generate ideas about the position of parents with mental illness in Australian society.

The submissions identified as presenting the needs of parents with mental illness were categorised into three major issues. These were (1) lack of services: (2) the lived experience of stigma: and (3) lack of acknowledgment.

5.3.1 *Lack of services*

Lack of service provision suggests that the policies driving community mental health service are not insufficient nor are they focused on the needs of parents with mental illness. For instance, one submission (44) outlined the issues of mental health services from the perspective of a consumer of mental health services, Nikki Wall who identified as “a mother and a wife”. She suggested that limited service provision and/or lack of qualified staff to support families resulted in “leaving the consumer and their family in a precarious and potentially fatal position”. (Submission 44; Nicci Wall - health service consumer).

This view was supported by another submission which advised that government should provide services for parents with mental illness because “parents state that anxiety about their children affects their recovery, and that barriers to recovery from mental illness affect their parenting. Flexible family and social supports which work collaboratively with mental health services are required”. Such inclusive practice should include education about parents with mental illness in schools, communities and other places. (Submission 386 -Vicki Cowling and Dr Adrian Falkov).

It was apparent that services are failing to meet the complexity of the lives of parents with mental illness. For example, a submission supported women and mothers with mental illness to be acknowledged, and noted the importance of this to “women’s current and future physical, psychological and emotional well-being”. The submission highlights domestic violence and mental health as intrinsically linked and requiring an integrated framework of prevention, support, and intervention. More services appropriate to the needs of “women with a mental illness who are often dependent on carers” may alleviate some of these problems. In essence this submission implies that the failure of services meant that women and their children continued to live in intolerable situations where domestic violence is a method of

controlling them and they were therefore more likely to have more acute and longer-term mental health issues. (Submission 51 -Toni Brown, Coordinator of Marrickville Legal Centre). The view that services were failing to meet the needs of their clients was also supported by other submissions which suggested a difficulty with connecting with clinicians. Part of the reason for this failure was attributed to the lack of training for mental health professionals to work with parents and their families and required “treatment system changes”. (Submission 286 - Mental Health Carers Network Inc).

ARAFMI Hunter presented the issues of carers of the mentally ill but also spoke about the needs of parents with mental illness. Their main concerns with mental health service provision were related to inadequate training of health service staff to support people with mental illness, lack of support services, and lack of knowledge about how to address stigma when supporting families. “ARAFMI Hunter also believes that all mental health professionals should be trained in Family Sensitive Practices so that they can better cooperate with primary carers in the treatment and recovery process.” They argue that failure to provide staff equipped to work with the needs of parents with mental illness perpetuated stigma of mental illness and creates risk for parents. (Submission 231 - ARAFM Hunter).

Continuing with this inability to meet the needs of parents with mental illness were concerns about “mothers who need professional help to treat their mental health issues and have tried to refer them on to both psychologists and psychiatrists, only to have them return without satisfaction and treatment”. Again, this view supports the other submissions which argued that there is a lack of understanding of the needs of parents with mental illness or commitment by service to help these people. (Submission 527 - Origins Inc).

A potential policy to support parents with mental illness was outlined in the previous chapter. The Promotion, Prevention and Early Intervention policy is raised as an example of policy that should ensure that services are accessible to parents with mental illness, however, it does not appear to be providing services to meet their needs. One submission claimed that the lack of services was disastrous for families, they urged for “accessible public sector services for parents who have mental disorders and mental illness - especially parents of infants and young children where the adverse impacts of these conditions are the strongest” were urgently needed.

(Submission 301 - NIFTeY Australia and the Australian Association for Infant Mental Health). They put forward the idea that more people would access services if there was a “single contact referral point for parents with mental illness ensuring access to services providing early intervention”. Lastly, this group felt that one of the major lacks in service provision was a failure of the “validation of their feelings” for parents with mental illness. (Submission 544 - Post and Antenatal Depression Association Inc).

“Targeted, intensive programs for high risk parents such as those with personality disorder, substance use disorder and parents with a history of abuse and neglect” was a potential future service direction from NIFTeY and Australian Association for Infant Mental Health (Submission 301). The issue of risk was also raised by another submission which suggested that women with mental illness were overlooked, although “women are at the highest risk of mental illness in relation to childbirth, for some their first episode of mental illness . . . Women who experience perinatal mental illness are at increased risk of long term mental illness. . . . Historically, perinatal mental health has consistently failed to gain genuine political, strategic and media attention, despite the enormous impact and ongoing cost to society”. This situation was partly attributed to the lack of acknowledgment, lack of training and the need for this area of mental health to be funded adequately through “mandated numbers of specialist mother/baby beds in inpatient mental health services”. (Submission 544 - Post and Antenatal Depression Association Inc).

However, it was suggested that “treatment as the answer” was not always appropriate and that “mental health needs [of parents] to be underpinned by a population health approach . . . addressing social determinants and risk and protective factors at a range of levels including individual, family, community and society”. Inherent within such a model would be a range of services responsive to consumer needs, incorporating workforce capacity and development. (Submission 441 - Auseinet). Whilst this may be true all the submissions describe the dearth of appropriate services or inappropriate funding of services. It was suggested that services specific to the needs of parents with mental illness were mostly left to non-government organisations who provided support in the community with inadequate funding and resources.

5.3.2 *Lived experience of stigma associated with mental illness*

The issue of stigma was strongly stated in the submissions. There were suggestions that stigma could be combated through increased provision of education and information about mental illness. Stigma is addressed in many of the national mental health policies outlined in the previous chapter (Chapter 4) but it appears from the analysis of the submissions that the discourse about ‘otherness’ of parents with mental illness was stronger than any interventions used to combat the associated stigma. There was an argument that lack of acknowledgment of stigma was an important issue for families with a parent with mental illness as they needed to be integrated into the community because of the “benefit from sharing the caring ... supporting and sustaining the caring relationship”. Inherent in these thoughts was the need for prevention programs to assist parents and families to live normal lives and therefore positive recovery should be a reality rather than just a policy ideal. (Submission 116 - Caroline Crosse, SANE Australia)

One answer to combating stigma was provided by Auseinet who suggested that much work needed to be done in “education in de-stigmatising mental illness and disorders”. Part of this work should be done through increased research into mental health issues and the development of an evidence base. (Submission 441 - Auseinet). This was supported by Origins Inc who also felt that part of a response to the issue of stigma would be to develop research in this area. (Submission 527 - Origins Inc).

The marginalised position of families who live with mental illness was also highlighted by Uniting Care. They said that “another concern . . . is the increasing number of children and young people caring for their parents. This is not only an unfair burden that the state seems to find acceptable but it also entrenches these children and young people in a poverty trap because they struggle to attend school regularly and achieve academic qualifications to ensure their future. . . . More than 50, 000 children in NSW alone care for a family member who has a long-term illness.” Uniting Care suggested that, “The reality of mental ill-health in Australia is a disgrace.” (Submission 279 - Uniting Care NSW/ACT).

Another impact on the daily lives of parents with mental illness appeared to be related to insufficient funding for mental health services which was raised as an issue in many of the submissions. For instance, The Mental Health Carers Network Inc

highlighted the lived experiences of families with mental illness; they suggested that “the plight of families must be recognised and adequate support, including respite for families considered as a high priority”. They have found a lack of continuity of care especially when a parent is admitted into psychiatric care creates significant issues for families. They also indicate that “mental health workers should endeavour to strengthen family relationships and empower all involved individuals . . . sometimes the family is not involved”. (Submission 286 - Mental Health Carers Network Inc).

Their view was supported by Cowling and Falkov who indicated that increased funding to support programs for parents with mental illness and “a focus on family would be more readily achieved with an inter-agency approach, compared to the individual focus that has historically prevailed in mental health services”. Cowling and Falkov proposed that as a result of the continued lack of acknowledgment of hidden children, there was an “overrepresentation of people with a mental illness in the child protection system”. They suggested that “procedures for early identification and intervention, and timely support for the parent and family should be implemented, and the outcomes measured - in an assertive attempt to reduce this prevalence rate.” (Submission 386 -Vicki Cowling and Dr Adrian Falkov).

Concern about the health and wellbeing of children in the early years was specifically raised by one submission, especially the need for parents with mental illness to be supported in their parenthood. It was argued that if policy was correctly enacted and promotion and prevention principles were applied to supporting parents with mental illness that “other mental health risks . . . post-natal depression, family violence and family break-up” could also be addressed. (Submission 301 - NIFTeY Australia and the Australian Association for Infant Mental Health).

5.3.3 Acknowledgment

The lack of acknowledgment of parents with mental illnesses status as a parent was emphasised by Cowling and Falkov who stated that basic work was needed to “determine the number of children who have a parent with a mental illness”. They propose that parents with mental illness and their children require recognition as a group because “until recently [they were] considered ‘hidden’ or ‘invisible’ from mental health service provision that is *children of parents with mental illness*”. They

encourage “mental health professionals to seek information about dependent children in cases where people present for treatment for mental illness”. (Submission 386 -Vicki Cowling and Dr Adrian Falkov). This lack of acknowledgment can be referenced to the literature already discussed where ‘hidden children’ (Fudge & Mason, 2004) or ‘silent parents’ (Boursnell, 2007) continue to be overlooked. Acknowledgment also suggests that the needs of parents with mental illness were not met through prevention or early intervention approaches. This continued lack of acknowledgment, creates barriers to accessing and using services. (Submission 279 - UnitingCare NSW/ACT).

The scarcity of service provision generally in mental health services created issues especially in the lack of support for families living with mental illness. Uniting Care felt that if there were an acknowledgement of the needs of parents with mental illness, that the minimal funding provided by government could be addressed. They suggested that this would reduce the “highly traumatic effect on the families of the people who suffer from it [mental illness]”. Uniting Care only receives limited funding for community support services and were therefore critical of the government’s inadequate support in the community and/or lack of coordinated services. “One of the strongest messages we received from our services was that the effect of mental illness on families and carers is completely ignored by Government”. (Submission 279 - Uniting Care NSW/ACT).

Concerns about failure to acknowledge the needs of women and their families were addressed by The National Council of Women. Similar to Uniting Care their main fear for parents with mental illness was related to inadequate funding. They suggested that limited funds affected service provision and they claimed this was responsible for discourses of stigma and consequential isolation of people living with mental illness. (Submission 436 -National Council of Women of Australia Ltd).

Three main solutions to the lack of acknowledgment of parenthood were raised. Firstly, acknowledgment need in terms of a policy response to meet the needs of parents with mental illness. The Royal Women’s Hospital, suggested that there was a need for services to be related to various gender-based issues, stating that “women who are pregnant experience mental health problems such as anxiety, depression and difficulties coping at a higher rate than the general population”. Royal Women’s also highlighted the links between women’s mental health and the prevalence of living in

situations of domestic violence, an issue again “strongly linked with the development of mental illness”. (Submission 466 -The Royal Women’s Hospital Melbourne). Secondly, it was suggested that the government should review its responsibilities in terms of care for people with mental illness. (Submission 286 - Mental Health Carers Network Inc).

Thirdly, it was suggested that there was an under utilisation of ‘consumer consultants’ to ensure policy is developed based on need. Whilst this is supported by policy there is a general failure to implement this practice. Even though mental health policies acknowledge the significance of the contribution of consumer consultants it was proposed that there is a lack of importance attached to their views. Ms Wall argued that recognition of their potential contribution to mental health service development would lead to normalisation of the lives of parents with mental illness. She said “At all times remember, the majority of the time for a large percentage of those who have a mental illness they live fairly normal lives, work, socialise, are active members of their local community, but whose brains occasionally malfunction. We endure and overcome more than most people could ever imagine.” (Submission 44; Nicci Wall - health service consumer).

5.4 Report of Senate Committee

The Committee presented the findings of the Inquiry in two reports. The first report was followed by a comprehensive second report outlining the Committee’s findings and recommendations (Report of the Senate Inquiry on Mental Health, 2005). The findings are now discussed and compared with the issues raised in the submissions relating to the needs of parents with mental illness.

The report addresses stigma of families living with mental illness;

(11.47) The experience of mental illness can be traumatic for family members, particularly for children and young people. Mental illness among parents can have a range of impacts on children, including: Children of parents with mental illness have a greater likelihood than other children of having emotional and behavioural problems; Children worry about their parents and are not given information by mental health professionals which would reduce their anxiety; Parents do not seek help and support due to fear of their children being taken from them by welfare authorities; and Parents and families are reluctant to talk with children about the mental illness of a family member. As a result children feel isolated not knowing that other children share their family experience.[1156]

The comment above does not normalise the position of parents with mental illness, rather, it could be argued that it compounds the stigma and fear of parents with mental illness. The report focuses particularly on the parentification of children of parents with mental illness. It argues that these children are at particular risk due to their parents' mental illness;

(11.49) One group of children particularly in need of specialised services and support are children whose parent or parents have a mental illness. Some children also bear the burden of caring for an adult with mental illness. This is an especially difficult task given the social isolation often associated with mental illness and can in turn affect the mental health of the child. These needs cannot be met by increasing capacity within the general service sector. Young carers and young people in families affected by mental illness should be identified as a priority target within children and youth services.[1159]

In terms of the lived experience of stigma, children of parents with mental illness and the parents are both identified as needing services due to their limited capacity to be 'normal' families. The report is suggesting that children of parents with mental illness are forced to care for their parents:

(11.50) The expectation that children can fill the role of carer on an ongoing basis can have a significant impact on a child's wellbeing and future opportunities: These children are foregoing a normal childhood because in most cases they 'have' to be the carer as there is no one else available to be. They are given very little assistance with their education and mostly leave school early with a very limited and interrupted education. Many are unemployed as a consequence of limited education, poor employment skills and the time-consuming role of carer. They are ashamed of their situation and are often bullied and victimised by peers who have no understanding of their situation.[1160]

The report does not create generosity towards parents with mental illness; instead it continues to compound their feelings of shame and guilt about having mental illness and not being able to be a 'good enough parent'. The report also suggests that parents with mental illness are not able to provide for their children's basic needs:

(11.52) Some of the particular needs of children whose parent or parents have a mental illness include: emotional and practical support; respect for their role as a carer; appropriate respite; support to maintain the family as a unit; advocacy services for their rights and needs; personal development; assistance to participate in education and social activities; and special training and education in their role as carer, particularly as programs developed for adult carers may not be meaningful for a young audience.[1162]

Whilst suggesting that resources are needed to provide services, this is driven by a deficit model, where parents with mental illness are identified as less than able to provide for their children:

(11.53) The Network of Carers for People with a Mental Illness recommended continued funding to programs targeting child and adolescent carers, such as Children of Parents with a Mental Illness and Paying Attention to Self, to ensure the needs of these young carers are met.[1163]

The discourse of stigma continues in the report when discussion on parenting is addressed. In these discussions the Inquiry labels parents with mental illness under the category of deviance by utilising the terms 'high risk' or defining them as 'families at risk'.

(11.70) Children of parents with mental illness are over represented in the child protection system,[1183] partly reflecting the lack of early treatment and support for parents. Catholic Welfare commented on one of its programs aimed at diverting families from the statutory Child Protection System: One of the most significant issues seen in this team is the number of parents presenting with symptoms deriving from complex, long term trauma for which they have received little assessment or treatment.[1184]

In adopting this position, the report makes the assumption that all parents with mental illness provide a risk to their children. The report assumes that all parents with mental illness are similar in their parenting, sociodemographic position, and limitations or capacity to parent their children:

(11.71) Service providers commented on the need for better integration between services to meet the needs of families at risk, for example collaboration between mental health services and wider family services such as family mediation and family therapy: Mental illness is one of the factors adding to the increasing complexity of family life, with a number of co-factors: including drug and alcohol use, intellectual disability, and family violence, it requires skilled, joined-up interventions to improve the outcomes for children and families.[1185]

(11.72) Some families need assistance with living skills and family functioning in order to create an environment conducive to mental health: There is no service available to give ongoing practical domestic support and role modelling. . . . Further resourcing and training for Family Support Services would greatly benefit the number of support groups and short term specific support able to be offered in particular to families with children between the ages of 12 and 18 years where support and programs of any kind is inadequate.[1186]

(11.73) The City of Port Phillip noted that Maternal and Child Health Services offers universal care and support to all families with children aged 0-6 years, giving access and insight into family circumstances at an often vulnerable stage in life. However the service is not resourced to provide the supports needed for families with mental health issues; there are limited counselling and support groups and long referral waiting times.[1187] With better resourced community-based mental health services, maternal and child health services would provide a good 'entry point' to identifying and assisting families struggling with mental health related issues.

The narratives of the parents provide the basis for the discussions in Chapters 6-9 in this thesis and present an alternative viewpoint to these positions. The lived experiences of parents with mental illness who participated in the research study do not necessarily suggest daily lives of risk but mostly lives where mental illness was

part of their lives, but did not occupy the whole their lives, as presented in the Senate Inquiry report.

The Inquiry report does raise the interesting issue of the transference of intergenerational mental illness. One of the examples provided was that of forced adoption. Some stories were provided by parents with mental illness who were deemed not good enough to be parents and, as a result, had their children removed from their care. The report suggests that the damage of this practice was not only limited to the parents who lost their children but also their children:

(11.75) Origins Inc outlined a litany of appalling practices common during decades of forced adoption, including: Denying mothers all knowledge of their legal rights and options, Preventing bonding by forbidding the mother to see or touch her baby, Forbidding the mother from being discharged until she had signed her baby away, Forced suppression of lactation with potent drugs, Unlawful administration of heavy sedation during and post labour, Maltreatment of the mother and treating her in a cruel and demeaning manner, Physically restraining mothers from seeing their babies, Informing mothers that their babies had died at birth when in fact they had been adopted, Using overt and covert methods of coercion to obtain consents to the adoption of the child, Not advising mothers of the permanent nature of adoption.[1188]

(11.76) The lifetime damage caused by such experiences can be immense, including loss of trust, shame, sorrow, damaged relationships, loss of self-esteem, denial, dissociation, inability to bond with other babies, educational failure and poor employment outcomes.[1189] A range of mental illnesses are related to damage caused by adoption separation, including depression, post traumatic stress disorder, dissociative disorders and panic disorders, alcohol and drug use disorders and personality disorders.[1190]

Links are also made in the report between mental health and other issues, for example, domestic violence, childhood abuse, drug and alcohol use:

(11.90) The link between sexual assault, child abuse, domestic violence and poor mental health outcomes is well established.[1208] It is estimated that around 50-55 per cent of women with mental health problems or disorders are victims of child sexual abuse. For some illnesses, such as personality disorders and dissociative disorders, the prevalence rate is as high as 70-80 per cent.[1209]

(11.92) The mental health impacts of family and domestic violence can continue through generations. Children exposed to domestic violence have a high risk of developing mental illness.[1212] Where a mother has been subjected to domestic violence, this can result in ante-natal or post-natal depression, reducing her ability to interact and bond with her child leading to early developmental problems and poor mental health.

(11.93) Collaboration between services and long-term supports are needed: Violence is a complex issue and an interagency approach to safety for women and children experiencing domestic/family violence is fundamental if outcomes for consumers are to be improved. This requires that the mental health sector at all levels of the mental health hierarchy, actively support and sustain collaborative engagement with other

agencies. Resolution of violence issues takes time and this requires that mental health change its focus to sustained involvement with some families.[1213]

The overwhelming focus of the report does appear to put the blame on parents with mental illness. The discourse apparent in the report is that parents with mental illness create a risk to their children. For example the report notes:

(11.97) There is evidence that some families may be exposing children to environments which may contribute towards the onset of mental illness or exacerbate its symptoms and effects. Mental health care should endeavour to strengthen family relationships and empower all involved members, and recognise that some families may need additional assistance.

A reason why the experiences of parents of parents is not normalised in the report is because as this analysis shows there are relatively few of the submissions generating a challenge to the assumptions about the abilities and capacities of parents with mental illness. The report does not appear to provide any evidence of the strengths of parents with mental illness nor the resilience of their children and families to live a normal life. The discussion in the report is linked back to policy, suggesting that a major difference could be made to parents with mental illness if sufficient funding were provided:

(11.98) There are a number of programs supporting carers and families in their roles, and it is also clear that the National Mental Health Plan 2003-2008 recognises that the voices of carers should be heard in the formulation of mental healthcare policy, planning and treatment. However, funding over the long term to sustain such programs is not assured, and there appears to be limited effort directed to benchmarking and rolling out effective carer and family services on a national scale. Given the critical role of families and carers in community based care, adequate resourcing must be provided to support this overworked and overburdened group in the community.

5.5 Recommendations of the Inquiry relevant to this research

The Inquiry made several recommendations relevant to parents with mental illness. These recommendations are provided below. The key words identified in the submissions were considered when analysing the recommendations and have been emboldened so that they can be clearly seen when reviewing the recommendations.

They are shown in Table 6 Recommendations of the Inquiry.

Table 6: Recommendations of the Inquiry	
Number:	Recommendation:
22	3.13 That the Australian Government fund and implement a nationwide mass media mental illness stigma reduction and education campaign.
47	3.38 That recurrent funding is provided to develop and disseminate community-based programs providing peer support, training and information to carers and families, addressing issues such as education about the causes of, treatments for and recovery from mental illness, support services available, building family resilience and parenting skills, and meeting the special needs of young carers.
48	3.39 That governments increase targeted, intensive programs for high risk parents such as those with personality disorder, substance abuse disorders and parents with a history of abuse and neglect.
49	3.40 That funding be allocated to develop and expand services specifically designed for supporting children who have a parent or parents with mental illness.
50	3.41 That there be an evaluation of the effectiveness of the <i>Parentline</i> telephone counselling service that assists parents and carers in Queensland and the Northern Territory with behavioural management, parenting skills, and interpersonal relationships, with the view to expanding the service across all states and territories.
51	3.42 That better links be created between child and maternal health services and mental health services, and funding be provided for programs to assist families identified through maternal and child health services as having, or at risk of, mental health issues.
53	3.44 That the Australian Health Ministers agree to establish a national post-natal depression helpline and provide recurrent funding for its operation.
54	3.45 That the Australian Health Ministers develop a national strategy for perinatal health services , including early identification, intervention, prevention and education and support of new parents regarding perinatal mental illness.

The main recommendations can be linked directly to the issues raised in the submissions, which are: (1) Funding - more funding is needed to provide programs and services; (2) Stigma - there is a need to address and combat stigma; and (3) Lack of services - there is a dearth of specific services, and a need for better links between services.

5.6 Chapter summary

This chapter has provided information generated through the Inquiry on Mental Health services in Australia. The Inquiry was driven by public mistrust of services and lack of service provision. These factors are in contradiction to national mental health policies. Policy suggests that there should be comprehensive services in the community after the process of deinstitutionalisation which led to community service models. In spite of this, the submissions to the Inquiry generated a bleak picture of lack of services and lack of expertise for staff working in these services to support parents with mental illness. A paradox also arises when discussing lack of services that people accessing services are likely to be stigmatised and labelled. Therefore, they are unlikely, even if services were available to access these until their mental health problem is acute. This difficulty is magnified for parents with mental illness who are further deprived, and as this report deemed to be ‘high risk’ parents who put their children at risk. Whilst there are no services to meet their needs, the report generates a moral panic about children living with parents with mental illness suggesting that they are likely to fail to provide for their needs. This rhetoric compounds the fear of parents who know that if they access services they are likely to be assessed and investigated to prove their capacity to be a ‘good enough parent’. This approach is in opposition to the model that would focus on their strengths as a parent.

Whilst the submissions were limited in number, it is probably significant that even within those presented by people with concerns about mental health services in Australia the needs of parents with mental illness were sidelined and overlooked. One of the major omissions in the submissions appears to have been the lack of attention within mental health policy to needs of parents. The Committee report, therefore, did not address the issues raised about mental health policies, and, as a result, there were no recommendations about the need for a review of policies and/or what could be done to close the gaps and prevent people from remaining silent.

The issues apparent throughout the submissions and carried into the recommendations suggest that funding services and addressing stigma will answer many of the dilemmas associated with parents with mental illness. However, it is difficult to comprehend how this top-down approach will meet the needs of the

parents themselves. The submissions, whilst generating important information about parents with mental illness, were presented not by parents themselves but by organisations providing support. It was the organisations' views of the needs of parents as opposed to the stories of the parents themselves which were discussed in the Inquiry and the subsequent report.

This thesis now provides alternative stories about the lived experiences of being a parent with mental illness from the parents themselves. The parents' stories challenge the discourse apparent in state responses to parents with mental illness. The accounts also provide an insight into why these parents choose to continue to be 'silent' and why their children remain 'hidden'. Mostly this choice is due to a fear of stigmatisation, not only from other parents but also from the service providers who should be providing them with support. Furthermore, their continued marginalisation is a reflection of the lack of generosity and understanding of their fragile position in society, which failed to be challenged in the Inquiry.

Part III:

The Lived Experiences of Parents with Mental Illness

CHAPTER 6: WHO ARE THE PARENTS?

6.1 Introduction

This is the first of three chapters which present the findings from the analysis of the narratives drawn from interviews. This chapter provides a picture of the parents in the study and begins to develop understanding about the silenced parents who live with mental illness. Chapter 7 discusses the concept of ‘the good enough parent’ and how this concept exists in the context of risk calculations by professionals and by the parents themselves. It describes how parents had imagined parenthood in comparison to their lived realities and their attempts to attain this imagined position of ‘good enough’. Chapter 8 then explores the parents’ journeys through treatment and rehabilitation. It records their concerns about services and the fracturing of their parenthood often as a result of their mental illness and treatment services incapable of meeting their needs. Finally, Chapter 9 provides an insight into how parenthood is managed alongside mental illness and employment. It explores how professional identity provides a mask behind which the parents are relieved of their responsibilities of their families and negate their concerns about mental illness.

The words of the parents are used verbatim as much as possible because this contributes significantly to an authentic presentation of their lived experience. For some parents, their participation in the interviews did, provide healing; in some cases, the participants said the interview was the first time that they had the opportunity to explain how they felt about being a parent with mental illness. They had never spoken before about their fears for their children or the thoughts they harboured that had frightened them. They had never explored their feelings about mental health treatment; the communication and interaction with health professionals both good and bad. Nor had they talked about how it had been to wake up each day and continue the business of being a parent. The parents can all be viewed as being at some point along what Goffman identifies as a career as a patient (Goffman, 1961). Some parents were in the pre-patient phase, albeit at differing positions, some still reeling with shock at experiencing mental illness, some only just accessing treatment etc. Other parents were living in the reality of the inpatient phase. These parents were telling their stories whilst struggling with acute symptomology or postponing interviews to go into psychiatric care. There were also

the parents who could be described as in their ex-patient phase where their mental illnesses were stable and they were able to maintain their parenthood with relatively little fear of state intervention.

Some conversations took place in the street or the shopping centre when parents recognised me and wanted to engage in discussions about their journeys from where we had left off in the interviews. These discussions are recorded. Treatment of these conversations as part of the collection is valued by academics such as Frank (2004) who would see this as a commitment to generosity.

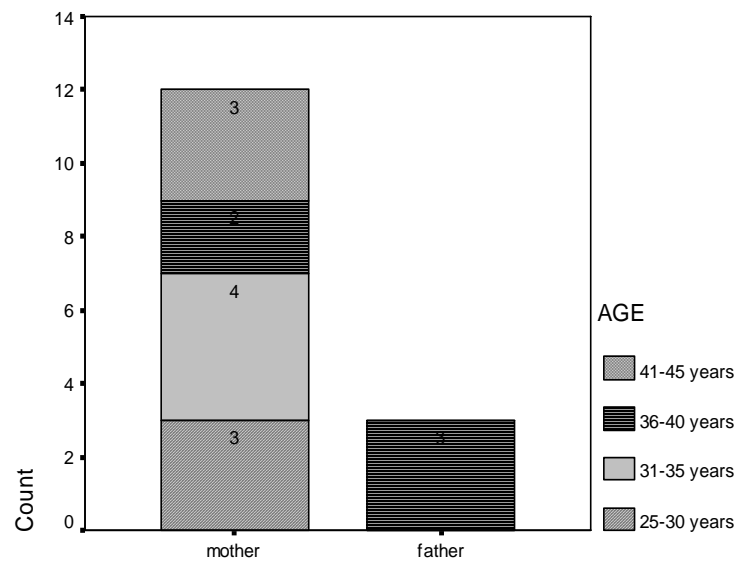
This thesis sets out the stories of the parents with mental illness in order that their suffering is no longer silenced and their stories not subject to the usual stigmatising reading.

6.2 Who are the parents?

This chapter presents a picture of the fifteen parents who were interviewed. Interviews were conducted in the homes of the participants, as they were most comfortable in their own surroundings. Most parents were proud to introduce their children and show off their homes, although for some this was problematic. However, these insights into family life provided a deep and rich understanding of the context of their lives.

The participants all shared some observable similarities: all were white, non-aboriginal, spoke English as their first language, and were aged from their 20s to mid-40s. There were twelve mothers representing 80% of study participants and three fathers equating to 20%. Official statistics indicate that women are more likely than men to experience anxiety disorders (12% compared with 7.1%) and affective disorders (7.4% compared with 4.2%) and access health services. Only 38% of people with a mental disorder are known to have used a health service, or (29%) consulted a GP for their symptoms in the previous twelve months (ABS, 2006). Figure 1 provides an outline of the age and gender of the participants and whether they were mother or father with mental illness.

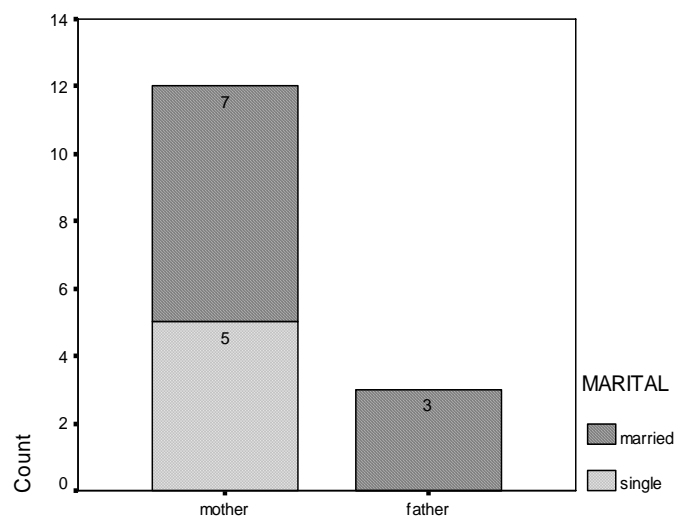
Figure 1: Age and gender of participants



As can be seen in Figure 1, the age of the mothers varied between 25 years of age and 45 years of age, whilst the three fathers who participated were all aged between 36 and 40 years of age. It was important that this research reflected parenthood and whilst there were only three fathers this is a realistic percentage when compared to the numbers of men who access mental health services in Australia (ABS, 2006).

Figure 2 provides an overview of the marital status of the parents in this study.

Figure 2: Marital status of participants



As Figure 2 shows that most of the parents ($n=10$, 67%) were in a married or cohabiting relationship and five of parents (33%) who were all women were single, divorced, or widowed. The other seven mothers were all married as opposed to living

in defacto relationships. All of the fathers were living or cohabiting with their partner and children, in comparison to the mothers who represent the single parents.

Figure 3 shows that the number of children for each parent ranged from 1-3.

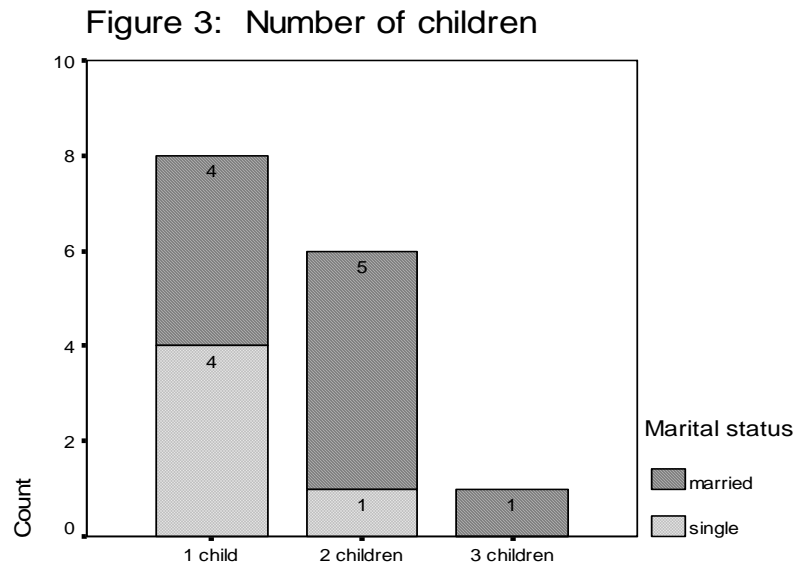
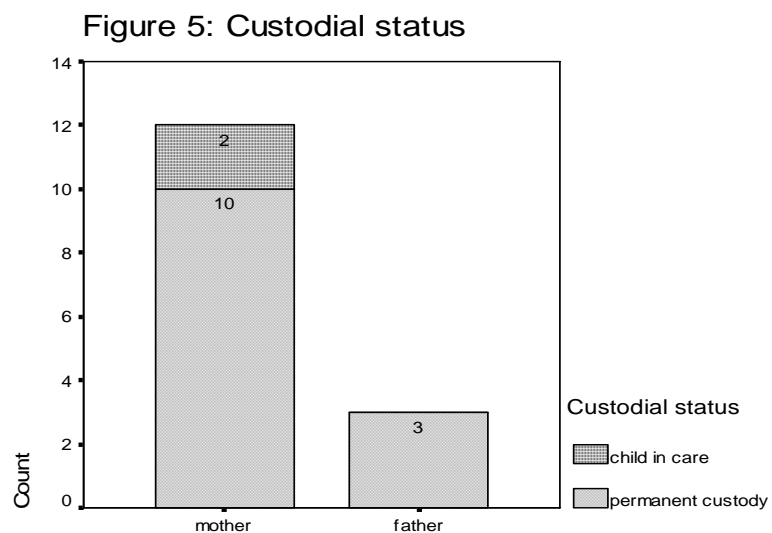


Figure 3 also shows that 53% of the parents (n=8) had only one child, 40% (n=6) had two children, and one father had three children (7%). All of the parents with one child were single mothers (n=4, 33%).

6.2.1 Custody of the children

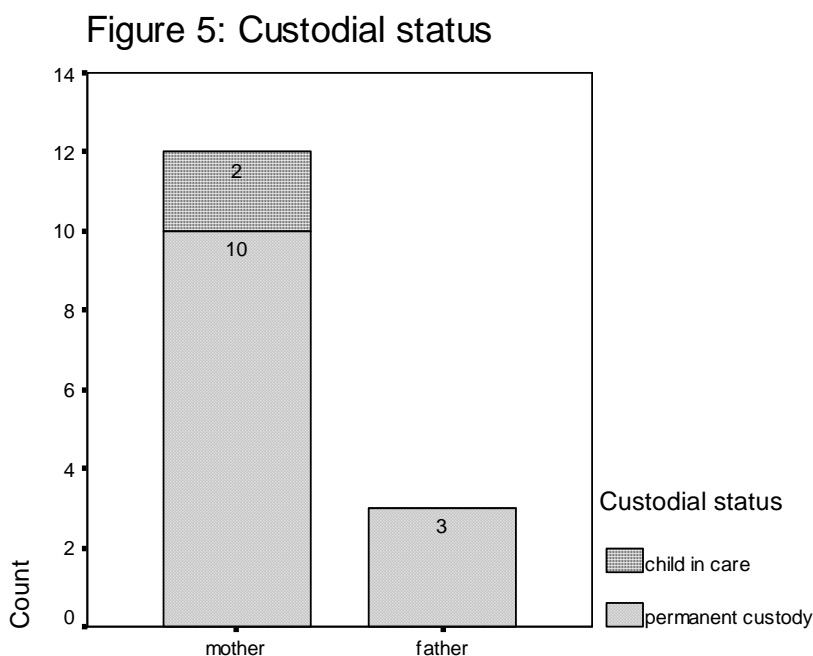
As Figure 4 below shows, 87% (n=13) of the parents had full-time permanent custody of their children:



Two women (13%) were involved with the Department of Community Services (DoCS) at the time of interviews. One of these women did not have current custody of her son but was hoping for restitution in the future. The other woman had ongoing involvement with DoCS over interim care order issues governing the custody of her children.

This information highlights the difference between fathers who were living in a 'normal' family situation with full-time custody of their children, and mothers who were more likely to be parenting alone without a partner to support them or assist in the care of their children. Mothers, therefore, were likely to come under the surveillance of DoCS. This concurs with Maybery and Reupert (2005), who found that whilst most children whose parents have mental illness come from two parent families where the mental illness is not severe, a small percentage of children live with a sole parent with severe mental illness and, therefore, more at risk of losing custody of their children.

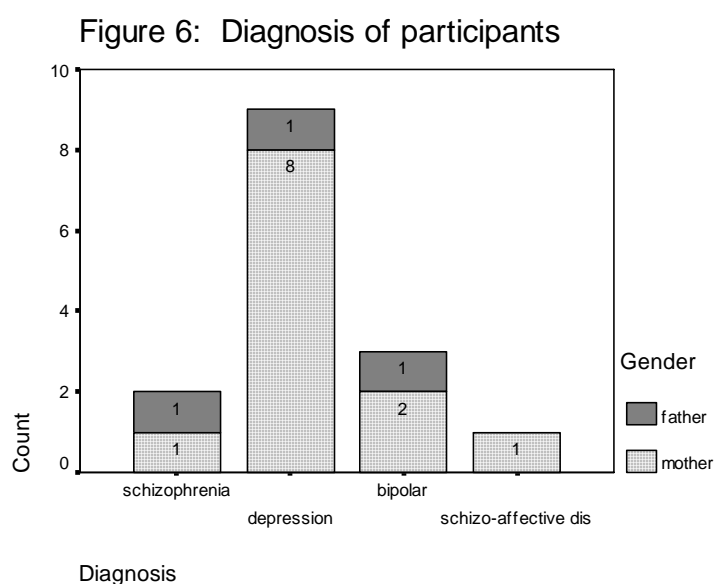
Figure 5 provides information about the custodial status of children by diagnosis of the parents:



It is important to note that the diagnosis presented above was not always medically diagnosed but relates to the diagnosis that the parents believe fits their symptoms. This is discussed further in the next section.

6.2.2 Diagnosis

Parents were not required to have a medical diagnosis to participate in this research. They did, however, need to be accessing services based on their experience of mental illness and need for support. The lack of the need for a diagnosis for participants in this study is a commitment to advocate the reclamation of parents' identities from medicalised labels, such as 'schizophrenic' or 'bipolar', and to see them as parents with valid, interesting, and significant contributions to make to our knowledge and understandings about their lives as parents experiencing issues relating to mental health. Figure 6 provides a picture of the diagnosis of the parents who participated in this research.



As can be seen in Figure 6, the parents all reported having been diagnosed as having one of the following conditions: schizophrenia (n=2, 13%), schizo-affective disorder (n=1, 7%), bipolar affective disorder (n=3, 20%), clinical depression (n=9, 60%). Some parents agreed with their diagnosis whilst others did not think that they had any mental health issues. Only one father had a diagnosis of depression, in comparison to eight of the mothers who talked about how they had been diagnosed with depression, some starting from a point of post-natal depression. Some parents had long-standing mental health issues, whilst others had only encountered issues related to mental health after the birth of their child. This information is shown in Figure 7:

Figure 7: History of mental illness

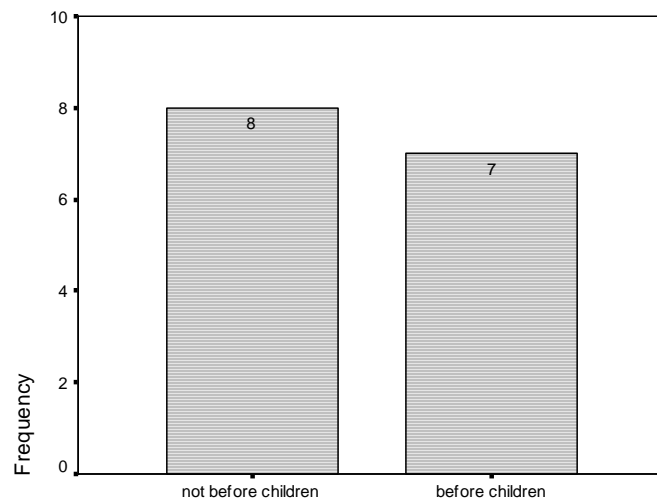


Figure 7, above, shows that eight parents (54%) had not been diagnosed with mental illness prior to having children or did not access services for support for their symptoms prior to becoming a parent. Some parents did say that they felt that ‘things weren’t right’ but that they had been able to manage or explain these feelings prior to having children. The other seven parents (46%) had a history of mental illness before entering parenthood.

Figure 8: History of mental illness - gender

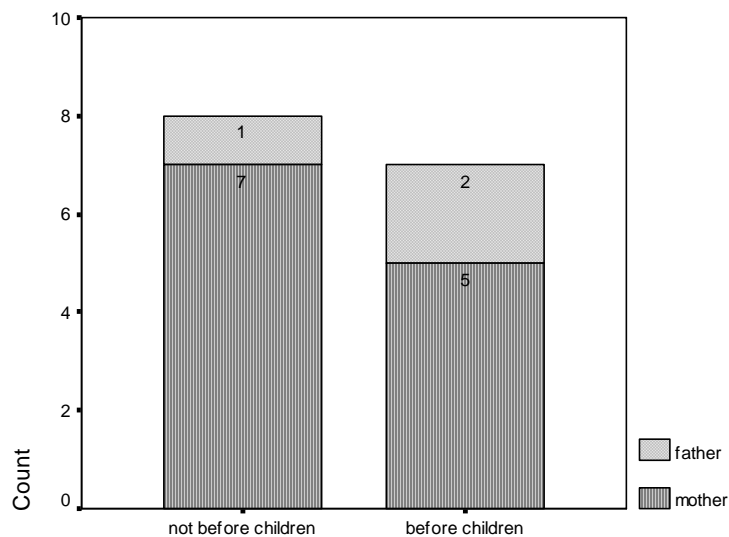
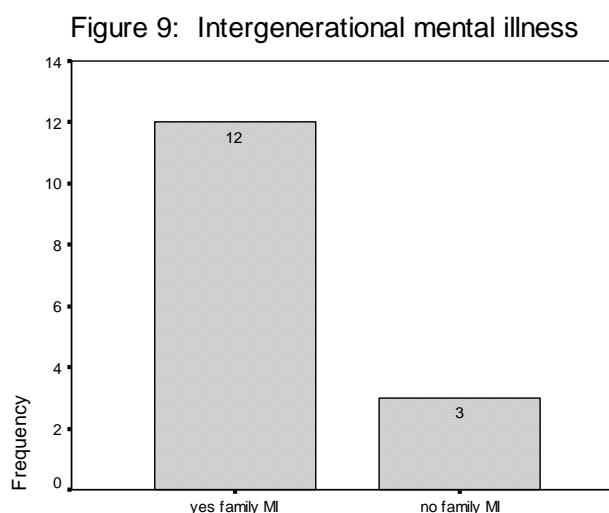


Figure 8, shown above, compares history of mental illness by gender. A greater percentage of the fathers (67%, n=2) already had a history of mental illness than the mothers (56%, n=5).

6.2.3 *Intergenerational mental illness/history of abuse*

Whilst parents were not asked about their diagnosis or other health issues, some talked about issues related to violence, abuse, or neglect in their lives. For a few parents, their history of abuse not only occurred during childhood but continued into adult relationships (for example, domestic violence). Their experiences covered physical, emotional, sexual, and psychological abuse. A number of parents felt that their history of abuse was interrelated with the development of their mental health issues. Other parents were able to associate other conditions with their mental health. For example, seven parents said that they had other conditions, in addition to the abuse, which had interacted with their mental health. These comorbid conditions were a physical disability or accident, alcohol and other drug dependency.

A further issue, as Figure 9 shows, was that of the intergenerational history of mental illness.

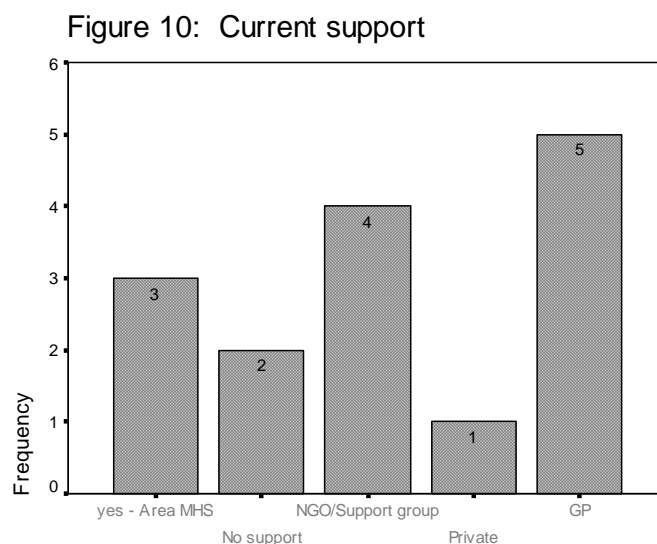


As illustrated above, twelve parents (80%) had a family history of mental illness through parents, grandparents, siblings or other close relatives.

6.2.4 *Mental health services*

The mental health support parents were receiving at the time of the interviews is shown in Figure 10. All parents needed to be receiving support from a non-government mental health organisation or support group to be referred to this research project. Some of the parents utilised different support networks according

to their needs at the time and the nature of their symptoms. Figure 10 shows their identified primary source of support.



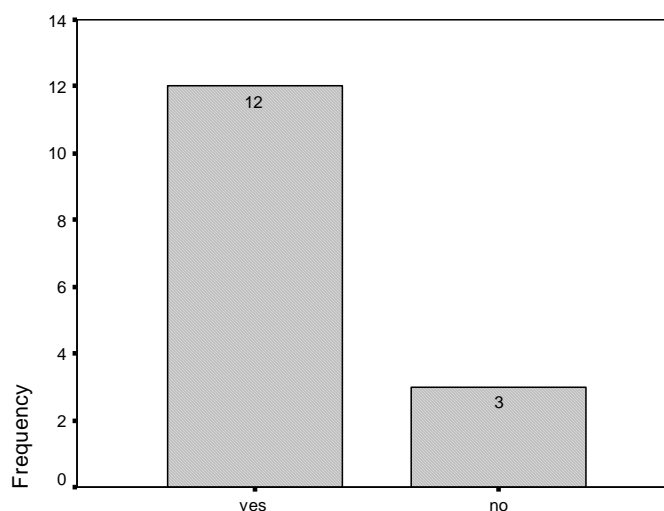
The information shows that most parents ($n=5$, 33%) accessed support through their GP. This can be attributed to GPs monitoring the parents' medication. Four parents (27%) said that their primary support was received through the non-government organisation or support group that they attended. For some parents this included support from mothers' group networks. Three parents (20%) said that they were current clients of the area mental health service. Two parents (13%) said that they were not accessing support of any kind at the time of the interviews and one parent (7%) said that his primary support was through private mental health services. The only apparent difference in utilisation of support services according to gender was that all the fathers were currently engaged with support services, whilst two mothers said that they were not currently accessing any type of support.

The use of support services by people with mental illness has been widely researched. It is suggested that service use is based not only on clinical diagnosis:

An individual's propensity to use formal health services for mental health problems is likely to be related to that person's willingness to adopt the sick role and help-seeking behaviour. Analyses of general help-seeking behaviour indicate that women are more willing to undertake such help-seeking actions. (Parslow & Jorm, 2000, p. 998)

Figure 11 provides an overview of the parents' history of inpatient treatment for their mental illness, as shown below:

Figure 11: Inpatient Care



The information shows that the majority of parents ($n=12$, 80%) had experienced inpatient psychiatric care. A gender comparison shows that 75% ($n=9$) of the mothers had experienced inpatient care, compared to all of the fathers (100%, $n=3$). For some of the parents this was private psychiatric services ($n=3$, 20%), and for some of the mothers this was at the private psychiatric mother and baby unit ($n=3$, 25%). Only three parents (20%) had never received inpatient treatment for their mental illness.

6.2.5 *Employment*

Worthy of note is the employment type of the parents. All spoke about their lives before they had children and after they had children and were coping with their mental illness. The majority of the women ($n=9$, 75%) had tertiary qualifications, and one was currently engaged in tertiary studies. Parslow and Jorm (2000) suggest that higher education and/or undertaking tertiary study is a positive enabling factor in utilising support services. All the men held vocational qualifications and were currently working but had been forced to retrain due to their mental illness. Figure 12 shows the employment type of the parents:

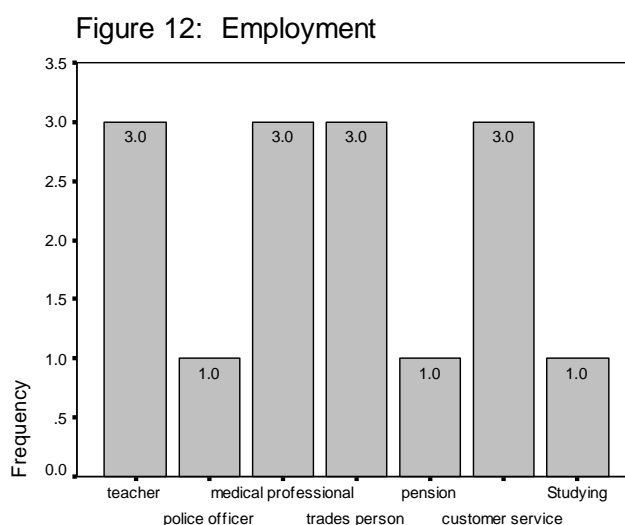


Figure 12 is a significant finding as the employment status of the parents challenges the generalisations that people with mental illness are not able to work and over represented in lower socioeconomic groups of society (SANE 2005; SANE 2006; Waghorn & Lloyd, 2005). This does not appear to be true in this data. The employment of the parents is discussed in chapter 9, as a general theme that emerged from the narratives was the difficulty of combining work with parenthood. The only parent not working was a single mother who also had a physical disability. The parents provided examples of the need to work for financial and identity reasons. This created issues in having enough energy left for their family at the end of the working day. This issue was compounded for the mothers parenting alone and working full time.

The information in this section has provided a general overview of the circumstances and realities of the parents' lives. A more in-depth picture is now provided about each parent in turn, introducing his or her children, their lives, and the issues that they faced as a parent with mental illness. The narratives are presented as much as possible in the participants' own words as they described their lives as parents with mental illness.

6.3 Introducing the parents

An overview of the parents who shared their stories is now provided. Frank (2004, p. 7) suggests that the importance of stories should not be overlooked:

Stories, unlike case studies in clinical ethics journals, are not models of correct responses to dilemmas, told so that others can act that way in similar situations. They teach us how to be serious about how we act wherever we find ourselves. . . . They speak clearly for themselves. But how to hear the stories - neither to decode them nor to admire them but to make them part of our own practices of generosity - does require reflection.

For some parents, their stories were of living through what Frank (1995) terms the 'chaos narrative', which occurs for people whose lives are chaotic due to illness or disease and who never imagine their lives getting any better. For some parents, their narratives were difficult to follow or comprehend due to the acuteness of their situation. For others, their stories were embedded within the 'restitution' narrative which Frank describes the most common form of narrative type. This type begins with health, which is interrupted by sickness but focuses on a return to health in the future. This narrative type is about assimilating health and illness, and the exploration of treatment. It is possible, for mental illness or physical illness to become a part of the person yet not take over their lives. Frank also describes the 'quest' narrative where "The interruption is reframed as a challenge . . . requiring the person to be more than she has been, and the occasion at first appears as an interruption but later comes to be understood as an opening" (p. 128). These terms have been used to explain how the parents operated and how they saw their mental illness within the context of their lives. Frank's theories continue to be interwoven into the narratives during this chapter.

The chaos narrative describes the lives of five of the parents: they were totally overwhelmed, despondent, and distressed by their mental illness. Examples of both restitution and quest narratives can also be found in the narratives of other parents who described their desire to get well and to be 'a good enough parent'. Some were also able to give examples of how their lives had been enriched in some way because of their experience of being a parent with mental illness.

This universal significance of stories is not some truth for all times and places. It's their ability to pose questions and offer examples that inform lives lived far from the story's particular time and place. The examples that stories offer - their heroes - do not tell readers what to do; rather they are examples of struggling to figure out what has to be done and gathering the resolve to go about doing it. (Frank, 2005, p. 7)

The sequence of the stories follows Franks (2002, p.76) “three underlying narratives of illness . . . these types are to be used as *listening devices*”. However, it is important to be mindful that “in any illness, *all* three narrative types are told, alternatively and repeatedly. At one moment in an illness, one type may guide the story; as the illness progresses, the story becomes told through other narratives.” (Frank, 2002, p.76).

6.3.1 Restitution

The restitution narrative was a strong feature of many of the parents in this thesis, in spite of Frank’s suggestion that restitution is not normally a feature of chronic illness, the mental illness of many of these parents whilst long term was not necessarily chronic. **Evie** was the first parent to be interviewed and her story was “filled out with talk of tests and their interpretation, treatments and their possible outcomes, the competence of physicians, and alternative treatments” (Frank, 2002, p.77). The interview took a while to arrange because her mental illness was not stable. Evie was a single, 40-year-old mother of one son who was 8 years old. She lived, without family support, but talked about a close group of friends she called her ‘psychological family’. She explained not only her diagnosis but also her interest in participating in this research:

I have bipolar disorder but it took them [doctors] about five years to come to that diagnosis. And that’s a problem because many of these mental illnesses have so many symptoms in common. So, in the early days, it was a lot of trial and error and trying that drug, having ECT, and just a range of treatments. They weren’t really sure what it was, they knew that it was a psychosis but they didn’t really know what to put me on. And I had better reactions to some drugs than others and I am trying to parent through that. Parents and mental illness, there is also that bias about that if you have a mental illness you are automatically a bad parent. There is so much more research that is starting to appear that is showing that it’s not the case and with adequate support services . . . it is not always in their best interest to have their children removed.

Whilst Evie did tell her story through the lens of restitution, she also showed elements of manifesto which is part of the quest narrative. She described her heartbreak over the loss of custody of her son but talked about how she would continue to fight for restitution but that this fight also contained “demands for action” (Frank, 2002, p.120). She reflected on how she had come to reach this point in her life:

I am probably a little bit different in that my illness started when he was born. I had pretty much, I guess, a normal upbringing - you know, went to university, got a career, and then decided I wanted a child, that it would make my life complete. I decided that I would do it alone if I had to and I did. Then, just the first five weeks was super-mum, was fantastic, loved it, and the normal sort of things. Then this severe psychotic illness arrived. So my son went into foster care when he was ten weeks. I had 32 psychiatric admissions by the time he was five years old. And he has been in and out a few times since then, mostly when I am having severe illness episodes. But, you know, in the scheme of things it's not so bad, some times were worse than others.

Evie was happy to talk about her life, which was rich and interesting. She was involved with advocacy work now but in the past had a successful career as a teacher. She was interested in research and saw its value in improving knowledge about parents like her who live with mental illness.

The second parent to be interviewed was Jen who also told her story through a model of how illness is to be told reflecting Frank's suggestion again of restitution (Frank, 2002, p.78). Jen was a widow in her forties with an 18-year-old daughter. Her home was a busy environment full of animals, possessions, and an accumulation of things that she had not managed to tidy away for many years. It was difficult to find a place to sit, and Jen became very apologetic. She acknowledged her home was very untidy and said that she did not want to live such a chaotic life. She appeared to be anxious and wanted to start the interview immediately. She was also visibly emotional about having the opportunity to tell someone her story:

I have an 18-year-old daughter and I have depression. This last episode of depression started in 2001 and I have been struggling with it since then. I had depression in the past which I don't think anyone took seriously enough. I think that I just suffered. I had post-natal depression till she was three. Then I got a lot better and then her father died, and I went into hospital after that.

At the beginning of her interview, Jen wanted to say that nobody had ever taken the time to listen to her. Although a qualified nurse, she had not worked for many years. She did not have any friends and rarely left her home. Therefore, she was very isolated, lonely, and angry about how she felt let down by the mental health services. She lived with her daughter and was concerned that she, too, would become mentally ill. She explained that history was repeating itself - again. She felt that her life had been deeply affected by her own mother's mental illness:

If I hadn't been taken from my mother as a baby, and if my mother had been a healthy person, I wouldn't be in the position that I am now. I would have been resilient to all the sad things that have happened. But because of that separation from birth it's messed me up. . . . It is when you are abused as a child, you learn to hide your feelings and pretend that everything is normal. That is what I did because I

had been psychologically and emotionally abused as a child. I had the skills to hide and look normal even though I was being traumatised. So that was what I did and it was being compounded. This is what happens [you get mental illness] if you come from an abusive background and I came from an abusive background, emotionally and psychologically. I've lost everything. I've lost my friends, you know, because of the depression and they just bugger off and you lose contact with them. It would be nice to have someone to share things with - I have never talked to anyone but you.

Jen's narrative was not the only one that was filled with stories of trauma. Other parents, too, talked about traumatic events that had contributed to their experiences of mental illness.

Sam (33 years) also had a history of depression. She was married and spoke about her partner in terms of positive support; she also had significant family support although her mother also had mental illness. Sam wanted to be cured because her life was busy; she had the "desire to remain *productive*" (Frank, 2002, p.86) explaining how she was working full-time and constantly juggling to maintain the balance in her life. Sam's family provided her with childcare so that she could continue with her career after the birth of her son. After the birth of her son her mental illness was acute and life had not fulfilled the preconceived expectations that she had about parenthood. She struggled "to get it under control" thinking that her mental illness was just a symptom of her new life path into parenthood.

I was feeling tired all the time and I didn't really want to go out and see people and things like that. . . . So I went to my doctor thinking that I was like lacking iron or something but she actually diagnosed depression.

Dani was 32 years of age and lived with her husband and three daughters; her illness was she hoped transitory. Before becoming a parent, she had completed tertiary studies in nursing and worked her way through to a senior position, which she enjoyed. She met her husband through her work. Shortly after their marriage, she became pregnant with her eldest daughter. Like most of the other mothers, Dani had not experienced mental illness before the birth of her children. Even after the birth of her first daughter, she was in denial about the onset of mental illness. She thought her behaviour was due to the enormity of entering parenthood and continuing to maintain a full-time career:

It got a lot more difficult when the kids came along. I found out the hard way that it was not as easy to juggle something like that. . . . I was involved in a lot of activity, and they - the doctors - saw it as manic behaviour. I was actually doing so many different things and it came to a point in my life where I just lost it and had a breakdown. I didn't know what was happening to me.

Dani then entered a previously unknown world where she had to come to terms with being a new parent and with the onset of mental illness. She reluctantly sought treatment and eventually was diagnosed with bipolar disorder but remained an active player in the remedy of her illness. She felt that this explained her need to keep busy but she did not find the diagnosis helpful. She had been staying up all night after the babies were born, making things, tidying the house, and generally keeping busy. She did not realise that this was not normal at the time.

Vinnie, who was a 42-year-old father of two girls fits within the restitution stories, however, as Frank points out (2002, p.94) “restitution stories no longer work when the . . . impairment remains chronic”. It could be argued that Vinnie’s illness remained chronic, or at times it appeared to be this way during his narrative. His house was quiet and incredibly tidy - the family was not home when the interview took place. Vinnie appeared to be a quiet reflective man. Part of his illness was reflected in this slowness, which was due to both physical and mental health issues. Vinnie had suffered a brain injury after he collapsed in the shower and subsequent to this had become depressed. Depression was now a major issue in his life, which he explained, had arisen through frustration with his new life:

I had all different brain function tests and that eventuated that I had the damage in the brain that happened was to do with emotion, reasoning, and some of the anger part of it, like mood - like mood swings and things like that. That is how it’s affected me, so it’s been very hard. Before that, I was fine 100%. Now I can’t take as much stress and I really avoid problems, sort of things, like, I really have to step back and calm down and really look at the issues. So, it’s really hard and I’ve had a lot of short-term memory problems and that’s how it’s really affected me.

The interview with Vinnie was one of the shortest as it was difficult for him to always remember things. He mostly talked about how life was now and how he missed the old Vinnie. He had not reconciled himself to the new Vinnie.

6.3.2 *Chaos*

Helen was 28 years old and living with her husband and two young daughters at the time of the interview. On entering her house she was quick to explain and provide “denials of the chaos narrative” (Frank, 2002, p.103). Helen had multiple issues, she was juggling her career as a teacher, she was living in a difficult marriage which was strained and talked of periods of trial separation. Whilst her husband had been

supportive of her in her mental illness, he also had his own comorbid issues with mental illness and alcohol use. She believed that it was these problems which put pressure on their relationship rather than her own mental illness. Helen's home was a reflection of her own chaos; she tried to sort through the piles of toys, papers, and books to find something to settle her daughters before starting her interview. Helen was very specific in the details of her experience of mental illness. She was fascinated with psychology and learning about why people do the things that they do. She talked about her long history of mental illness which had commenced during childhood:

I already had an underlying depression issue before I had children. I had already had episodes of major depression during my teenage years and perhaps even going younger than that, but I didn't know it at the time. . . . My brother has severe depression and my sister and my cousin have bipolar, so I know it's in the family and I know it's not just me. . . . As a child . . . it was not wanting to eat and getting that anxiety thing in your tummy and just feeling like you are looking through a real thick cloudy window into the outside world and not feeling connected with it. It was as if people are laughing but not understanding how they could think that was funny . . . utter dissociation really. I felt pretty unloved because Mum made funny remarks when I was younger. I was a hyperactive child and Mum said things like, if you don't behave yourself when you are older, you will go to the naughty girls home. And so things like that started falling into place. . . . I had real issues and I think that what I wanted . . . I wasn't getting attention from my family; they were too involved in their own issues to really think about me.

She had begun to associate with feelings of difference at a young age:

I remember going to school and always pretending to limp. They had disabled kids at school, and I remember just feeling for those kids and having an immense, like, just a compassion for them. I became friends with a few of the disabled kids and I remember even trying to pretend to my other friends that I was one of them, and I'd use the crutches. I used to come home from school and play [about being disabled] and I knew that I wasn't meant to do this at that stage. I knew at that age you aren't meant to play and verbalise, but I would.

Subsequent to the interview, Helen's life became more chaotic as she separated from her husband and lost custody of her eldest daughter. Chaos also dominated the life of 38 year old **Ursula** who was a single mother. Resembling Helen, her story was filled with intense suffering from life-long acute mental illness. Ursula's mental health issues were also compounded by physical disabilities she had received due to a car accident. Until recently, she needed to walk with the aid of a stick. We sat outside her rented unit with the sound of the ocean lapping in the background and the sun warming us gently as she reflected on her journey:

I don't ever remember as a child being happy. But when you look at how my life was it could just be situational depression. Dad adopted me, he wanted a little girl, and she [her mother] couldn't have any more children. DoCS people don't realise the hell of a

life that I've had with her and my brothers. My brother was physically violent and was physically abusive.

Whilst Ursula had signs of mental illness from a young age, it went undiagnosed until her late teenage years because of her family situation. She felt that part of the reason for this was her family background had stripped her of self-confidence and she felt it had made it difficult for her to feel able to access support. Even when she became a parent, she felt that her family undermined her ability as a parent:

I had so many diagnoses before that. I was diagnosed with just depression, then I was diagnosed with bipolar or something else. I do get a bit over it, totally. I have schizoaffective disorder. . . . It is all denied, and because I have a mental illness, people believe everyone but you. They say, oh well, she has a mental illness, she is being delusional, you know. But I have a lot of insight into my mental illness and I know when I am sick, and take myself off to get my medication changed.

The interview with Ursula was emotionally draining; some of her stories were so horrific that it was difficult to just listen without becoming upset. Ursula's chaotic life had changed her out of any self-recognition (Frank, 2002, p.103). Her narratives are explored in more detail in Chapter 8, which addresses the parents' experiences of mental health services. After the interview with Ursula, the healing nature of the interviews, which was good for the parents, left me, at times, fighting for breath under the weight of these very precious but moving narratives.

Mike, a 39 -year-old father of three, lived with his wife and children. Mike was clearly unwell and he was reminded before the interview started that it could be postponed to another time when he felt better. However, he wanted to tell his story and, therefore, the narrative was gratefully collected. Mike had been aware since his early twenties that his behaviour was potentially self-destructive but continued along this path for a number of years. Mike was not unfamiliar about living in a state of chaos as he was aware of a family connection with mental illness, so chaos had long been a feature of his life:

I never really had any self-worth, and was self-destructive since the age of 21. I used all my energy in the Special Forces and I was pretty self-destructive trying to find out the key to life. I have always been an extremist, you know, never ever flat lining. . . . I got full of angry pills which weren't healthy . . . But I was very successful at it [self-destructive behaviours]. My parents separated when I was probably 13 or 14. My father was a successful banker and he ended up dying - he was obviously manic depressive. He was very insecure, paranoid. He killed himself, although nobody ever said that.

Mike felt that his family kept him safe. Without them, he said he would not be alive. As if to explain this poignant comment, Mike introduced me to his wife and his children. His wife was attentive to his needs and often added comments sporadically during the interview. It felt as if it was her way of being concerned about him, as he was clearly unwell. The interview with Mike was long and difficult as there were times when his behaviour became erratic. He would throw his arms in the air and would shout aloud for what felt like a few minutes but was probably only seconds. The children, all watching a film in the next room, seemed oblivious to this behaviour. His wife would pop her head around the door, and I would sit and wait. Then, without saying anything, he would continue from where he had left off and we would begin again. We continued in this way and I would check if he was all right to carry on, which he did well into the night.

As with many of the parents who were in the chaotic stage of their illness their interviews were challenging to follow and sometimes difficult to understand, **Jane**, 44 years of age was no different. She had been one of the first parents who had volunteered to participate in the study; however, attempts to make arrangements were always interrupted by the fragility of her mental health. Three times interviews had been arranged and each preceding time, she had been admitted for inpatient psychiatric care and it was postponed again. Jane remained anxious to tell her story:

I don't have a mental illness but sometimes I just don't cope. I am doing what I can do. I am living, working and doing it all on my own with two kids. There is lots of stuff that happened to me in my life and it's all of that stuffing me up. [. . .] I just want to be loved and I want someone to love me. I have no-one; no-one cares about me. I go to work and come home and lock myself in the bedroom. I am not bothered about life.

Jane did not have a diagnosed mental illness, but over the course of time that it took to arrange the interview, she had three psychiatric admissions. On all of these occasions, her children went into foster care because she did not have any family living nearby. Jane called after the interview to say that she had another psychiatric admission, which had provided her with a diagnosis of post-traumatic stress disorder that she was happy with.

The last interview of the chaotic parents was with **Jasmin**. Her interview came after a gap in referrals of potential participants for the study, at a time when it was being considered that saturation point had been achieved. Jasmin was 31 years of age and living with her partner and child. For Jasmin, parenthood was particularly special

because she had longed to become a mother. Still, this perfect or imagined reality was shattered during the end of the pregnancy when she became desperate for the baby to be born and felt that no-one was hearing her distress:

I had wanted a baby for almost six years and would have done anything to get one . . . that was how I was thinking before I fell pregnant with my son. . . . I wasn't happy and the doctor made me go past 40 weeks without any help and support and I was starting to become depressed. . . . I went home and said to my husband - I told him that I was going to cut the baby out as I couldn't stand it anymore.

Jasmin verbalised her continued distress about entering parenthood, which she felt had exacerbated her mental illness. She continued to ask for help but felt frustration due to people not listening to her.

6.3.3 *Quest*

Jo was a 31-year-old health professional with much theoretical insight into her mental illness; she spoke eloquently “the language of automythology . . . with words like *momentous*, *decisively*, *universe* and *destiny*” (Frank, 2002, p125). She was married, had one son, and had mental illness prior to his birth. She attributed the severity of her symptoms after his birth to two factors. Firstly, she had stopped taking her medication whilst pregnant to reduce the risks to her child, but secondly she retained anger at her colleagues who had failed to take seriously her concerns about her mental health status towards the end of pregnancy. Jo was able to clearly identify a shift in her attitude towards parents with mental illness reflecting her individual change as a result of her quest. Previous to the birth of her baby she had thought that mothers who struggled were all just ‘bludging’: “It’s been like a real eye opener for me and a gift. I think, you know, to get off your high horse and meet other people . . . like me”.

Seeing herself like other parents with mental illness, as opposed to a medical professional who tried to provide help and support to mothers like her, challenged not only Jo’s reality but also her years of medical training. She called this new reality a ‘gift’. In this way, Jo was able to incorporate this into her professional practice, without disclosing her issues “an unwilling hero, but he is never an unwitting one” (Frank, 2002, p.123).

Liz who, at 25 years of age, was the youngest parent in the study also lived a quest in that she talked about accepting her illness as part of her life. Liz was living with

her partner and her son. Liz talked about feeling that she was disadvantaged in her role as a parent even before her son was born, due to her age and background of abuse. She reflected on this:

I coped, you know, because I had a lot of things happen in my life and I coped . . . with everything really well, but then I think that everything caught up on me after I had him.

Liz was reflecting on the trajectory of parenthood where she walked a similar path to her mother who had mental illness, and had lived with her children and with a partner who was violent and abusive to the family. This intergenerational impact was a flag to the medicalised system and prevented Liz from interacting with her new born child due to the process of assessing risk when the baby was born. Liz also supported her partner who had mental illness. Liz attributed the early intervention in her parenthood (directly after birth) as part of her problem, which resulted in her breakdown:

I had my son and the birthing experience wasn't the best and I wanted to hold him straightaway and start breast-feeding and they took him . . . from me . . . for three hours. And I couldn't hold him or anything and he was in a totally different section of the hospital and I cried the whole time. I was saying, I want my baby, and I was saying that I wanted my partner and I want my mum . . . you know. But they said, no you can't see anyone. . . . It was so ridiculous.

Darren, a 38-year-old father of two lived with his wife who he described as supportive, but to his dismay, he also lived with his parents' in their house. Darren's life had been marred by mental illness. The onset of mental illness was not a surprise to Darren due to family connections. This long history of mental illness provided him with a different perspective:

I had voices since I was about 12 years of age, but I didn't really know that was unusual. So my imaginary friends were a little bit more imaginary or real than most people's. I look back now and realise that maybe things weren't right - I was always feeling, like, manic, but the original diagnosis they gave me was bipolar. . . . The generations pass it on, my dad's brother is schizophrenic, and my grandfather was schizophrenic. I knew that my grandfather was different, but towards the end of his life, he came off his medication and he was quite normal, you know. I never knew him to be any different, but Dad said when they grew up he was very different, he was quiet and withdrawn. But I get like that, too, you know when I am going through an episode and I put the walls up around me so that no-one can hurt me.

Darren was now settled into the routine of family life with his wife, his story reflected Frank's explanation of *manifestos* (Frank, 2002, p.120) "the truth that has been learned prophetic, often carrying demands for social action". His life was an exemplar of change and action to assist others with mental illness. He was very proud that at 38 he had begun an apprenticeship and undertaken a career change.

This choice had been difficult at the time. Due to his mental illness, his previous career as an electrician had resulted in an electric shock at work that nearly killed him. He pursued a new career in joinery through an organisation that supported people with mental illness but also helped in supporting other people. Darren also found solace in his involvement in his church and a local support group for people with mental illness.

Nita's story bore many similarities to the others on a quest, at least in the beginning. Nita was a 36-year-old public servant, immaculately dressed and ready for work. She began her narrative explaining her situation:

My husband and I split up when my son was three months old. I was depressed; I thought that it was post-natal depression. Although I didn't really know that anything was wrong with me. But other people said that things weren't right, and perhaps they could see what was happening. I knew that I couldn't carry on and I couldn't be there with him anymore, but then I was still bad [with her mental illness].

Nita talked about the past - what she could remember, as she said it was cloudy; she saw her mental illness as an “interruption . . . reframed as a challenge” (Frank, 2002, p.128). After her relationship had broken down, she had suddenly become not only a new mother but also a single mother. Nita was still single - she attributed this to her experiences when her son was born. She said that because of her experiences of mental illness at that time, she did not think that she would ever be able to have another child. The fear of another episode of acute mental illness would far outweigh the experience of parenthood again. Like five of the women Nita was facing parenthood alone.

Sarah was in her 30s and wanted to participate in the research but wondered what she could provide. Her story provided a *memoir* (Frank, 2002), and as with the others, was very valuable. Sarah was married with two boys. Her life with mental illness had been shaped when her mother died. She thought that this was the time when she had first had ‘issues’ with coping: “Not long after that [the death of her mother] I had to go to the doctors and get sleeping tablets because I wasn't sleeping and wasn't coping.”

After her baby was born, her pattern of symptomology related to not sleeping was exacerbated due to the needs of her young child. She said nobody listened to her cries for help, and then her grandmother died. Her grandmother had provided her

with parental support. She was also the person Sarah had modeled her ideal of parenthood upon:

About six weeks after he [her first child] was born, my grandmother died and we were close. And I think that it's in my nature to be strong for everyone else and then once everybody else seems to be ok, then that's when I just fell.

This position resulted in her mental illness becoming so acute that she was admitted to inpatient care.

6.4 Chapter summary

This chapter casts light into the lives of parents with mental illness. It provides a picture of the demographics and stories of this group of people who remain on the margins of society hidden by stigma and submerged by overwhelming demanding discourses about parenthood. It becomes evident that they are to a great extent everyday parents who also happen to have mental illness. Their stories provide a snapshot of their jobs, their qualifications, and other aspects of their lives as parents. They are grouped according to Frank's (2002) typology of storytelling by those living with sickness.

Parenthood can be seen to have provided a significant identity for the participants. Whilst some had encountered mental illness before they became parents, most were delighted to enter the parenting phase in their lives. For some, the joy was overshadowed by other intense and unexpected feelings that signified the onset of mental illness.

In the chapters that follow, further analysis of the parent's lives, as told through their narratives, provides an insight into specific issues that they faced. The next chapter, Chapter 7, begins with a discussion about the concept of 'a good enough parent'. This phrase was used by some of the parents to explain how they felt about the societal notions that created pressure for them to attain an idealised standard associated with parenthood. 'A good enough parent' as a status does not always sit easily alongside the diagnosis of mental illness and the attached expectations and stigma. In Chapter 8 the discussion engages with the parents' experiences of mental health treatment, with examples of good, bad and gaps in services. Finally, Chapter 9 provides an insight into how parents manage to juggle the different aspects of their lives; illness, their working lives and parenthood.

CHAPTER 7: RISK AND THE GOOD ENOUGH PARENT

7.1 Introduction

This chapter focuses on the parents' narratives specifically, where they discussed thoughts about how they could be 'a good enough parent'. The notion of 'a good enough parent', a theme that will be continued throughout the chapter, is often found in the literature about parents with mental illness. In this study, the parents used this term to describe how they felt about their status as a parent with mental illness. Determining who or what a good enough parent is appears to be strongly related to societal expectations, professional power inherent in assessments, and systemic expectations regulated by ideologies about parenthood. The question of what is 'good enough' is difficult for any parent to answer. As one of the parents who participated in this research project said: "I know that I am not a bad parent - I know that I was a good enough parent and I know that I did the best that I could under the circumstances (Evie).

Parents used the phrase 'good enough' themselves to try to explain how they were often made to feel incapable of being 'a good enough parent'. Inherent in these stories were their concerns about child protection services and the possibility of having their children removed, due to questions about parents with mental illness being able to care for children without adequate support. Frank suggests that when people have an illness or disease they are often viewed as a body under treatment, as opposed to being seen as individuals: "Images of illness and disability are generated as part of the complex representations that any society creates and perpetuates. Individuals are then defined in the terms that these images propose" (Frank, 2004, p. 60). This chapter looks at how the parents who participated in this research coped as their identity was transformed by both parenthood and mental illness and how they managed these new images in the context of prevailing discourses of risk.

This chapter will discuss a number of issues raised as the parents told their stories. First, what it means to be a parent, for example, the parents talked about their joy at the birth of their children and their distress at the onset of mental illness. They also discussed their attempts to attain the status of 'a good enough parent', and the

support they had and how they found this. Next, parents talked about risks associated with their mental illness. This section is split into four: the parents' lived experiences of risk and how they understood it; the real risks that their children were exposed to because of mental illness; imagined risk, often policed through DoCS, which was always a threat to their ongoing status as a parent; and the risk of isolation and lack of support. Finally, what parents felt about the effects of mental illness on their children is discussed. This study did not seek to gather views from children as to how their lives were affected by their parent's mental illness, as research is available on this subject (for example, Camden-Pratt, 2006). However, in studies that focus on the lives of children who live with parents with mental illness, the experiences of their parents are often overlooked. This research, seeks to redress this imbalance and show how the experience of mental illness is for parents.

7.2 What it means to be a parent

In order to situate the discussion of how the ideological status of 'a good enough parent' can be achieved, this concept is nestled amongst the realities of what it meant for the participants to be a parent. As Frank points out (2004, p. 9), "accommodating illness has never been easy, either as an attitude toward life or as a practical problem." For the parents who lived with mental illness prior to entering parenthood, their reality and expectations were different from those who experienced mental illness after parenthood. They often they talked about their concerns during pregnancy and trying to access help in advance of the birth of their children.

Darren and his wife had discussed whether or not to have children. Darren was concerned that his history of mental illness would not only affect his ability to be a good parent but that a genetic predisposition to mental illness would also put his children at risk. Consequently, he sought to inform himself about the risks of passing his illness onto his children:

One thing I was worried about before I had the two children was that I wouldn't pass the illness on. I actually went to see a female doctor who specialised in men's things. I asked her to speak to someone about punching numbers to find out about passing it on because I was diagnosed at the time. They said the chances were probably fairly high, like one in 200 000, or that sort of thing. It was enough to make me concerned.

Although the risks were fairly high, Darren and his wife decided to have children. As Devlin and O'Brien (1999, p. 20), found in their research, "While there can be little

doubt that there is some level of genetic influence in the development of mental health problems, it is not clear in the majority of cases whether it is the disorder or a more global vulnerability that is inherited.” Taking that chance left Darren feeling anxious; he spoke about wife’s pregnancy as a stressful point in his life:

I swore at one stage that I wasn't going to have kids. Then my wife and me decided we would have kids. Then when the birth came around I just went off and said this prayer, and that's why I have got two girls because I went and I prayed aloud for girls. I said I don't want it to go any further in this family. I look at my girls and they are quite happy, but I am always looking at them to see if they are behaving differently or anything like that, because I am aware of the triggers and stuff like that.

Parenthood establishes a person as part of an adult society with the related expectations. A first pregnancy or the birth of a child marks a significant turning point, which invites subjective societal views about parenthood (Krumm & Becker, 2006), these are now explored.

The birth of his children provided a positive impact on Darren’s life:

I have two wonderful girls and a wonderful marriage, and I am so far away from where I was 10 or 12 years ago. If you had told me then that I would sitting here doing this interview saying about schizophrenia, and all that sort of stuff, I would have said you need the straight jacket.

In contrast, Jane, Jo, and Ursula had concerns about entering parenthood also related to their history of mental illness. These concerns were specific to their experience of mental illness and their requirement of additional support during this transitional period in their lives. However, they all found little support or generosity toward their specific needs.

I remember the obstetrician asking me [about mental illness] . . . because I went private, but it was sort of like off the cuff. And when I said, yes, I had depression for years and I thought that it was reasonably important he didn't do anything, he just went, oh yes, well, whatever . . . like, you know, and they asked me again at the booking in at the hospital. Again I think that they just said, yeah, oh right . . . if it is bad then, you know. But they didn't offer anything. It seemed like it was just a question that they needed to tick off, they didn't really have anywhere to go with it . . . I was starting to feel a bit angry that I was pregnant and all that sort of stuff . . . like, you know that I hate the baby and this sort of stuff. And when the baby came, it was just like, almost like, from the minute he was born just this anxiety and panic about it (Jo).

Jasmin’s had also felt desperate and wanted to ‘cut her baby out’ whilst pregnant, but felt immediate relief when her baby was born, “I loved him from the moment he was born.” Ursula also had complications during her pregnancy due to her mental illness:

I don't think that pregnancy suited me much. . . . When I fell pregnant with my son, they took me off the drugs because he could have been retarded or something. During my pregnancy, I was catatonic. I was off my medication until my son was born. My friends would sit on the bed and tell me to talk and I'd move my finger like this and Mum would put food in front of me. . . . It's not as bad as you think; it's just bad for everyone around you.

Ursula's story of being catatonic through most of her pregnancy was one of the most acute stories told. For other parents, there were no complications to entering parenthood. They had been excited about becoming parents; mental illness was not an issue they had ever considered. Parenthood brought a different perspective on life and allowed them time to enjoy their lives. Mike spoke of his joy at being a parent:

I like to do things with the kids and get them involved. I just smother the crap out of them with love; there is no shortage of that. In addition, I just think that, whatever, man, I just love my kids.

Parenthood marked the beginning of a monumental journey. For Evie and Dani becoming a parent also marked the beginning of their mental illness. The birth of their children became a time of confusion, despair, and disbelief clouding their lives. Their stories fit within the 'chaos narrative' whereby "its plot imagines life never getting better" (Frank, 1995, p. 97).

The first year of my son's life, we spent probably three or four months in hospital [psychiatric] together. We went to a mother and baby unit and that was probably one of the most difficult stages because I was really sedated and I had very high expectations of myself as a parent. I think that maybe because I had been thinking of myself as a parent. I had been a teacher for many years in the childcare field and I had many nieces and nephews, so it was not as if I didn't know how to parent (Evie)

I wasn't getting any time to myself, like I wasn't sleeping, so sleep was a big issue. I was awake at night doing things like doing bottles. I was vacuuming the floor and loading wood into the fire, and I was just doing things, all this crazy stuff, when I should have been in bed. I was not myself in those days, and it's weird because you think, well, how did I get like that? (Dani)

Even Darren, who had carefully planned his entry into parenthood, also found the birth changed his world and caused his mental illness to become acute.

I managed just to hang on, and I don't know how - it's just I got an electric shock at work because I hadn't slept for days. The birth of your children is just the best day of your life and no-one can take that away from you. It is joy I am sure everyone experiences. It was one of the most spectacular things, you know, seeing your child born. I was probably a bit more extreme with my mood, you know. It's hard to explain but I was quite manic with my mood.

The societal notion of 'a good enough parent' is accompanied by discourses which suggest that there is a strong biological drive to care for your child. Just as people sometimes idealise marriage, they can also conjure up romantic and illusionary

beliefs about parenthood. Many of the parents believed parenthood would be easy, assuming the biological notions were true. They had imagined fulfilling these idealised expectations:

Everything was just going to fall into place, and for the first few weeks it did. He was feeding well. He was a good baby, the routines were fine, and caring for him wasn't a problem. Then, just bang. The only thing that I noticed was that it started off like a post-natal depression. I did get sad - I started feeling that I wasn't a good parent. I remember thinking to myself that he would be better off without me and that I should put him up for adoption . . . I was just so excited about having this baby ... when I started getting these feelings that I wasn't a good parent. Everyone was saying that you are fantastic and you do everything for him. It was this sort of guilt ... then I think that lack of sleep didn't help. I did feel really tired . . . I had 32 admissions in five years - I had a lot of admissions and one of them was, like, three or four months straight, and it was very distressing for him (Evie).

I got pregnant and everything was fine and I was really enjoying it and so calm being pregnant, and then it just sort of hit me. The baby was born and it was traumatic because I was so idealistic about how I was going to give birth, so I was disillusioned with the whole thing, that the birth didn't go the way that I wanted it. I was so happy and normal then during the pregnancy and I did learn about things, but I remember just feeling alien. I remember feeling like, almost like, when I heard myself speak it was too loud - it was almost deafening to me, it was really strange. So there was a bit of altered perception going on there, and I was aware of that and it freaked me out a bit. (Helen).

I didn't want to admit it, like, but that's why I didn't tell anyone. I couldn't understand why I couldn't look after them. Like I'm thinking, why am I feeling like this way? This is just ridiculous; this is what I am born to do, to look after children and to make sure that they are safe. They are my children and what have I done wrong? (Dani).

That feeling inside, of it sitting on your chest. I don't think I can ever have any more children because of it (Nita).

Breast-feeding was also a major issue and affected the parents' understanding of their ability to be 'good enough' in similarity to the findings of Bortiz Wintz (2004). For Helen, breast-feeding became an obsession, for Sam and Nita, it was an arduous chore. Liz and Evie had both been distressed when they were pressured to give up feeding their babies due to medication. In contrast, Jo found ending breast-feeding liberating.

I did start getting very perfectionist about breast-feeding . . . I was being very bizarre in that I was just really strange and so obsessed with breast-feeding. I just felt really off kilter then and really weird, and because I couldn't get it right [breast-feeding] it was freaking me out and I was even paranoid when people went to touch the baby (Helen).

I had breast-feeding problems and I had a caesarian and all this stuff happened. So then . . . the breast-feeding was a real problem and it was awful. And, like, I was being pressured from everywhere to keep going, keep going, and it was just not working. . . . And I was crying all the time and my hormones just went haywire and I was thinking that I wasn't well (Sam).

Breast-feeding made me feel more as if I was a failure. I remember that I did it when we were at the hospital. I did it a lot of the time when I was there, but I think that's what made me think, no - that's it. Then the midwife came around, and I said I had finished doing it, and she said that I shouldn't have. But I just wasn't coping (Nita).

They got someone in - a social worker - and they talked to me and they wanted to know everything. And that was a trauma as well. I would never do anything to my baby and I was so . . . so angry and I was angry the whole time . . . how I was treated and they were pushing me to bottle-feed him and it was awful (Liz).

Stopping breast-feeding and starting medications again just made a huge difference in terms of . . . stop panicking all the time and being able to have more interest in actually how to look after the baby, and starting to get on with things (Jo).

This discourse suggests that breast-feeding is best for the child. It fails to account for the risks inherent in breast-feeding when a parent is required to take anti-psychotic or anti-depressive medication. Parents did not talk about how this affected their decisions as they could only see the failure to breast-feed as an individual deficit they were responsible for and attributable to their status as mentally ill. An oppositional point of view would be to see these parents as being insightful, being careful, turning to alternative methods of feeding to reduce the risk of their children ingesting the drugs the parent was being treated with. The discourse is, however, challenged when a parent is identified as a risk to her child, breast-feeding is then deemed to also be too risky for her to undertake.

It was important, therefore, for the parents to be listened to. Many of them voiced frustration at the lack of agency in that they were supposedly in hospital after the birth of their child, but were not able to access help and support to deal with the issues raised by their mental illness. One of the most valued support systems appears to be found through family who were often the only ones entrusted with the knowledge of the parent's mental illness.

7.3 Support from partners and family

Muhlbauer (2002) has suggested that mental illness should be seen as a family process. The tragedy for many parents was that whilst they had supportive families, reaching out and asking for help shattered their illusions that they were coping. The focus of pre-natal care is often on women and their bodies which are both medicalised and placed under a risk discourse. Sarah and Liz talked about the issues raised by parenthood which was a new role for which there was no gradual transition. Typically, many expectations of parenthood are derived from societal discourses, the

media and observation of others; preceding birth, there is rarely a time when parents have the opportunity to practice or try out their new role.

It's kind of then you think, am I really prepared for this? . . . Just coping in the first year of being a parent. It is life changing and it's brilliant, too. But, yeah, it is also very demanding and there are the stereotypes that you see on television and this . . . about the perfect parents, and they just breeze through parenthood. And I was going for nearly six months, you know, telling myself look at me - I am fine (Sarah).

Everyone focuses so much on the pregnancy and the labour, and there you are in the big wide world and no-one prepares you for that (Liz).

Parents with a partner appeared to reduce their anxieties about not being good enough. Partners played an essential role in family life especially when the mental illness of the other parent was acute. Examples of this are provided by Jen, Dani and Jasmin. Jen knew that her husband had bonded with her daughter. She rationalised this with her own feelings of estrangement from the child:

I read somewhere if there is one bad parent and one good parent that the child will be fine. So my husband was in love with her and he gave her contact [that Jen could not give her]. I didn't provide for her mentally. She was neglected. After my husband died, my daughter transferred her affections from her father to me, and I had this little girl who adored me and I thought that was how life should be and I deserved this. After he died, she would sleep in my bed and have her arms wrapped around my arms and her legs wrapped around my legs. I had to sleep like this, and I had to go to bed with her or she would stay up with me. I couldn't even talk coherently. [But when] Her father was there, so that was ok, but then he went back to work and they all said, now you have to look after her. I said, I am not well enough to look after her. I couldn't give her the eye-to-eye contact that children need, which was very detrimental. It was very hard caring for a baby when you have got psychotic thoughts going through you to concentrate long enough for you to do anything (Jen).

I was involved in a lot of activity - the doctors see it as manic behaviour because I was actually doing so many different things. But it came to a point in my life where I just lost it and had a breakdown, but I didn't know what was happening to me. My husband would throw a lot of 'sickies' to give me a break because he would know that I hadn't slept all night. I was embarrassed for them to see me the way I was. It was terrible, and I said to the nurses that my eldest knew what was going on, and she tells her friends and her teachers that I am in hospital and she even brought up dying, like, I think my mum might die. Like, everyone knew. It has been the hardest experience for our family. My husband had to take on extra responsibility because I haven't been around and I play a huge part in this family, I realise, if I am not well. I guess if it was a physical illness or something like that, then you are physically limited and I was very limited for weeks and months (Dani).

My partner was mainly supportive at the time but sometimes we would have our bad days but we helped each other through it (Jasmin).

The issue of single parenthood was raised again during discussions about risk: for example, when the parents needed inpatient psychiatric care, those who lived alone with children were more likely to need support and help from DoCS in caring for their children and is well documented in the literature (for example, Ackerson 2003;

Mowbray et al., 2000). Some of the parents who were parenting alone, for example, Jane missed having someone to share things with; all she wanted was not to feel “hopeless, unloved and uncared for”.

I had been telling him the whole week that I felt like committing suicide and I wanted to die and he kind of just . . . he didn't help me.

Support from family was also important for the parents. Whilst Sarah provided a positive example of this Helen provided a different view of how family support created additional stress in her life.

I was sick, you know, and Mum took him during the day and when my husband was out, and he would pick him up. And that probably went on for about six months. It was very hard then and it was sad because I missed a lot of his younger times as I couldn't really look after him. And if I did, it was just maintenance things really (Sarah).

There were a few other little trigger things that were just putting that little bit more pressure on me. In terms of parenting, everything I was trying to do with the baby was wrong, because everything my mother said was right and my thing was wrong. I said to my husband, I don't feel ok, my anxiety is bad, I just can't focus on anything, and I just felt like not eating things. Flashbacks from when I was younger and when I was not able to eat because of the anxiety, and I thought the ground was breaking up around me (Helen).

Helen, Ursula, and Liz all lived with partners who also had mental health issues. They acknowledged that in their experience having two parents with mental illness created significant issues in their relationships which often impacted on their children.

The youngest was freaking out; she was, like, looking and shaking [when the parents are yelling]. And the older one was, like, don't you do that to my mummy! And they were so affected by it (Helen).

I never dreamt that people could do that to their own child, but he has schizophrenia - although you cannot blame what he's done on mental illness. I reckon we are going to have to be careful with him [her son] because of the trauma - trauma is really mental illness. I have a hard time with my son because he has been hurt badly by his father and he just yearns for a lovely male figure. His father is very self-centered, he locked him up in the house and went out at night and made him watch scary movies. That is the trigger [raising your voice], every time his father raised his voice he knew that something was always going to happen to him (Ursula).

Liz, by contrast, talked about her partner being supportive especially after the issues that they had with intervention after the birth of their children and the investigations in the hospital over their suitability as parents. Whilst questions were raised about Liz's ability, her partner was supportive until his mother had come to stay with them and support them:

My mother-in-law came up and she did the same thing, you know said this . . . and that . . . it was just awful. And me and my partner started fighting because I can't stand his mum and he, you know, he likes her so . . . We had a huge fight and then he ended up telling me that he had taken all of his anti-depressant tablets. And he was on them because his dad killed himself, and he's still not over that because he's never spoken to anyone about that or all those issues . . . And I've gone, oh god, and rushed him to hospital and yelled at him the whole time in the car on the way to the hospital. I was screaming and I was so angry saying you know how you felt when your dad killed himself, why are you doing this to our son? (Liz).

Some parents had become aware that there was unacknowledged mental illness in their own families. Corrigan & Miller (2004) suggest that often family distance themselves from mental illness due to shame, blame and fears of contamination. Jo reflected this when explaining her father's attitude to mental illness:

He doesn't really believe in it, like he just thinks it's all a big made up kind of modern life thing, you know. I don't know, she [her sister] just doesn't like to think about it or talk about it [mental illness] (Jo).

However, reaching out for support and finding that people do not want to assist, especially when they are family, created an increased sense of isolation for the parents. Gray, Robinson and Seddon (2007) also suggest that inherent in this isolation is an increased likelihood of risk.

7.4 Risk as a lived experience

One of the greatest concerns for the parents in this study was that they might lose custody of their children. The discourse of risk and the political orientation to risk management within health and community services create real concerns for parents with mental illness. Lupton (2003) suggests that the risk discourse is primarily a tool that could be used in order to blame parents for their mental illness. As a result, government is able to apply regulation over the private institution of parenthood. Risk discourse is embedded within ideologies of mortality, danger, and, in this case, aspirations about 'a good enough parent'. Risk, as it is used in modern society, therefore, cannot be considered a neutral term.

Modern day lives are increasingly regulated through risk. Green (2007, p. 396) draws on the work of Beck and Giddens; he suggests, "One of the defining beliefs that emerged from the industrial era was that we could predict, manage, and control our exposure to dangers and hazards." The medicalised discourse is now strongly

associated with assessing risk in order to prevent the dangers associated with certain identified conditions; one of these conditions is mental illness. Risk, is a fluid concept, continually affected by the policy of the organisation assessing the risk. During the interviews, the parents appeared to speak about two different types of risk. Firstly, they talked honestly about the real risks created by their mental illness. They did not try to disguise times when their mental illness prevented them from caring for their children. They also talked about how they saw their mental illness affecting their children.

The real risks created by mental illness, are often clouded and overlooked due to the discourse of 'a good enough parent'. This discourse perpetuates the imagined risks, created by the discourse of 'a good enough parent', which is enforced by DoCS. The risk created by the discourse leads to further risks, in that it subverts the parents' attempts to access help and support. Some of the parents acknowledged that there were times when parenthood became too difficult. These were times when they needed support, help, and understanding, and had to make the decision of how to get the support that they needed. One of the critical issues when talking with the parents about risk was the different understandings of what constitutes risk and how risk is assessed. In NSW, agencies do not share a common risk assessment framework, they rely on the practice knowledge or policies of the particular agency (NSW Health Policy PD2006_104) informed by state legislation (Children and Young Persons Care and Protection Act 1998) and Interagency Guidelines (NSW Health, 2006). For some agencies, risks to children from parents with mental illness are not considered in their assessment of the parent.

7.4.1 Parents talk about real risk

Risk - as a discourse was applied to the parents by professionals and communities when their mental illness became apparent. Most of the parents did not talk about risk directly attributable to personal risk but at certain times on their illness trajectory some had considered that there might be risks to their children due to their mental illness. Again, most parents were acutely aware that if their mental illness became known, this would result in increased surveillance from the Department of Community Services (DoCS). In her research, Sands (1995, p. 91) found that "mentally ill mothers did not describe themselves as mentally ill and preferred to speak about problems, stress or nerves". This, reflects the attempts of parents to

steer themselves around the barriers created by the medical discourse that continues to be the dominant ideological form of social control for mentally ill patients who are parents.

Most of the parents discussed how notions of risk failed to account for the experience of illness. However, they knew that there were times when their child were at risk of harm as their mental illness, got in the way of their ability to maintain functional tasks associated with parenthood. This finding was not unusual and concurs with findings of other research. For example, Rutter (1966) was one of the first to suggest that there is always a concern that children may be incorporated into the delusional state of the parent.

We are like any other human being. We have good days and we have bad days. There are times when you might not be able to care for your child, but that doesn't mean that you are a bad parent, it means that you are a sick parent. . . . It is one of the hardest jobs out there and you can't really study to be a parent. I mean, not even me doing years of education at Uni. It didn't prepare me to be a parent. I have been a fantastic teacher and I was prepared to do lovely things with my child, but it didn't prepare me for the emotions that were involved [in parenthood] (Evie).

From then on it got worse. I had lost my life as I couldn't cope with the baby, not sleeping all day and not sleeping all night. I started to hate him and yell and scream at him (Jasmin).

I was thinking, straightaway, you cannot be serious expecting me to take this baby home. . . . I wouldn't be able to look after him properly, and there is no way I would cope. . . . I was planning to leave him there - leave the baby, and I was thinking, they will have to deal with it. I certainly didn't tell anyone that I was, like, thinking that I was going to leave him there (Jo).

I can't really remember much of when he was a baby - it is all blanked out really. It's just difficult to think back then. I think that I was scared that I was going to get to the stage that, you know, you hear many of these things. And I thought that I might hurt him, you know. People do hurt their children, but I never actually got like that (Nita).

It was very bad, like, I was yelling at them, and because I wasn't, like, well. I would actually not hurt them or anything, but, like, I would go into another room and shut the door. I wouldn't let them in but I didn't physically hurt them, or anything like that - I would just shut them out because I couldn't cope with them (Dani).

It is really surprising that there must have been really three or four of us who had, like, an actual plan of what we would do or how we would kill the baby. And we were all thinking, like, I can't be left alone with the baby because I already know what I am going to do (Jo).

For three weeks, I just, yeah, I could not switch off and I couldn't get any sleep, which for me is a trigger. . . . And I start feeling depressed and it just snowballs. There was only one instance when I kind of looked at him, and I was that deep in the depression, that I just looked at him and just didn't feel anything. That was only one moment and I can remember that quite vividly. I didn't resent him or anything like

that. It was just this one deepest darkest time, and I just kind of looked at him and there was just . . . nothing (Sam).

Risk of harm when observed by others creates the potential for investigation by DoCS. Reports made to DoCS, seem to rely on the parent's positioning and on observations by others. Jane's concern about discovery was related to her own positioning as a mandatory DoCS reporter:

I have done DoCS reports in school as a teacher - I understand the system with disclosures and stuff. And then it is embarrassing, it feels embarrassing, to be at the other side of it and to know that there are much worse cases and DoCS isn't doing anything about them (Jane).

Devlin and O'Brien (1999) suggest that parents' coping mechanisms are sometimes exceeded by their mental illness and at these times they are just too sick to care for their children. The parents did acknowledge that risk was sometimes created by their inability, to provide the basic needs for their children. Jen, Helen and Nita had all wanted to be noticed and wanted intervention but failed in their attempts to access help. Their issues were related to everyday parental duties, such as bathing, feeding and interacting with their children.

I didn't use any strategies for her. I did enough to keep her alive. A neighbour of the woman who lived next door looked after her when I was in a psychiatric hospital and she did day-care so she called her 'Mummy'. I was pleased about that. I thought, thank God there is someone she can feel that connection with. She wouldn't have anything to do with me. She would push me away when I went near her, she would put her hand up and push against me, really push me. If there was no-one else to care for her, she would tolerate me, and when her father was home she wouldn't have anything to do with me - I was sick, you see, and I didn't get the help that I needed (Jen).

I couldn't pick up the baby. Every time I went to pick up the baby, I would get a panic attack, and it felt different to hold her, like the weight of her had somehow changed. My body just lost it after the birth and I was, like, fitting and carrying on and everyone was worried that might trigger off another emotional breakdown. And I was paranoid because it was just a life or death situation. I came close to death. It was terrible. And I would get, like, that panic feeling but I would force myself through it. And I thought I could get over this because I knew a lot and I do know a lot about psychology. I knew I was just on the edge and, you know, not even able to hold the baby. I was shaking; I couldn't even keep still for a minute, that's how bad it was. (Helen).

I can't understand now why I would have been scared [of bathing him] when my sister has kids and I bath them and I had done all of these things with her kids. I saw a friend yesterday in hospital having just had a baby. She was really down and depressed and I thought I just never want to be like that again. It was frightening. I was in tears, and I could cry more (Nita).

The last thing that I want to do is sit down and do homework with my own kids. And then I feel guilty because I am not putting enough effort into my own children and their lives because I am exhausted and I know that my kids really resent that. My children really don't like that . . . they tell me . . . you should do this and you should

do that. The children do help me and I say to them, thank you for helping me. But they do get self-righteous because I retreat and I just go into myself and retreat from them as well. I just sort of drift around on my own and just get really introverted. But if the girls come up to me and talk to me that's fine and I don't push them away. (Jane).

These risks, can lead to the parents becoming 'demoralized' (Frank, 2005) by their status as 'not good enough'. In viewing parents as 'not good enough', there is a suggestion that they have failed. Parents in this study often accepted blame under this discourse. This research study challenges these notions by suggesting parents with mental illness are trying their best but lack adequate support. Support such as classes to develop parenting skills, were identified as a beneficial type of support by the parents. Jasmin and Liz had both, at time, felt totally defeated:

My mother and my mother-in-law would always tell me how much they coped with and that they had, you know, all this crap all of the time about how it used to be so much harder. And I am saying, well, why can't I cope? And, you know, if they had it harder than me, it makes me feel guilty, you know. I didn't really say anything because I felt like I should be able to cope (Liz).

My belief about depression was that people made you feel like you were incompetent, and this makes me feel like I was worthless. And I was always sad, and I knew it was affecting my relationships with my daughter, but I did believe that depression was crap [before diagnosis](Jasmin).

Managing children's behaviour was found to create problems for some parents when their mental illness is acute (Maybery, Reupert & Goodyear, 2006). This study also supports these findings, especially the narrative of Dani, Vinnie, Sarah and Darren. Their stories provide examples of the collision of discourses; their attempts to be 'good enough' collided with unrealistic expectations of parenthood:

Just their behaviour and the fact that they were so demanding and it doesn't stop: I'm hungry, I'm thirsty! And then the baby was just screaming all the time and I would just let her scream. It didn't get better, like, it just kept getting worse. And I felt so suffocated, and I thought if another kid comes near me again I will . . . What am I going to do? It got to the point where I left them alone in the house. And one day I overdosed at home when it was just them and me. Like, it was probably half an hour or more from when I had taken the tablets and a whole heap of them. Then I thought, oh god, what have you done? And I rang my sister (Dani).

I'd just get cranky and they would say, come on Dad! But I would just want to go off and do my own thing and have no real interest in anything and sit and watch the TV the whole weekend. If someone disturbs me while I am reading or whatever, I just get really snappy even when the kids aren't doing anything wrong, but you are really biting their heads off. It's taken a fair bit to get used to, because I used to have a lot more patience and enjoy doing more. But I just don't have the strength to get up and really do a lot. And, you know, the kids say, oh, let's go for a bike ride or do something, and I just can't do it (Vinnie).

I think it [mental illness] had made it much harder; I just don't have the patience . . . Like, I look at some of my friends and I think, you have so much patience, and I just

think that sometimes I just can't cope with these kids . . . When they are naughty, you know, I think that I would be better off without them (Sarah).

I mean, they are noisy sometimes. I get a bit frustrated with it, but they are kids, so I can't scream and yell all the time and say I want it dead quiet. I used to nap every day and I would try to get most of my work done before I did that. It was good to spend the time with my kids, though, you know, being able to go to pre-school with them and for little things. All dads don't get that time, so it was a blessing (Darren).

The experiences described in these excerpts may be explained by Frank (2005, p. 15) who suggests: "Demoralization means more than low morale." Low morale is shown by the parents to lead to a lack of belief in their ability to be 'a good enough parent' and negatively affects their mental health. Some of the parents did feel that their mental health was at stake; their demoralisation led them to question not only their ability to parent but also whether life was worth living.

7.4.2 Imagined risk related to the notion of 'a good enough parent'

Most parents were very aware of a lack of ability to cope with their children. They did not need to be told that they were not fulfilling the idealised notion of 'good enough', because the strong societal discourses reinforced their feelings. They talked about feeling under surveillance because they had a mental illness. They were also concerned about hiding their mental illness, fearing that if people knew about their illness they would make a judgment about their parenting abilities and report this to DoCS (NSW Health, 2006). Anyone who suspects, or has reasonable grounds to suspect, that a child or young person is at risk of being neglected or physically, sexually or emotionally abused, is encouraged to let DoCS know of their concerns. People who make reports do not need to confirm their suspicions or provide solid proof. DoCS' reporting process is required to consider whether another person, when faced with similar information, would also draw the same conclusion. The 'reasonable grounds' are the standard, and anyone who makes a report to DoCS about a parent with mental illness must apply their judgment about what is 'good enough' or standard expectations of a parent. DoCS must then assess whether a child or young person is, or may be, at risk of harm from abuse or neglect.

Green (2007, p. 402) suggests that workers are under pressure to meet the organisational needs associated with risk and have themselves been forced to take responsibility for their assessment of the danger of a parent from the limited information they can glean from the client's files. Liz provided an example of

imagined risk due to her family background of abuse and agency knowledge of her mental illness. The gaze associated with her situation meant that assessments of her situation was from a deficit model and she had to prove that she was not a risk to her child. From the moment her child was born she was under DoCS' surveillance as a possibility of danger had been reported. She felt that part of the reason for her treatment was her age:

They treated me badly because I was young and had this baby. And even at one point they accused me of hurting him - there in the hospital. He had a bruise on his leg and it looked like a hand mark. And the night before he just cried and cried and the nurse came in and she had taken him away so I got a bit of sleep. But I could hear he was crying the whole time. I think that they were just covering themselves and they were blaming it on me (Liz).

Most parents were aware that anyone could make a report to DoCS with concerns about their ability to care for their child. The risks of being reported to DoCS could be reduced if they were not identified as a parent with mental illness. However, as Sawyer (2005) suggests 'risk thinking' has become the dominant model of assessment of capacity for parents with mental illness. The parents therefore, had to live with this risk cloud above their heads and this lead to some of the parents wanting to advocate for the importance of the lived realities of mental illness to be understood:

Its funny how there is still that stigmatism, you know, like, you are going to cut someone's head off with an axe or something. They think of gun-toting madmen or someone, you know what I mean. And they are the extreme and not all of us are like that (Darren).

Jo, Sam, Dani and Jane also did not want people to think differently of them. They were concerned that if people knew that they had mental illness that they would treat them differently so they subverted their feelings and lived a private life with mental illness. This reflects their experiences of stigma similar to suggestions by Angermeyer & Matschinger (1996) who suggest widespread societal ignorance about mental illness. As a result the parents had adopted varying strategies to maintain a position of anonymity.

I don't know I was so worried about being a bad mother . . . that I would get really depressed and hurt him that was the other thing I was worried about. I couldn't believe how much I loved him, and all that kind of stuff. And I just didn't want to hurt him, and I didn't want to be like the reason why he had a bad life (Jo).

This probably sounds weird, but if you say you have post-natal depression rather than depression. It is more accepted. They just seem to think it's an extreme case of the baby blues . . . I think that people's perceptions of someone with mental illness, is someone curled up in the fetal position and just rocking backwards and forwards. (Sam).

It was hard, because people would come up and say, how are you, are you all right? We've missed you; we were really worried about you, and everything. And that was really hard hearing that, because you go from doing everything on your own to people saying that (Dani).

I just turn it on . . . I just smile and I get on with it . . . It's like acting, you know, you can't let your personal life get involved in the world outside - you can't let people know (Jane).

Sam had found that because people knew she had been in hospital due to her mental illness, they were not able to talk to her about it. She was unsure whether they were embarrassed by it or thought that she did not want to talk about it. She felt angry:

When I was released from the hospital and saw people all over again, it was, like, kind of, as if nothing had happened . . . with close friends. I was quite upset about it. It was a bit hurtful (Sam).

Helen had a similar experience in that people who became aware that she had a mental illness were generally supportive, although they were only people who were close to her:

Those who are going to judge you are the ones who don't know you well anyway. I haven't lost any friends because of this. I haven't lost family over this. And everyone has been supportive, and all my dad said was that he wished I could have got help sooner (Helen).

Lack of awareness and understanding in society is, perhaps, an explanation for the dearth of information about parents with mental illness, this argument supported by research (for example, Corrigan and Watson, 2002a). It also reflects a lack of acknowledgment by policy and mental health services about the parenthood of clients, again widely supported by other studies such as Bassett et al., 1999; Maybery and Reupert, 2006; and Thomas and Kalucy, 2003. Furthermore, societal discourses are supported by traditional notions of family; many of the narratives show parents living lives that are opposed to traditional ideals. However, this continued perception by the parents of failing to reach idealised standards of parenthood created significant issues of guilt for them. Vinnie and Dani felt that their families had suffered significantly because of their mental illness:

I can't take as much stress and I really avoid a problem. . . . That's how it's really affected me. I've really put my wife through hell. It's affected the whole family. I don't even realise when I'm starting to go off track a bit. I feel guilty because I have caused a lot of that. . . . Mental illness has affected everyone in the family, one way or another. . . . It does fall back onto me, if it didn't happen in the first place. Every now and then, I get overloaded and I feel a bit, oh shit, oh what have I done here to my family? (Vinnie).

My biggest guilt [when she was in hospital] was that I couldn't afford to be here because I have so much work to do at home - like, who was going to look after the kids? When the babies were born, I was manic to the point where I didn't sleep for

days. And when the eldest We were very close right from the start. . . and I went back to work. I could fit everything in. But when I had the second one, I didn't know what happened. I was an irritable mess and I felt like I was getting more and more out of touch with reality - like, what was going on in my mind. And I felt my husband wasn't giving me enough support, and I was really struggling, and I needed more and more (Dani).

Depressive feelings associated with mental illness often compounded feelings of not being 'good enough'. Frank describes this as part of an 'oppressive identity': "They are oppressed because their identity is rendered oppressive to them" (Frank, 2005, p. 23). Oppression appears to result in parents feeling guilty about not being there for their children. Mike and Evie provide specific examples of guilt related to experiences and issues their children had that they felt could be blamed on their mental illness:

Society will always label them and they might go to school you know and say, my dad's got bipolar, and the other kids will go, you know, ha, ha, ha, ha, ha, your dad's a nutter! You know; because kids are cruel, mate.

With mental illness - and you have enough guilt as it is having mental illness - I see what my son has been through. I see all the tears in his eyes and the grief when I was in and out of hospital and he didn't know who was picking him up from school. The foster carer again, if I had been rushed off to hospital. He would walk out of the classroom, burst into tears, and say, my mummy is in hospital again, isn't she? So I had a little kid who was devastated, you know, so the guilt was just unbelievable. And I think that a lot of my suicidality at the time was around I felt that I didn't deserve to be his mum - you know (Evie).

As Frank (2005, p. 23) suggests, "Principal among these damaging conditions is others' unwillingness to hear stories in which storytellers place their actions within worthy, significant moral frameworks." Knowing reality is very often not like this; Jo partly attributed this to doctors: "The medical professional has a lot to answer for in terms of how much they don't really talk about mental illness". Jo felt that parents should be empowered to take responsibility for challenging the stigmatising discourses themselves. As a mother with mental illness she felt that it was mothers themselves who were failing to support each other:

There is kind of this myth is perpetuated that you are going to be sitting around and the baby is going to be beautiful and fantastic you know. Mothers are the worst in terms of lying to each other, like, the whole thinking, and we continue to lie about how it is. And people need to talk about it in that way a bit more.

Evie and Sarah felt that due to the stigma of mental illness they had begun to feel very unworthy as parents.

I started feeling that I wasn't a really good parent. I remember thinking to myself that he would be better off without me and that I should put him up for adoption (Evie).

I wouldn't give them [the children] up or anything. But I just feel that I shouldn't have been a parent. . . . In that respect it makes it very hard at times (Sarah).

Mental illness is not the same for all people. It is often described as falling on a continuum from healthy 'normal' to severe mental illness. Some mental illnesses are themselves classed as severe, for example, bipolar disorder or schizophrenia, and are, therefore, dependent on a diagnosis. Illness should also be viewed through the medicalised lens defined by the cultural setting (Sutton, 2000) in which families live. In some cultures, mental illness is not perceived in isolation, or set apart from conflicts with family, job, and other relationships. The parents felt their mental illness was treated in isolation from the rest of their lives. The stability of their symptoms was affected by treatment regimes, support, and self-monitoring. There were many expectations the patient or parent was required to meet in order to continue to operate at a functional level and care for their child. Not being able to operate at a functional level led to self-blame and was problematic for parents with high self-expectations. Some of the unrealistic ideals appeared to have been shaped by societal discourses of good parenting. Daily issues related to family life were acknowledged by Jen, Dani and Nita as more difficult when their mental illness was acute. This was complex and raised issues related to guilt, grief, and loss.

I wasn't able to move. How she survived and how I had enough drive in me to feed her, was through the guilt, not because I was a loving mother (Jen).

I suppose that it was because I did have all of these expectations about what it was going to be like when I became a parent (Nita).

Like, you think you are in the right place and you need to be there; but you think you should have stayed at home and gone through the community - trying to do the right thing for you and your children (Dani).

These narratives show the parents striving to achieve the ideologically driven status of 'a good enough parent' which positions parents at the oppositional end of the binary of good or harmful. As Sam said: "You feel like you are the most unnatural person on the planet, I have never felt so much pressure". Inherent within the concept of 'good enough' appears to be this notion that parenthood is natural and therefore private because it happens within the home. However, Evie and Sarah had begun to question the concept of 'not good enough':

That is something that in the last few, sort of, years, I have found out that you don't have to be the best parent - it's just being a good enough parent and meeting those basic needs. So I am learning to relax a little bit more, and I must admit my son was

probably two - before I actually felt that I could really enjoy him. It was such a struggle with the illness and all the treatment. And even though I gave him wonderful care, I couldn't enjoy him. I understand what happened and I know that I am not a bad parent. I know that I was a good enough parent. I know that I did the best that I could under the circumstances. But it's getting it through to DoCS. Their attitude is that you couldn't have been a good enough parent, you know you neglected him, you abused him; you know you have terrible attachment problems with him.

I do crazy things, like I go to McDonalds, and I like climbing on the play equipment with my son and chase him around and play with the kids. I did that and I had supervisors from DoCS reporting me having this fantastic time with my son. DoCS have piped up and said that it shows that she is mentally unstable. So then, I sat there and didn't interact and then they said, well, she's not interacting with her child. On other occasions they made attacks on my parenting. And then they told me that I had severely psychologically damaged my son and by the time that he was fourteen, he would be beyond help. That it was all because of my mental illness and I am a bad parent (Evie).

I realise that we [parents with mental illness] aren't the only one's doing it hard. But it is really hard for us. . . . In television and in movies they have these kids and take them home and the houses are spotless and, you know, dinner is on the table at a certain time and the washing is on and you get the reality. I think I should be able to do this and still have time to play with the kids and do some of these things. But I have learnt, you know, who cares about what I should be doing? So I am not as bad anymore trying to do what I think I should be doing and worrying about that (Sarah).

Frank would describe these dialogues as 'self revealing' and that whilst the parents try to do what is expected of them, they require the support of an understanding witness. As Frank (2005, p. 25) notes, "The failure to offer witness perpetuates everyone's demoralization." Parents in this study talked about their efforts to be 'a good enough parent', but were often doing so from a position of silence where their issues were hidden and unacknowledged by the agencies of power.

Broadhurst (2003) found similar examples to these narratives, and suggests that "Perceived costs to seeking help from formal services might for example be social consequences or loss of control of problems, and the help seeker is seen to weigh these against the benefits of receiving support/solutions to presenting problems" (p. 346). For Evie, the lack of witness to her story, combined with the lack of appropriate systemic support and understanding led to the loss of relationship with their children and the loss of hope for the future. She felt her rights and status as a mother were undermined and consumed by her diagnosis as a patient:

They arranged for me to go into hospital with him, but I kept deteriorating. Then he went into foster care. . . . It was horrific, mainly because I was fully breast-feeding and they just took him. So, here's this baby who I was fully breast-feeding and he was just taken. I was only allowed to see him for two hours twice a week, or something like that. I was very distressed, and my mother actually rang all the way from Queensland, to DoCS, or whatever it was then, and said, look, if you don't let her see her baby, I don't know what she will do. So then, they actually increased the contact

to three days for two hours - how are you supposed to bond with a new baby when you see them for two hours three times a week?

I tried to keep up the milk supply because I wanted my son to have the best. I was using pumps and expressing the milk, freezing it, and then taking it over to the foster carer so she could feed him. Then I found out that she was tipping it down the sink; she wasn't giving it to him because she thought that he was better on formula. I wanted him to have that milk. But then it just got to the point that it was too difficult to keep up the milk supply, and also they were starting to try me on drugs. Then there was that risk that the drugs might get into the breast milk and then affect him.

Jane had also experienced custody hearings with DoCS. Her life was dominated by the fear that, "I might lose my children". She was also confused, like other parents who had been involved with care proceedings, about how the system worked:

They promised help and stuff, and I haven't received it. And I have to go to court next Monday about this . . . after 11 weeks of not hearing from anyone and not hearing from DoCS, no follow up, no feedback, and then being hit with this.

Parents also reflected on their children being young. Jen and Nita saw their mental illness in terms of loss of a chance to enjoy parenthood as it was difficult for them to recall their children as babies due to the acuity of their mental illness at that stage of their children's lives:

Because I had been through depression before and my daughter was older, she wasn't as helpless, it made it easier. I didn't present the normal parent to her because I was always in bed and I didn't always get things done. There was always chaos in the house, it wasn't organised or smooth running, and it was sad for her (Jen).

I would be going out with my baby all dressed up and then I had trouble getting out of my pj's. And I would get really flustered because I was obsessed with cleaning and everything had to be clean (Nita).

Because of the feeling that they were not 'good enough' many parents withdrew from society. This was Evie's experience: "I just felt too down to go out and just hated that sense of isolation." However, this need to isolate themselves from society is driven by ignorance which continues to remain unchallenged by policies and unacknowledged by mental health services.

7.4.3 Risk created by lack of support and lack of acknowledgment

Some parents had become involved with government agencies (DoCS). For some of these parents, their engagement with DoCS was about risks associated with their mental illness or because of their children's problems. Differences were observable in contact with agencies between parents who had supportive partners and the

parents who were parenting alone. All the narratives concur with the understanding that parents with mental illness continue to be viewed under an individualistic discourse that associates culpability with the parent who has a mental illness. These views are derived from an individual pathologised perspective as opposed to a population health or prevention orientated perspectives that encourage society to take responsibility. Under the latter discourse, we would consider levelling blame at services for failing to provide support instead of at the parent for having mental illness. This is supported by Frank (2005, p. 69) who argues, “When one person falls ill, the entire universe is involved.”

7.4.3.1 *Lack of support*

Three of the four mothers who were single parents had experiences of their children entering DoCS’ foster care system. They provided stories about how the risk discourse blames mothers even when they take responsibility and attempt to get help and support for their mental illness. Evie talked about her son and his illness:

They have even tried to say that he doesn’t have autism: It is because you are a bad parent - you have abused him. I know it’s just that he was diagnosed, but there is just this sort of blame, they are willing to lay blame. That has been a real issue, as once again I am trying to defend my parenting. When he went into care, it was not because I was a bad parent - he’s gone into care because I was unwell and both of us needed to be safe and secure. We needed good routine and the predictability, and I needed the time to really get on top of this illness.

Jane, having voluntarily sought treatment for her mental illness, was distressed at becoming involved in a custodial battle with DoCS for the return of her children. She felt that whilst DoCS was willing to provide foster care for her children, she had not been offered any personal help or support, or help for the family to be reunited. She could not understand this. She felt violated that her status and identity as the mother of her children was at risk; she had tried to be a good parent and to seek help and support as opposed to putting her children at risk. She felt that her parenting skills and concerns for her children were not acknowledged by DoCS.

Whilst Jane was a single parent living alone and unsupported with her children, not all parents, even those in similar situations, came under scrutiny. It appeared to be a lottery: DoCS’ intervention rested on someone identifying a risk of harm to a child and reporting this to DoCS. Nita, who was also parenting alone, had not come under the surveillance of DoCS and had been quite surprised about the lack of interest in her:

I just thought that someone would take my baby away. But I was never really worried that I would hurt him, but I think that I could have quite easily hurt myself and not him.

One issue that is of concern to DoCS is the relatively isolated lives that many parents with mental illness live (Gray, Robinson & Seddon, 2007). It appears from the narratives that parenthood did bring loneliness and isolation for some parents. Nita and Helen explained how they withdrew from society, as was part of a strategy to overcome the stigma and attempt to steer her life away from the agencies of surveillance (DoCS):

I got angry. I did get angry and I would throw things but I never crossed that line. I could sit there all day and just hold him. I don't remember many things of when he was a baby because of the depression. I didn't even want to go out, I just wanted to stay home with him and sit and hold him - and he made me feel safe because I knew that I was fine with him (Nita).

I just wanted to hide in a little ball and get under my blanket, and I was shaking the whole time. And everyone is saying get out of bed, but I can't, I couldn't even talk. I got to the point where I could not even put a sentence together (Helen).

In problematising isolating behaviours, the reasons why parents choose to do this may get missed. Withdrawing from society appeared to be an easy way to deal with the stigma associated with mental illness. Isolation is a well-documented concern arising from stigma because of the impact it has on the children of parents with mental illness (Hinshaw, 2005; Nicholson, Sweeney, & Geller, 1998).

Everyday life is often interrupted by mental illness and in spite of efforts by the parents to retain normality; there were times when this became too difficult. Practical issues were a problem for many of the parents along with lack of motivation which is often associated with depression, a diagnosis that both Nita and Jen had received, which created issues in carrying out daily chores which they acknowledged created risks for their children.

I try and do all of these things in my life, to be the best parent that I could be, and some days I can't get up (Nita).

When I was very depressed, I would start cooking and just walk off and leave the cooking. And my daughter would have to dart off to the kitchen and make me go back (Jen).

Helen, also felt the pressure to do things that were at times beyond her capabilities:

I remember I still wanted very much to do things. And I have a perfectionist trait, not always in cleaning the house or whatever, but, like, just wanting to get it right [being a good mother]. But I couldn't deal with her [daughter] on an emotional level and that was very sad.

The parents' narratives provided evidence of situations where mental illness, at times, can become the focus of the parents' lives. At these times there is a need for additional support to be provided to assist them with many practical everyday tasks. However, because their needs are not met, the risk created is not so much about their mental illness but about lack of support. The next section builds on this shifting of responsibility from the parents to the agencies that should not only be supporting the parents but also acknowledging their needs.

7.4.3.2 *Lack of acknowledgment*

Jen provided specific examples of lack of acknowledgement. She found recalling her experiences stirred deeply embedded emotions. The interview was halted a few times so she could compose herself, as her rage was clearly heard and the emotions were strong - even though she was talking about events that had occurred many years before. She took a deep breath, and although she was shaken, wished to continue. Her need to tell her story was important so she started again. She spoke about the things that she wished that she could have done for her daughter when she was younger, and felt that mental illness had robbed her and her daughter of opportunity and chances. Over the years that Jen had lived with mental illness, she had encountered many opportunities that had been lost and where supportive interventions for parents with mental illness could have provided practical help:

I couldn't let her do things that she wanted to do. Like, she wanted to play soccer, and I was too scared to go out at night, and I said, absolutely not. She wanted to do little athletics and that was in the dark, too, and I ruled it out all together. But I feel sorry for her now because other children have to do it. It [mental illness] stopped us from doing many things . . . I honestly believe the very first thing that you need to do for women - especially mothers with children of any age - the first thing that you do is have a large team of cleaners who can come in and clean the house.

It is evident from the narratives that a lack of acknowledgment of the needs of parents occurs when they withdraw because of their concerns about surveillance of their parental capabilities and the stigma of not being 'a good enough parent'. This also raises serious questions about how such parents can be supported and acknowledged. How can we make them feel safe in their role as a parent whilst they are engaging in treatment? What do they need in order to feel safe enough to participate in society? According to Frank (2005, p. 64), "Participation is the means

and medium of being moral.” The parents were clearly trying to be both ‘moral’ and ‘good enough’.

Ursula spoke about the issues raised by lack of acknowledgment of the needs of parents with mental illness in discussing her medically isolated existence throughout her pregnancy. Whilst this isolation was caused by the acuity of her mental illness and being medicated as soon as her son was born, she spoke about the assumptions that were made about her but never checked out during the period of her confinement. The actions of the medical professionals, attributable to their awareness of her mental health history, were severely flawed as they failed to undertake a thorough clinical review of her situation. In focusing on her mental health issues, her rights as a new parent were overlooked. Ursula felt this was unfair: “I went into this health centre and got this pamphlet on post-natal depression. I read it and every single symptom I had, and they just blamed it on my mental illness.”

A further example of lack of acknowledgment was provided by Evie who was also a parent living under the regulated gaze of statutory services. She saw that providing for her child and being able to do this well should lead to increased generosity and interpretation of her ability as a parent - that she was ‘a good enough parent’. Evie wanted her capabilities to be acknowledged:

Right through those very early days, everyone kept saying to me that I never lowered my standards and I always wanted what was best for him. He was always well dressed and people used to say that I was a gourmet cook when it came to his meals. I never had the tinned stuff, you know, I made him tuna mornay and dishes right from when he was tiny, because I was very particular. I was very much into his development and a lot of stimulation and I guess being a teacher helped me. I was probably a very good parent, probably a little bit on the affectionate side.

The lack of power that parents have if they have mental illness was often interpreted through a fear of losing custody of their children. The fear was part of daily life for the parents. They had concerns about DoCS making the decision that they were not able to care for their children or making a judgment about their capacity to attain the ideological status of ‘a good enough parent’. In upholding these discourses, barriers to accessing services and receiving help or treatment were created, as Jen discovered:

Well, they think their children are going to be taken off them. You need to be handed a bit of paper from the doctor when you get your medication, and now, this is what you need, and here is a piece of paper promising that we will not take your child off you because you have mental illness. Because you are depressed, we promise on

paper, as a legal document, that we will not take your child from you - that would be a start. When I was very ill I was concerned about losing her. I was very anxious because of the type of woman I was. I was thinking they would be on me like a tonne of bricks because I was so depressed and my family was at the stage that they had enough of me, you know, and wanted to get on with their lives.

This stringent authoritarian lens was also experienced by other parents who had interactions with DoCS. Evie explained how normal, everyday behaviours could be reinterpreted by the authorities as incidents to support notions that parents with mental illness were not ‘good enough’ parents:

Most parents don’t get the same scrutiny that parents with mental illness do with DoCS. I was told that I shouldn’t get Josh back because I was a bad parent because one contact visit I didn’t buy him a drink and I bought myself a drink. I am thinking, that makes me a bad parent? And I went back and I looked at the report - I forgot his drink but my friend said to me, oh no, it doesn’t matter, I’ll go and get it. So, I sat down and I had a milkshake. I mean any parent can do that, and it doesn’t mean that I am a bad parent.

For parents with mental illness, every move appears to be scrutinised once they are put under the glare of agencies that are interested in their diagnosis and label as a mentally ill parent. As discussed earlier, there are times when mental illness does become an issue and times when the parents accepted that their children were at risk. However, the parents were able to identify and acknowledge the effects of their mental illness on their children. The constant stress on the issue of risk merely positions the lives of the children as more important than those of their parents. Furthermore, this discourse suggests that the lives of the parents are only seen as worthy in relation to the impact of their mental illness on their children which is a very disabling message.

7.5 Effects of parental mental illness on children

There is much literature documenting cases of reduced opportunities for children of parents with mental illness (for example, Aldridge & Becker, 2003; Blanch, Nicholson, & Purcell, 1994; Devlin & O’Brien, 1999; Nicholson, Sweeney, & Geller, 1998). So the question arises: Are children being affected by their parents’ mental illness? Foster, O’Brien and Mc Allister (2005, p. 67) have said, “Children of parents with a mental illness have been identified as vulnerable to experiencing a variety of psychosocial effects arising from the impact of parental mental illness.” The parents provided much insight into this issue; all talked about how their families were affected by their illness and how they saw their children coping. All the parents wished to be well, confirming Frank’s (2005, p. 55) contention: “They want to get

well. Getting well may be all some ever want. But some whose world is taken apart by sickness want the world they put back together to be different.”

This section will consider the parents thoughts and feelings as they watched their children coping with their mental illness. This covers the restitution narrative where by preparing their children to cope with their parent’s mental illness and possible acute episodes of mental illness in the future, the parents showed “the extended logic of restitution, future sickness will *already have been cured*” (Frank, 1995, p. 90). Liz’s experience however challenges Frank’s notion of restitution because she had lived a life already affected by mental illness and abuse and found this position disempowered her ability to access restitution. Liz rationalised some of the impact on her child was due to her situation as a young mum. Her acceptance of self-blame due to her age was just one part of her complex situation:

Because of the abuse in my family - the family was a risk, and so I was a risk to my child even before he was born. They had already decided and they had this counsellor speaking to me whenever I went to the hospital. My mum had been in hospital and everything, you know, so . . . And it was the same hospital, and they knew about it [history of abuse]. It’s awful, yeah, but you get used to it.

Evie provides another example of the effects of parental mental illness on children when she was admitted into a psychiatric unit with her son. She found that this was positive in terms of reinforcing her parenting. However, her perception that she did not feel being in an adult psychiatric unit created any risks to the safety of her son was problematic:

When the psychosis hit, it was late one night, and I saw what I thought were demons coming out of the television into my son. My son turned into a demon and it rather went downhill from there. I never dreamed I would have a problem to get into a mother and baby unit. Most of them are private. I had to wait for a place to come up . . . [when they were admitted together to an adult inpatient unit] I found the other patients were fantastic with him. They would want to hold him, wheel him around, and nurse him. And I was getting into trouble with the staff for letting the other patients be involved with him and touch him. I found that it was actually good for him and for the other patients because it actually mellowed them. I didn’t see any impact of risk then. Maybe now, actually, having spent more time in psychiatric hospitals, that might be different, but there is an element of risk in everything.

Without doubt when the parent’s mental illness is acute there are numerous impacts on children. Dani and Vinnie both provided examples of, not only guilt through separation, but also of financial stress, related to their inability to work and sadness at the loss of their former selves.

I did find that the separation anxiety was very hard because it made you feel guiltier that you weren't at home doing your role in the household . . . I think that many women and many dads choose not to access help because they know that they will be separated from their families. That places huge burdens financially on them, because we spent big money whilst I was in hospital and I wasn't working (Dani).

I still deny, sometimes, that I am getting picky or things like that, so I've got to listen to the kids a lot more, you know, because they pick it up straightaway. I just seem to go off into a corner by myself (Vinnie).

Frank would call this a 'loss of moral participation', whereby Vinnie's description "expresses the problem that people who are ill or disabled have staying in networks of participation, and participating on terms that are meaningful to themselves and are recognized as meaningful by others" (Frank, 2005, p. 64). Vinnie saw his problems in participating as being related to his changed identity to that of disabled father. He provides specific examples of the difficulties of accepting things about his new self that were different to the non-disabled body. Vinnie was highly aware he was still grieving the loss of former self. He was concerned his younger daughter who had not known him before mental illness: "Like, she doesn't know me, how I was before all this happened." Vinnie also described the person he was before mental illness as a better father than the person who now lived with mental illness and its associated symptoms. In this he exemplifies "a body . . . that has become *it* - no longer *you*, no longer a face" (Frank, 2005, p. 65).

Jane and Mike also saw their mental illness from a deficit model which has been explained by Hinshaw (2005) where mental illness not only affected the parents but also impacts on the children. They both talked about her children suffering because of her limited ability to interact with them. They both felt that their relationships with their children suffered when her symptoms were acute, they would withdraw from their families. However, in comparison to Mike Jane did not have a partner, so her children were left to fend for themselves. Her eldest daughter would take over as mother, and Jane acknowledged that this parentification was problematic but felt helpless to change it. These feelings of guilt and regret were explained as causing her increased distress and guilt;

She has taken over the mother role and she chastises me like I am the kid and she is the mother . . . She looks a lot older than she actually is. . . She is only young but she is a mature girl, you know, and she takes on a lot of responsibility, and then I feel guilty for that (Jane).

The family keeps you together, I suppose. That's where you can't juggle it and that's where you do get hard on yourself and go, oh, god, juggling with everything. It's the pace, you know, [keeping up with the children] and my wife is just saying, you know, get up, come on. She is good like that, and she always knows (Mike).

Mike saw his children as unduly burdened by his mental health problems and being discriminated against because of his lack of ability to continue to participate in society. He explained this in a story about his children being stigmatised by his mental illness as he described an incident where his son had been involved in a fight at school:

The kids will end up coming home and going, Jesus, do you know, like, you'll never believe this, and this is what happened to my son in the playground. Some kid has gone, you know, your dad is this and has that. And then he was suspended for punching out some kid. He's deep, he's shy, you know, like everyone says about the kids, they are very polite and they are very deep. That's the biggest thing, you know, the biggest reflection because they always say, you know, history repeats itself, you know. So if you are going to carry on like that, you know, then it is going to rub off on the kids.

Mike was one of a few parents in this research who not only shared concerns about their children's mental health and wellbeing but felt that their own mental health status had, in turn, been affected by their parents' or other family members' mental illness.

7.5.1 Intergenerational reflections on mental illness

Research suggests there is a broader system of neglect within the discourse of psychiatry: research with children of parents with mental illness is needed to develop prevention opportunities that can then counter embedded stigmatised notions (Sartorius & Henderson, 1992). There is limited evidence to support the arguments that there is an intergenerational transmission of mental illness (Oyserman, et al., 2000; Repetti, Taylor, & Seeman, 2002). Indeed, some parents in this study were determined that the lives of their children would not be affected by their mental illness. The issue may not be the intergenerational transmission of symptoms but rather learned behaviours, self-fulfilling prophecy and expectations that their children will become mentally ill. Education is, therefore, important for children of parents with mental illness (Ackerson, 2003; Sands, 1995). Some of the parents had lived lives as children of parents with mental illness. They were able to reflect on their experiences and sometimes incorporate this into their own parenting practice.

Mike provides an example of the impact of intergenerational mental illness. He had a deeper insight than most into the effects of living with a parent with mental illness, as he was a child of a parent with mental illness (COPMI) himself. Mike remembered

the sensitivity of his father, which he felt, was partly due to his mental illness although as a child this had never been explained to him.

It's frightening though, you know, wanting to hide and needing a security blanket, because I have got three kids and they think, yeah, brave man . . . Just seeing that everything that you are doing with the kids, you are like a mirror and before that, you are just a reflection of you in all three of them . . . I am passionate, and my old man was, too. I remember as a kid watching this Skippy or some movie - you know, like, Skippy fell off a cliff, you know, and the old man would be bawling his eyes out. I was, like, what is this shit, what is wrong with him? And it's heavy, you know, but I am the same. I never understood the oldies fighting and all the other things around me, yeah, it's always just like that. And then all of a sudden the old man just died, and it was like, bang, straight into the big wide world with no answers.

Mike's situation supports the need for increased provision of information, education and literature about mental illness to children and families (Devlin & O'Brien, 1999). As Mike explained, having lost his own father to suicide, he was perhaps more sensitive to the effects of mental illness on children. A concern is raised, therefore, that parents' lack of recognition of the effects of their illness on their children creates fear and concern for the children, especially if they do not understand what is happening to their parents. Personal experience prompted some parents to attempt to live within what Frank terms the 'restitution narrative', where "the responsibility is limited to taking one's medicine and getting well" (Frank, 1995, p. 91). An example of living this ethic is explained through Mike's adherence to a medication regime in order to be around to participate in his children's lives.

All the parents in the study acknowledged life after mental illness had been different from life before mental illness. As noted above, some stories were deeply affected by having a parent with mental illness. Jen, Sam, Jo and Jane were also affected by growing up with parents or family members with mental illness and they were all vigilant in attempting to break the cycle of intergenerational transmission of mental illness or shield their children from similar experiences they had as children. Jen and Jo felt that information for children about mental illness was paramount, whereas Sam was conscious of avoiding disruptions to her parenthood created by institutional care.

I wasn't eating, I was doing nothing, and she was watching me. This was her first year at school. Mental illness needs to be part of their lives, she knew about it. It's not just about the parents; it's also about the kids (Jen).

My mum was great, but she was also very scared for me to go into hospital because she went into hospital and it was bad. I just remember her crying quite a bit, sitting at home crying, and just not understanding that it was depression at the time. A few years later she told us that she had depression. But I still didn't really understand it,

you know, the ramifications of it all, and what she was going through . . . We never really talked about it, but from an early age, I knew that she had depression, but I didn't ask a lot of questions (Sam).

She has got lots of anxiety problems herself, and that kind of thing . . . She has got this real thing that everything is inherited. I just couldn't believe how much I loved him [her son] and I just didn't want to hurt him and I didn't want to be the reason why he had a bad life (Jo).

Jane's background was very complex with not only mental illness but also abuse and substance misuse. She felt however that this made her resilient and self-motivated to help herself: "I am my mother's daughter - she says that you can't rely on anyone, you have only to rely on yourself, and she's right." Jane reflected on the difference between the path her brother had chosen and her own:

My brother escaped by drugs and alcohol and he's been missing for 20 years now and he would be 42. But I escaped by being a good student and then getting A's and topping my class and studying. I escaped that way until I married the girls' father and he was abusive. And then I started drinking and I would drink everything until it didn't hurt anymore.

In their narratives, most parents embodied the notion of responsibility without challenge. They talked about wanting to be open about their mental illness with their children - providing them with answers as to what might happen if their illness became worse and they needed to have inpatient care. Indeed, this research concurs with Maybery et al., (2005) which supports educating children about mental illness to provide them with the knowledge and empowerment to deal with the issue. Only Nita and Vinnie had talked to their children about mental illness - because, as they said, their children were older and better able to understand what it meant. Other parents had younger children so had not reached a point where they felt that it was important for the children to know about their illness. Jen, who also had lived with a mother with mental illness, had been talking to her daughter about mental illness since she was young:

I think I have managed quite well even though I have been depressed. I speak to her like an adult but appropriate to her age, and I explain things in a way that she can understand. There were times when she didn't understand and she would want to have it explained. I explained it and she still didn't get it. She would get stroppy even if I explained it bluntly. I would say, see, you are not going to be able to understand till next year, and we will go through it next year to see if you understand or we will go through it again in six weeks if you understand then. And then she accepted that and she ran off to play.

Several families had sought support from ARAFMI who provide programs for children of parents with mental illness. For example, Vinnie and his family had sought help

from ARAFMI to provide information about mental illness and support for their children:

They understand, like, we have explained it to them - we have been to counsellors. So they understand, but they still find it hard. Counselling really helped. [Talking about his elder daughter] she finds it hard because she knew what I was like before and she can see me now.

Darren and Dani had also thought about talking to their children about their mental illness but thought that they were too young to understand. However, they had both broached the subject of mental illness:

They are both still quite young and don't really understand, so I haven't really sat them down and told them about it. I hope I don't have to do that, but, you know, I won't be a hypocrite when it comes to it (Darren).

We didn't go into great details, but said that Mummy is having some time on her own, like, she is having a little holiday, and when she comes back she can be a better mum and she can continue to look after you girls. And we just said stuff like that (Dani).

For some parents there is the possibility of a transmission of symptoms between parent and child. Whilst acknowledging that this cannot be explained, it will be explored during the discussion section of this thesis in order to theorise about potential explanations. There were a few parents whose children had already been diagnosed with either a disorder or an illness and this is discussed in the next section.

7.5.2 Children of parents with mental illness who are diagnosed as mentally ill

The parents were not denying that their illness had an impact of their children but were often not supported in resolving issues that may have been connected to their illness. There are common things that can be done to support children of parents with mental illness, particularly during 'a major mental health episode', such as "other siblings as supports in times of crisis; and the development of various coping mechanisms" (Maybery et al., 2005, p. 7).

Some parents talked about their children also receiving a diagnosis of mental illness. This is not surprising as one Australian research study suggests that "between 25 and 50% of children with affected parents will experience some psychological disorder

during childhood or adolescence and 10-14% of these children will be diagnosed with a psychotic illness at some point in their lives” (Devlin & O’Brien, 1999, p. 21).

Behavioural issues had arisen in the children of some of the parents, whether or not this was related to parental mental illness was not always clear. For instance, Ursula’s son had been diagnosed with Attention Deficit Disorder (ADD); this often resulted in him being violent towards her but she felt that this was not attributable to her mental illness. However, Jen, Helen and Evie were all concerned about the history of mental illness in their families impacting on their children.

When he goes mental, there is nothing I can do. He gave me a bloody nose last week; I think that gave him a shock, though, that one. It’s not my mental illness that causes a problem - I have never been as well as I am now. Sometimes I get sick because of stress, but you would if you had your kid beating up on you, too (Ursula).

I worried that it was affecting her mentally because she was deprived a lot as a baby because I wasn’t - I didn’t do a lot of that loving stuff. And there have been times since then that the depression has been out of control again. I was just left with that poor kid, that’s cruel, that’s not right, but who cared about the baby? No-one cared about her and she’s damaged now - I am sorry, you know (Jen).

She would not go to preschool before, for one hour, but there was a lot of stress at home. She has anxiety issues - she would have panic attacks and I do wonder about her nervous system. She gets little phobias about things, like transition sort of stuff (Helen).

I was a bad self-harmer. He never saw me self-harm but he saw the aftermath. He saw the bandages and talking about it, and so he started, he was starting to mimic some of those behaviours. There was a definite issue to be addressed there of the impact of my illness on him. I mean, you know, like DoCS could have sat down with me like the other services did and said, these are the issues, this is what is happening now, and it’s got to stop. As soon as I realised what I was doing, I stopped, and I haven’t self-harmed since then, when I realised that it was affecting him. I haven’t done this since, because I don’t want my son to use these sorts of behaviours to resolve issues, you know. If he is stressed, I don’t want him to be chopping himself up, you know. I guess what I am sort of saying is, if a parent with mental illness has enough insight to be able to understand what he or she is doing and can stop it or change it or work on it, and they shouldn’t have to lose their children (Evie).

These comments suggest that some parents can be harsh critics of their own behaviour. The parents measured themselves against idealised notions of ‘a good enough parent’ as portrayed through the media and often incorporated into policy. Whether these notions reflect reality is arguable. The discussion and findings section of this research will consider this issue in more detail (see Chapter 10). The ideal for many of the parents with mental illness was to be able to live well so that they could maintain good mental health and reduce the times when their mental illness disrupted family life. Children provided the parents with ties to the future and a

need to continue their lives for their sake. Dani and Darren explained this through keeping themselves alive by not attempting suicide.

I took my first overdose and I'd never done that before. I was so low and really desperate, and I could see that I was over committing myself, but it was very hard for me to say no. I can't even remember what I overdosed on now; it was lots of different medications. My partner found me and the next thing, I was in hospital and they were pouring charcoal down my mouth and they scheduled¹⁵ me (Dani).

You do [go on] because you can't give up, you can't give up. It's easy to give up and they say suicide is a selfish thing, and I have been there and tried it myself, so I would never accuse people who commit suicide [of being] cowards (Darren).

The narratives highlight a continued failure of mental health services to provide support or prevention-focused interventions. As Devlin and O'Brien (1999, p. 26) suggest, "The neglect of preventative practice has resulted in many social justice inequities. Children of parents with mental illnesses are large-scale users of mental health services."

7.5.3 *Lived experiences v idealised notions*

The 'good enough parent' is arguably a mythical concept. All the parents in this study loved and cared for their children. The difference between these and other parents is their illness; many parents live with physical illness and do not come under the same spotlight. Jo provided an example of the difficulty in challenging idealised notions with the reality:

I don't know what to do, but people should definitely stop pretending, they should stop carrying on the way that they do and saying things are ok. . . . But then having said that . . . there are still people that I think that I am not going to tell, you don't know that they will understand (Jo).

Mental illness, however, does not define the lives of the parents; it was part of their lives, a part often smaller than other parts:

The children are the least of my problems. There are other problems, like money and finances, and they are my big problems. I am fortunate enough that I am well enough to go back to work, because people with chronic schizophrenia will never go back to work. I have seen people like that, and you wouldn't wish it on your worst enemy if you were a caring human being. Some people are just so tormented (Darren).

¹⁵ Dani, like Darren, is referring to being 'scheduled' or 'sectioned' meaning that she was placed in psychiatric care under a Treatment Order provided by a Magistrate which detains a person in psychiatric care until this order is either revoked or runs out as stated in the Mental Health Act 1997.

I just don't want them taking this [mental illness] on and saying look, don't worry about it, it's all right, and it's not a bad thing (Mike).

Whilst the reality of daily life meant that there were some days when the parents felt very low, their role as a parent motivated them to carry on and keep their mental illness on an even keel for their families. The parents, therefore, adhered to their medication regimes and, for the sake of their children, forced themselves to do things that they did not want to do. For Sarah maintaining a balance in life meant having to submit to this regime of medication. In complying with medication regimes, the parents weighed the effects of the medication and the limitations that these placed on them against the consistency the medication provided in preventing symptoms. Part of the problem was that parents did not like the side effects of medication, but accepted that the medication had a positive role in controlling their illness. However, the motivation that parenthood is a significant role; attempting to be 'a good enough parent' provided the parents with a "heavy sense of responsibility" (Frank, 1995, p. 91) and was the strongest motivator in their lives.

It was very hard then. . . . The doctor did try to put me on medication and then I would take it and because I was feeling sick I wouldn't take it and then . . . In the end, I thought, look I am going to have to stick with it (Sarah).

The biggest thing for me is the kids growing up, and you have no choice. As an adult, though, I can't cheat it. You have to take the tablets for them [the kids], and if I push my luck and have a drink, then I pay the penalty for it. I do believe, you know, in that energy and I am not religious, but you bring that in [to your relationships with your children] . . . My kids - they are my joy (Mike).

Since my son has been born, I have had one accidental overdose. That is amazing, with all the overdoses, that I am still here. It's amazing that I am here because things, weird things, happened that stopped me dying, because I planned things very well sometimes when I was doing that, knowing that I would be able to die. I just have this terrible fear of becoming ill one day and losing him for good because I would be stuck in an institution (Ursula).

Deinstitutionalisation has partly created real contradictions in medications being the easiest and most available method of treatment. Liz explained that whilst her illness was acute the effects of the medications exacerbated her feelings:

I was extremely frightened to be by myself, scared of what I might do and it was hopeless . . . He put me on the meds and I put on 10 kilos and I went back and said, I am not taking these anymore because now I am depressed because I am so fat . . . I am struggling with this.

The role of parent has already been explained as a motivating factor for the parents. It was the reason that parents monitored their mental illness, took their medications, and kept themselves safe. Parenthood is rewarding and made parents put their

mental illness to one side even on days when they were unwell. Darren explained a difficult day:

I used to have to take them to swimming lessons and I remember having to - the first week out - having to take my daughter. And I had to tell the instructor that I was having a bad week. I was finding it hard to get through this lesson and I had to get into the pool with them. Then I had to interact with other people and I was finding it really hard. I was thinking I just don't want to be here. Then I was thinking that I just have to push through this for her, and it gave me something to focus on rather than focusing on myself. If it weren't for the girls, I would have probably just sat at home and withdrawn from society. You aren't as self-centered - you don't think so much inside your own head and you have something else to focus on outside (Darren).

Trying to define what 'a good enough parent' looks like is difficult. The parents acknowledged that they tried to live up to the societal expectations. Dani, Helen and Jen suggested that part of the problem with parenthood is that people are often unprepared for the reality of being a parent and in need of practical support:

It's not always going to be perfect, and you are not always going to achieve everything that you want to achieve in a day. People think that pregnancy and child birth is difficult, but it is not until you start parenting that the lack of sleep and added responsibility and commitment of a young child and everything changes (Dani).

There isn't a formula for parenting. It works or it doesn't work, and sometimes you get it and sometimes you don't (Helen).

You are a loving mother, and that's what they need [other mothers with MI]; we need lots and many people - a huge team to go through these mentally ill parents, get their lives in order so that they can relax. Try to supervise them or have other people supervise them, pay your bills, let's go clean the garden or the pool or the shower and do this now. And that's because people don't have the get up and go to do that (Jen).

Stigma and cultural notions of 'a good enough parent' are strong and powerful. Whilst Evie took care to seek help for her son when she was unwell, she was told that having mental illness and trying to be a parent meant that she was a child abuser. Just because a parent has mental illness does not mean that they do not have insight into how their mental illness may affect their child and neither does it mean they lose the ability to care, love, and protect their beloved families. In summarising her thoughts, Evie said:

I was an excellent parent. I always made sure that he was safe when I was sick and I always knew when I was becoming unwell and I would make sure that he was with people to care for him so he never witnessed anything bad. I guess what I am sort of saying is, if a parent with mental illness has enough insight to be able to understand what he or she is doing and can stop it or change it or work on it, then they shouldn't have to lose their children.

Parenthood is not simple; it is interwoven with challenges - being a parent with mental illness is just another hurdle. Nita and Helen both showed resilience in their approach to being parents with mental illness:

I am much stronger now I know that I have to do this. I can't let people walk all over me because of my son. I look back now and think that it's sad that I have had depression for so long. But then I tell myself that it has made me a much stronger person (Nita).

I am learning about mental illness and that helped me. I am a different person now to the person that I have been all my life. Now I feel like I am living for the first time in my life and I love being me . . . I don't have to feel guilty any more and I have been that person who didn't fit into any box, so I think that it's only natural for me to feel different (Helen).

These narratives have highlighted the assumptions made about parents. There is an expectation of what is 'good enough' and what is not acceptable however there is a general failure to engage in discussions about the similarities or differences between parents, such as those who live with mental illness.

7.6 Chapter summary

This chapter has provided an understanding about what it means for a parent with mental illness to be 'a good enough parent'. The parents explained their concerns about parenthood, which included the joy they experienced in anticipation of parenthood, but how this also brought with it the unknown and the uncertainty of trying to strive to attain idealised notions of 'a good enough parent'. Being 'a good enough parent' was not always an effort, it was a joy, the most important joy in their lives. This was so for Nita who said:

I had to start doing things to try and make me happy, instead of trying to do things to please everyone else and be a good mother.

As the narratives have shown, the reality of parenthood was a pivotal time; for some it also marked the commencement of mental illness. The parents described the collision between parenthood and mental illness as alarming and disturbing, but they realised both were interrelated and interconnected. They provided examples of situations where they needed support but found there was none - sometimes practical assistance was needed, sometimes a friend was needed to witness their suffering and combat the isolation.

The parents also provided an insight into the lived experiences of risk, particularly for their children when the reality of mental illness meant that the parents were not able to practically and emotionally provide for their children. These times, however, were rare, and while the parents expressed their concerns at what might happen to their children, they also showed that their children's needs were always paramount as they tried to provide for and protect them. The other side of the risk discourse shown in this chapter was imagined risk. The documented, politically driven benchmark continues to subvert and stigmatise parents with mental illness. It operates from a deficit model and once the label is applied, can lead to a loss of parental status and responsibility.

Within the discussions about risk, this chapter has also provided an insight into how the children coped with their parents' mental illness. Some parents openly acknowledged the adverse effects of living with a parent with mental illness. In most cases, mental illness was stable and the pressures of acute episodes were limited or cyclical.

Parenthood, mental illness and the lived realities are layered with the business of everyday living and the need to fulfill practical tasks relating to caring for children. These everyday matters are also affected by life's pressures, which can sometimes become more important than mental illness. However, for some parents, parenthood was the motivating factor in getting out of bed and facing the world.

This chapter described not only the physical transition to parenthood but also the metaphorical journey that differed quite markedly from other aspects of the parents' lives, such as becoming a spouse, or taking on a new job. The fact that parenthood is for life perhaps created some panic and in some way may have also contributed to the onset of mental illness. But above all was a sense of belonging, of responsibility and of inevitability - there was no turning back as the children were dependent on them.

The parents' narratives have been discussed to "redraw the boundaries of a community's recognitions; [to] render[s] present what would otherwise be absent. As recognitions change, so do obligations. An obligation presupposes a face, and a face presupposes a story" (Frank, 2005, p. 62). As a society, we continue to fail to recognise the place of parents with mental illness. This can also be seen in the

failure to collate national data about the numbers of parents who live with mental illness.

The next chapter, Chapter 8, explores the parent's narratives further to provide an insight into their experiences of good and bad treatment as they sought help from mental health services. The chapter also highlights the need for mental health services to support parents with mental illness and their families.

CHAPTER 8: PARENTS' EXPERIENCES OF THE MENTAL HEALTH SYSTEM

8.1 Introduction

The parents who participated in this research project discussed their experiences of accessing and entering the mental health system. The interviews describe their expectations of good mental health care. Like any patient, they wanted to know that they would be treated with respect, with dignity and without judgment. Being heard, listened to, and understood were prerequisites to their expectation of good care. The interviews describe in vivid detail the effect of the stigma of mental illness and the way in which it can motivate or prohibit treatment-seeking behaviours. These sometime shocking accounts of the lived reality of these parents show that mental health treatment often fell short of the ideals of 'generosity' described by Frank. Rather their descriptions of mental health treatment reflect being in what Frank refers to as 'The Tunnel':

The Tunnel is an evocative metaphor of the experience of being ill. Stories of . . . life-altering illness - deep illness that casts its shadow over the person's whole future - often use metaphors of suddenly finding oneself in a tunnel-like space where it's difficult to breathe, the light is blinding and distorting, any possibility of movement seems caught in an inescapable track, and ominously unknown shapes are coming out of the distance. (Frank, 2004, p. 14)

The parents would have liked to have felt some connection with their clinicians. But they felt that dialogue was often not a feature of their medical encounters, especially with clinicians who were lost in 'the tunnel'. Frank suggests that even in times when health needs are acute we should not overlook how dialogue affects experience:

Part of what I love about 'The Tunnel' is how its characters find themselves called to dialogue by a situation they have not chosen. But there they are, in the tunnel. When we go through such tunnels together, dialogue is not a choice, in the sense of an optional extra. Dialogue is a demand. (Frank, 2004, p. 53)

This chapter enters 'The Tunnel' in order to understand the impact of mental health services on the lives of the parents with mental illness. In doing so, it acknowledges that generosity was experienced as problematic for many of the parents.

8.2 Inpatient treatment - experiences of and feelings about . .

Many of the parents had unfortunately; found themselves in need of acute psychiatric care. Some had experienced psychiatric inpatient care numerous times; for others, their one admission and their experience of institutional care had been shocking, revealing, and provided them with life-long negative memories. Liz provides an example of deficient listening and communication skills. Her counsellor failed to understand the difficulties she was having being a parent with mental illness. Control over her symptoms had already been taken from Liz, as the counsellor said that she was not as bad as she was feeling. This situation was compounded by her family, who failed to hear her distress. Out of frustration, Liz decided in spite of the acuity of her symptoms to do something herself:

The ambulance came [to take her to hospital] and the police came as well and it was awful. So everyone was there on my doorstep and the counsellor told them to go away, which I was angry about. . . . My partner came home and they told him I was doing this because of my mum. So I ended up taking myself to the hospital and it was hopeless. And someone spoke to me, and she was just, like, you know, I have had kids and you just have to cope . . . She was just telling me to get over it, and she had me in tears. I said to my partner, I am not leaving until I get someone who is going to listen.

Liz's story of attempting to be a good parent by accessing psychiatric care is an example of the lived experiences of a system issue with mental health treatment, which devalues respect for patients. Priebe and McCabe (2006, p. 69) suggest, "Mental health care revolves around relationships between clinicians and patients." Such relationships should incorporate respect and understanding of the needs of the parents especially as the experience of being mentally ill and having to undergo inpatient care is also viewed from a negative perspective. The parents however, provide an insight into different experiences of inpatient treatment. For example, Darren had vivid memories of inpatient care, so tragic that he talked about never wanting to return to the site of his trauma. Darren subsequently maintained stable mental health by attending to his symptoms and medication routines. He never wanted to have to be sectioned again. However, he had recently visited a friend in inpatient care and was despondent by this reality. He had thought that revisiting the place where he had been an inpatient after so long would enable him to see and feel changes. He had hoped that this return would be cathartic, banishing some of the ghosts of the past:

The doctors were overdosing me and my blood went septic, so I was in intensive care for four days and then had a medical injuries claim. So I didn't have a lot of faith in the system after that, and the doctor involved accused me of taking a drug overdose - but they hadn't taken my levels. The other week I went to visit a friend in the mental

health unit. And it was ten years later, and I realised that it was still the same; nothing had changed in ten years. Lack of funding, lack of care, lack of interest - ten years and nothing had changed. . . . There is the new mental health unit (Unit 2). This beautiful, painted place, though, but it is so very sterile and glass and nothing seems to have changed in there [since he was an inpatient 10 years ago]. It hadn't changed, and I was thinking, man, you just get me out of here. I said that this is the first time that I have stepped in one of these places without being a patient and I don't find it very comfortable at all (Darren).

As mothers Sam and Helen both had reservations about the reality of inpatient care and separation from their children. Sam experienced this stigma whilst Helen found generosity in her admission to the maternity ward as opposed to the mental health unit. Like other parents, they were both concerned about the stigma attached to this type of care:

I was just trying to grab as much help as I could for me and for him [her son], and eventually I had to go to the hospital - it was the lowest of lows . . . There was just nowhere else to go, basically, and I just fought them the whole way, saying, I just don't want to go . . . Saying, I just don't need to go, you know, blah blah blah. I was heavily sedated and they were chopping and changing my medication. And I was constantly trying to put on a brave face for my son because they told me that babies can pick up on this, you know, on you being upset (Sam).

The best thing about being in hospital - one good thing was that I went into a maternity ward, instead of putting me into Unit 1. If they had put me in Unit 1, I would have just said, give me a knife and I will finish it right here. Because I did have issues with that place (Helen).

It appears that stigma provides the major barrier to parents accessing mental health services. Pescosolido, Link, Stueve and Kikuzawa (2007) argue that culture continues to sustain knowledge and attitudes towards mental illness and creates a climate where parents and children feel able or unable to access services. Therefore, the cultural climate significantly affects people's perceptions of what people with mental illness are like, how they are expected to behave. Some parents positioned themselves as 'other' from people that they had encountered whilst in acute psychiatric care. Vinnie and Mike both provided their thoughts on the stigma associated with mental illness:

In the last 12 months there seems to have been these really high profile people coming out and saying that they have depression or something. But it's still a dirty subject. I have spoken to a couple of people and said, you know, that I have depression and they just back away. It's a bigger issue. I don't think that people still want to know about it. If I have a really bad trip and go down big time, I don't want to - I am always very cautious of what's going to happen to me, because I don't want to end up back in a place like that (Vinnie).

You think, you know, it's like being segregated with the lepers. Understanding people and understanding why anything, like with AIDs or anything, or any disease in this society. If you get a disease, straightaway, the way we are brought up, people just go, oh, yeah, you know, blah. Anything that people don't understand, they are scared

of. I am stoked about it [having MI] and she [his mother] gets the shits, you know, because I am stoked, you know. People are so narrow minded. When you look at when I was growing up as a kid, you know, they would say, oh, he's gay, or, you know, he's this or that, and look at it like that - big deal. But all that came from the red-neck culture of some big bloke footy player who is probably gay himself. Fear stems from insecurity and everything goes from that and that is how I deal with my insecurity which I have heaps of. I turn that into hate (Mike).

Unfortunately, prejudice is so deeply embedded in society that most of the parents had also encountered stigma, Mike and Jen from within their own families, and Evie from friends and acquaintances.

She [talking about his mother] is hopeless, and she just denies it, and she just doesn't want to know about it. She is really heavily into the church, and all that. She is praying and, like, that will help. And I say, it's an illness, you know; face it really (Mike).

It was a total surprise to the family because I really was very depressed. They knew but they weren't sort of doing anything - ignorance - they were in denial, and I think that they didn't care. The reason that I didn't get help was because my brother, my brother-in-law all said, well, you are not sick, you are all right. And I thought, I am not sick until I do something to the baby. My family said to me it was an excuse [mental illness], just pull your socks up, stop going to the counsellor and get on with it. Just stop it, you know, you are just selfish (Jen).

Unfortunately, some of these big government departments still have it, they still have this stigma. You have mental illness, and you are dangerous to this child. You are a child abuser, you are stupid, you know. I get that one a lot, you know, people think that if you are mentally ill then you are also intellectually disabled. I get it with my studies - I did a TAFE course a couple of years ago and I topped the whole year and I got straight distinctions. I hadn't told people that I had a mental illness, you know. And then I told people, and they said, but you topped the class. And I said, so ... really? I said, having a mental illness doesn't make you stupid. And people are just somewhat stunned. They say, you can't have a mental illness, and I say, I can, I can, that's right. I am Evie the person first, and I am Evie the mum second, and fairly well down the concept of myself is mental illness. Some people, for example DoCS, see that I am mental illness Evie - not Evie, you know [and I said that in court]. I said, my name is not Evie Bipolar, my name is Evie and I have Bipolar Disorder.

Sarah and Jo had solutions to the issue of stigma explaining that information for parents with mental illness is needed. Jo also felt that projects addressing the stigma associated with mental illness would also be beneficial to parents:

Everyone focused so much on the pregnancy and the labour. And then you are in the big wide world and no-one prepared you for that. And that's when reality hits and you realise how hard it is, and there is, like, 16 or 18 years or more of trying to cope with this (Sarah).

I guess, like having information on line. Maybe if it was provided to you it would be good. Most of the books, they don't really go into very many steps about the kind of adjustment and how much change there is after the baby, and, like, how much pressure it puts on you. . . . If you have any weak spots, like mental illness, then they are going to give. (Jo)

However, stigma about mental illness is deeply embedded within society and most of the parents thought that people were making judgments about them or negated their symptoms as part of an overactive imagination. Sam, for example, said: "I had a new GP because I had moved, and he kind of laughed and said, oh, surely you can cope". As a result of these types of attitudes some of the interviewees, Sarah had denied their mental illness or believed what they were being told:

I was going for nearly six months telling myself, look, I am fine. And if only I had got treatment earlier or got the help . . . but I don't know about other people. But I was in denial and I wanted to keep it a big secret.

Other interviewees provided other stories other people categorising them as bad people because at times they were unable to care for their children, or failed to live up to the stereotype of 'a good enough parent'. Jen was terribly upset about her experiences, not only her failure to fulfill societal notions of 'a good enough parent' but also the lack of support from within her own profession:

I am a little bit more accepting of mental illness because I am a nurse. I didn't punish myself as much because I thought that I would get help. I really believed that deep down within myself I would get help. It was, like, no-one punishes a diabetic who goes into a coma because they've mismanaged their medication. They are all over them trying to help them - but not me - they are horrible. There was no help, even the nurses in the hospital. . . . I was too upset to really be too distressed to worry too much, I knew that I was in the right place. She [her daughter] watched me go into hospital three months after my husband died. I didn't get out of bed. I was hardly feeding her and I didn't get out of bed all of the time.

Frank suggests that it is the system that makes people feel either welcome or not wanted within treatment services: "Society sets up institutions that determine access to the tools of treatment; which services will be reimbursed at what level" (Frank, 2004, p. 28). Helen had lived the reality of 'The Tunnel' whilst receiving treatment, in spite of the fact that she had been admitted to the maternity ward: "I am an open person, so I can imagine someone who isn't very open feeling worse. Like people were judging me and that type of thing".

Evie had never been ashamed about her mental illness; she believed that mental illness should not be hidden away in a shameful fashion, but again her narrative told of the lack of shared beliefs about mental illness:

I wanted him [her son] to see that having a mental illness was nothing to be ashamed of. I wanted him to see that mummy had it [mental illness] and mummy needed to be treated and made better. Now I feel that I don't know what is happening to him that DoCS are trying to tell him that it's a bad thing having mental illness - that it is bad. They say to him, you have been taken from your mother, she has mental illness, and it is bad. Which is so wrong, and it is no wonder that we have stigma in society, you know. So, one of the things that I will do when he comes home, is that I am going to

be working with him again, to build up that knowledge that it's not a bad thing, that it is no different to any other illness.

The culture of psychiatric units appeared to have been very distressing for the parents. Not only were they separated from their children, but their parenthood was 'left dangling' during their hospitalisation, often considered unrelated to their experience of inpatient care.

From reflecting on the stigma associated with being a parent with mental illness, the parents' narratives move into discussion about their feelings of being the 'other' or not belonging within acute psychiatric inpatient care. Helen and Vinnie had both encountered these feelings, which only compounded their guilt and shame at having to accept treatment:

I felt like I didn't fit in, and I got really paranoid, like, because I didn't fit in there, and that people might ask me why I was there. And I felt like that was part of my issue that I felt ashamed (Helen).

I knew that I didn't belong down there, but I was sick. But I thought, no, you know, you see some of the people down there and you think, oh, you poor bugger, they have really got problems. . . . So they took me to Unit 1, and I didn't know . . . Like, I had heard of Unit 1, but, like, I'd never been there, and I just went there and just freaked out. That's when they said, well look, we are not going to let you go. And my wife rang a friend - she works in the MHS - so she had a few pointers on what to say and how to get me out of there. Once I got out of there I was fine. (Vinnie)

Accessing psychiatric treatment was raised as an issue, either, not being released or being released before they had fully recovered. Dani provides an alternative example to Vinnie of her experience of discharge after an extended psychiatric stay of over three months. Her story provides a breakdown of generosity in treatment including failure to refer to community mental health services. She talked about how this reflected a basic lack of understanding about her needs and lack of acknowledgment about her role as a parent, created unrealistic expectations for parents with mental illness. She was expected to return home to care for three young children without any support from mental health services. Few parents experienced anything like continuity of care or generosity, which Durbin, Goering, Streiner and Pink (2006) suggest affects patients' prospects of recovery. Corroborating this theory Dani explained her short period at home resulted in her trying to cope devoid of help from either family, friends or services. Dani attributed her return to psychiatric care directly to this lack of assistance:

They knew about my nursing background, so I got a really hard time. Then I went home. But it was not long, though, four months afterwards, when I was readmitted. I did an inpatient admission in the Shire and it was terrible. It was awful. They gave me

such a hard time and were very judgmental towards me. They picked fights with me because they thought I was smart. The staff didn't want me there. They didn't think it was a good idea for me to be there, so they sent me away to another area. Do you know, they didn't even ring my family and tell them what they were doing to me? I felt trapped in there. It was awful. One night I ended up in seclusion and they were like sticking needles in my butt and that to sedate me. And I said, what did I do, what did I do? And, like, I didn't do anything. I remember I had a fight with one of the staff. I don't think that I was irrational or, I was just stating my opinion and, like, the head nurse made up his mind. He says, we are putting you in seclusion - from the office and that's the end of the story. I said, what have I done? And he said, you have played up all night and we are sick of you.

From that day I was as quiet as a mouse. I never said anything to anyone. And then I saw the psychiatrist and he said, look, it's not working having you here, the staff don't like you and we would like to send you to a better place. I felt like a prisoner in Unit 2. I felt like you could not do anything. I hated Unit 2 so much that I even tried to hang myself in the bathroom with the cord off my dressing gown. It was a while before anyone came down, went, oh shit, and put oxygen on me and they said, are you all right? and got a doctor down - things were bad in there for me. I was very isolated in there. Not many of them spoke to me, and if they did, it was just a grunt, and it was really horrible, like, I knew that they were judging me.

So, I went down to another mental health unit, and I was in the high dependency unit. They [the children] didn't come into the unit. I had to go out to them because they didn't allow visitors in there. We sat, like, on tables and chairs, you know, and just talked like that. But they were a bit little so that they didn't really understand what was going on. I sure missed them [her children] because I was on the ward on my own (Dani).

Not all of the experiences of inpatient were negative. One parent reflected positively on her admission to psychiatric care. Whilst acknowledging that the way that she arrived in inpatient care was detrimental to her children, she did feel that it was a place that she needed to inhabit for a time. She highlighted systemic issues of other agencies who appeared to have no skills for managing her mental illness in the community:

It's a bit of a safe haven I guess . . . I mean, you feel embarrassed and you say, like, should I be here? And that sort of thing . . . The police took me there and I did feel like they were judging me and that they didn't really know who I was . . . because I wasn't me, I wasn't myself. And it was like a dream because I don't normally behave like that, but I just lost it. . . . The police restrained me but I was quite compliant . . . They put me in the back of the paddy wagon. . . . they took me to the police station and I was saying, what about my kids? And he [the police officer] was quite rude, and he said, you should have thought about that before you left (Jane).

Whilst Jane's arrival in inpatient care was therefore problematic but she felt that it was an appropriate place for her to be at the time, momentarily suspending her role as a parent.

8.3 Being in inpatient care with their children

The lack of care and generosity experienced by most of the parents who took part in this study does not sit well alongside research which suggests, “Mental health nurses have a unique opportunity to identify risk factors, enabling intervention at the individual nursing level . . . thus service can be modified to accommodate family-focused intervention for individual families or groups of families” (Devlin & O’Brien, 1999, p. 22). Such research findings are not often reflected in clinical practice nor have they been transferred to increase funding for clinical services. Slack and Webber (2008, p.72) suggest that whilst “the impact of parental mental health is well known . . . children’s very existence may fail to be recognized by adult mental-health services”. This continued lack of acknowledgement means a failure to provide public mental health services. For some parents with private funds, specialist psychiatric units could accommodate and meet their needs. Dani talked about her experience when she was eventually transferred from a public psychiatric unit to a private unit for mothers with mental illness. This unit allowed her to have treatment and access care whilst remaining with her child:

I went there [to Hospital 3] to a post-natal depression unit there where you can actually take your child. It was so lovely, it was so good there. Unit 2 was like hell on earth, and Hospital 3 was so nurturing, helpful, like, I really felt that I came a long way there. They asked me about my kids all the time because I had photos and everything. They would come into my room and say, oh who are these beautiful girls? And I would talk to them about everything. They would say we have got to get you well for those girls; you’ve got to get well for your girls. They would give you positive comments, like, you are doing well, you are having such a good day. And I would be excited about it, about the days that we spent with the babies. And I realised that I was sick, but I was also doing ok. It was very informative, very educational. As far as I know, it is the only one in New South Wales. I felt the communication was very poor because clients didn’t really know what to expect in public mental health system. The private mental health system was much better, but I just wish there was something up here.

Some mothers were fortunate to be able to access the private care system. Other mothers, due to their geographic location, would be prevented from accessing this service, as were fathers. For example, Sam had accessed the private mother and baby psychiatric unit (Hospital 3) and talked about her experience. She said that she had not recognised how sick she had become until the doctor said that she must go into care:

I go there, and they said, you have to go. And so I kind of had to call my husband to leave work, and he had to come and get me and drive me there. I still kind of didn’t want to go, but they said that you have to go. . . . It is so expensive. And there was one girl there and she didn’t have private health cover, and as well as being unwell,

she had the added worry of how they were going to pay for it . . . I remember thinking when I was there, why isn't there more places like this? As soon as a girl would leave, another would be interviewed and in there to take her place . . . There were never any empty beds . . . Its location as well, there are all of these women who suffer from mental illness living in rural areas and they just don't know anything about it.

The main advantage of having a psychiatric unit where mother and baby could be together was that it maintained their parenthood and enabled them to learn skills associated with managing their mental illness alongside the role of parent. For Sam, this provided the opportunity, for example, to “enjoy normal day-to-day routines in a hospital environment”. The staff would encourage the parents to feel confident about being a parent, and provide a normalised environment explored through group sessions with other parents facing similar issues. However, the lack of availability of inpatient psychiatric care where new mothers can take their children created issues for other parents, as their psychiatric needs became paramount and for a while, parenthood was on hold. This was Evie's experience:

We couldn't get into a mother and baby unit. There is the dilemma, there were not enough places and I did have private insurance but I wasn't covered for psychiatric conditions. I never dreamed I would have a problem, and so to get into a mother and baby unit, most of them are private. And you've got to wait for a place to come up in a public hospital and very few psych units do this. So initially, it was really foster carers [who cared for the baby].

The benefits of having mother and child together far outweigh the risks. We were kept a little bit separate from the others. I think they didn't seem to have a problem, as I said, when I was in there. I had a separate room with an en-suite and I had my own nurse with me and I was, sort of, never left for other patients to attack. Then, later in that first year, we went to another hospital in the city and it was much the same. I had my own room with en-suite and I had my own nurse with me. You know, they were good in terms of - they let me mix with other patients. That's the thing with psychiatric hospitals, you don't see people who are crazy - you know most people, they are just they are like everybody else, they might be a little bit sad, they might be medicated or something.

Helen's situation was interesting. Her father was part of the medical system and very influential. Because of his fears about her treatment, he had stepped in to ensure that Helen was not admitted to a psychiatric ward but, instead, placed in a maternity ward. Whilst Helen managed to circumvent the psychiatric inpatient unit and had been placed back on the maternity ward, her experience of treatment was still problematic:

My dad said, maybe we could put her back into the hospital. And I said, I don't want to go to Unit 1, and I won't go there, and I don't want to be a crazy person. And I didn't want them to take my baby; I really thought that they would take my baby. So I went onto the maternity ward and they looked after me there. . . . No-one really talked to me about it [mental illness], no-one came and I did get worried. I tried to make it known how I was feeling, and I did try to tell the nurses and they said, oh

yeah, that's normal. But they didn't really read my notes to know that I had a breakdown with my first baby.

The vignette provided by Helen is not uncommon. Other research has also found that having someone willing to listen “to families’ experiences with the mental health care systems” (Jensen, 2004, p. 34) was more unusual than usual. Generosity does not appear to be a feature of the mental health treatment experiences of most of the parents who believed that no-one was interested in their struggles:

I've needed to share it, but there was no-one who was prepared to hear, and people aren't interested. It was all meant to happen, though, and I am glad that you have seen this as a need. I did some parenting course, which was fantastic, and I also did some residential parenting courses with him [her son] and they were great. Great with the parenting side, and I was supposed to be confident with the parenting. But it was managing the mental illness and parenting. There is nothing specific to how to be a parent and manage mental illness at the same time (Jen).

It does appear from the narratives that lack of awareness is quite widespread within the mental health system where no-one asks whether a patient is also a parent. When Sam became sick, there was nowhere to turn to find good support due to the lack of psychiatric care units that could provide care for parents with mental illness. The reality for many parents was that they were separated from their children who then entered foster care. Although Jen had experienced being cared for in a mother and baby facility, she also suggested that being recognised as a parent with a mental illness was not something that would always have a good outcome:

Throughout my whole pregnancy, and when I went back for my visits no-one ever mentioned it. And then when I left hospital, one of the nurses kind of said to me that, you know, you are more susceptible to getting sick, so make sure you look after yourself. . . . They never asked me if I was a parent, but [if I had told them] social services would have taken her [her daughter].

Some parents had to be resourceful in finding family or friends who were willing to take care of their children whilst they were in inpatient care. Evie talked about how she had managed to access alternative care systems in the early days of her son being taken into care. From the start, she had been provided with an understanding and openly supportive foster carer. This continuity of care was not only beneficial for her son but also allowed Evie to negotiate her way through the acute stages of her illness whilst continuing in some way to be a parent. As an alternative, Evie also had a family friend who was willing to provide care for her child whilst she was receiving treatment:

Even now, nine years on, we still have [foster carer support], and not only did she care for him [her son] but she also cared for me. She'd let me stay over, and if things were getting tough and I needed support, she would let me stay and would have me

for the night when he sort of finished being in foster care. She was always saying, well, come back and see me if you need me. So now, they don't do that now - you don't have any contact with foster parents, which is a shame because that really made a huge difference.

He was actually with my best friend. In terms of security, it was fantastic. Unfortunately, she was finding it very hard to manage him and didn't get the support from DoCS. They also . . . we were being illegal in that we were organising visits without them knowing because contact was so restricted. I didn't like that, and I felt that my son should see me more. Plus, with my son living with my family - my adopted family, I was being cut off from all support, because DoCS were saying that you can no longer do things with your family because he was there. So it was like, well, who is going to support me now? Because I am a part of that family, and if we have a family function I can't go anymore. I can't go for Christmas [laughs]. I can't [laughs]. It just got really, really difficult (Evie).

Evie spoke about issues for parents with mental illness in continuing to maintain their parental identity whilst also receiving acute psychiatric care. She was hopeful that generosity (to be discussed in the next section) could become a part of mental health service practice:

I had respite care. I had a whole range of services. Unfortunately, they were limited. So, when things started to get tough again, I had nothing, there was nothing to turn to. Trying to get people to help was hard. I seemed to slip through the gaps - not only for parenting support, but for mental health support, too. I just seemed to slip through, and financially it was obviously a struggle. We just got to the point where we were going to be homeless. I went to the Department of Housing and they said, we can't help you until you are on the street. And I thought that if I was on the street, I would end up losing my son, which I did end up doing. I think there should be some help out there.

I only found out that - at the beginning of this year - that there is a residential service in the city. They are a residential service for people with mental illness and their children up to the age of 12, and you can stay down there for up to six months. You have your own unit and you have 24-hour support. The thing is that they look after you; they make sure the child is safe and they help you manage your mental illness. Then the school is just across the road and the school is very much involved. Now why DoCS didn't think of that? Like, two years ago my son and I would have been in that service. We would have probably been out and back home again by now because I would have recovered.

Evie was philosophical that generosity was possible, not only as a concept but also in time allocated to providing care and set aside to gain an understanding of the needs of parents. The services accessed by the mothers who had been able to be with their children and to learn how to coexist with the role of parenthood and life with mental illness were rare.

8.4 Generosity of care

Perhaps Frank would respond to the lack of generosity of care experienced by some parents within the mental health system by asking: “Do they create a medical practice that can be a template for the relations of care we want to have prevail in a moral society?” (Frank, 2004, p. 28). The lack of generosity in the mental health services discussed in this research was seen in different ways by the parents who participated in the study. Parents who were inpatients thought some of the staff inhabiting what Frank refers to as ‘The Tunnel’ were too deeply embedded to change the ideologies inherent in institutional care. Darren, for example, talked about his observations as an inpatient:

Some of the people [staff] in there, they don’t know what they are doing, but that is neither here nor there, I suppose. I would never go back into an institution again and that’s my choice.

Other parents saw a lack of generosity in their interactions with their psychiatrist or the person who held the power over the direction of their journey through care. Mike and Ursula both had long term relationships with their clinicians but both provided examples of interactions as lacking generosity. It appeared that prior medical history of the parents appeared to sometimes cloud the judgment of a psychiatrist and encourage this continued lack of generosity in listening carefully enough to the parent’s symptomology.

I’ve only been seeing the psychiatrist for the last year and a half and I can never really understand. However, I have a lot of respect for the guy, you know. I just go in there and talk and wait for an answer [that he doesn’t ever get]. But she [his mother] pays and that’s, you know, 300 bucks a pop, you know, but you don’t get any feedback. I am talking and then at the end, you know, I am going, how did I go, you know? Good story, man, you were pretty intrigued by it, man. And he will look at me and say, yeah, you are like, full on, man (Mike).

The psychiatrist, he basically said, she’s got a mental illness. That’s all, and they kept dosing me up with things for the mental illness. But for two and a half years I was post-natally depressed (Ursula).

Ursula felt as if her rights had been subsumed by her mental illness. The fact that she was catatonic throughout her pregnancy meant that she had been treated with a lack of respect:

I don’t like two meals the same and they were making me eat stale cheese sandwiches every night at 2am to inject something into me when I was pregnant. I can remember that I used to think, oh, if they give me another cheese sandwich, I am going to throw up, because they had been sitting there all day. They were stale because no-one wanted stale cheese sandwiches, so I got them. And because I was, like, you know,

not really quite right, they gave them to me because they thought it wouldn't bother me, you know. But I used to really hate it (Ursula).

By contrast, Helen's example of mental health inpatient treatment highlights a position of increased opportunity for good care because of her father's position as a respected medical consultant. It also provides an example that suggests that even her connection to powerful agents who have some control over the system did not ensure that she was provided with help beyond the hospital to assist her rehabilitation. Helen also encountered lack of generosity in a myriad of ways from the mental health professionals in her stay in the maternity ward:

The psychiatrist talked with me and he was all right, but they tried to pinpoint it to something. But no-one gave me any relief and they didn't know what to do, and I just didn't know. The psychiatrist said to me that you have to go to Unit 1 and we will try to deal with you there, or you go home and start planning what you are going to do even if it is diversional. It's going to feel really strange, but it doesn't matter, just act like you are normal and you will be.

When I was in hospital there was a little support [on maternity ward]. There was nothing - no-one ever tried to understand me. There were a group of people who came, social workers, they came in and she was lovely. She gave me information and told me about support groups and I was, like, yeah, whatever. But I was really not convinced that there was anything that could be done because it was such a weirdo thing.

Helen, Jane and Sarah had all suggested that community support was limited and offered as information as opposed to practical services that would help the parents on discharge from psychiatric care. Jen had cried aloud for support until she became desperate, but the limitations of the system made her realise that more was needed:

I said, I am not coping very well and I need help. The ladies there said, oh, ring back in three weeks. So, I rang back in three weeks, but it took me about two months to make the phone call, and my mother found the number because I couldn't see properly or concentrate to ring the number or be still enough to dial. Why wasn't I believed and why did it take them so long? I needed to go straight into hospital to be sedated and taken away from the baby. There was one woman who came in all glazed over, being led. They sat her down and she held her baby for a while, and then she went back to the psychiatric place. I thought, well, why can't you do that to me? I rang them back, and they said, oh you are all right, and I said, no I am not. So I said that I had her by the neck and I am going to kill her if you don't do something. They put me in three to four days later. I didn't go into a locked ward and I didn't have my husband rushing home from work to look after her whilst I went into the hospital (Jane).

There is basically no real support here . . . There are groups, but I have never been to them, because if you go there and listen to their stories, it makes you feel worse . . . I have been to counselling, but every time I have been they just say to me, you are a smart person, you can work this out. It's hard when you are trying to get help and each time they say this to you, and they say, you know what's going on and you can work it out (Sarah).

All of these parents provide examples of the need for time and insight to become part of medical interactions. None of the parents provided stories about their community service providers, all of the stories were located around statutory mental health services which appear to operate under standardized models of care which fail to meet their needs.

8.4.1 *Lack of generosity in support and diagnosis*

Getting through the doors of the hospital does not ensure that support will be provided. Many of the parents had lived their lives feeling distressed because of the lack of generosity. Many shared similar experiences of having received bad treatment: some parents talked about needing to tell workers what they thought they wanted to hear, simply to engage them in their lives. Some parents recalled that they embellished their stories and provided more interesting tales than the issues associated with what was really happening. In effect, they played the sick role, the role of a parent with mental illness - while not actually getting to the core of the issues. Jen and Jane both felt that no-one was interested in listening to her thoughts or feelings:

When we were in care, I wouldn't get out of bed. I was distraught and they told me to go and do my washing. So, I went and did my washing, and I thought, I have to do something. So I walked into the kitchen with my wet washing and put it in the soup and I thought this should fix this (Jen).

I couldn't tell you how I really feel, what was the point, why bother? No-one really wanted to hear what I had to say. Then if they did, what would they have done? Nothing (Jane).

Helen provided another dimension to this debate, she thought it was amusing that because she had been diagnosed and in need of psychiatric treatment, whatever she said would be interpreted through a medicalised lens:

That's the problem. Sure, they come out and, you know, talk about it [mental illness] for half an hour. I told them a story, and she was trying to connect the dots as to why I was like this, why I might be feeling like this. I told her this crazy story of, like, of this old ex-boyfriend, but it really had nothing to do with anything, but she was so happy. She thought that it was such an amazing story. She thanked me, and it was as if she had enjoyed this story. She probably did, but I just thought that it didn't have relevance.

The services that the parents had experienced were generally described in terms of having been exasperating and ineffective and in need of being changed. Ursula was able to compare her experiences of good and bad treatment:

All I can say about my experiences up here is that it has been trouble. And there I was before, stuck out in the bush, and they had more support and less funding, but my case manager used to come and see me if he was going past, in his own time - they cared.

Mental health services continue to assign little concern to supporting and providing preventative mental health services. This is supported by national mental health policies, which prioritise mental health services directed at people with acute mental illness. This discourse, therefore, encourages the lack of awareness for parents with mental illness, or limits the knowledge as to how many parents have mental illness. For many parents, their symptoms were often associated with the fact that they were inexperienced in parenthood. For the parents, this lack of understanding meant limited services designed to support their needs:

I got to the point I couldn't go on with how I was, so I went to the doctor and got some medication, after two nurses said that I needed some. The doctor wouldn't believe me that I was sick. The medications were no good, and they didn't listen to me. I have always said I would have been better to go to the shop and get lollies! So after that, every two weeks, I would call the doctor and any doctor I could think of trying to get help of some kind. And then I got onto a counsellor and she said, oh you are a first-time mum, you will be fine. . . . They wouldn't do a thing for you here if they didn't have too. There are only a couple of good ones. I did a lot of community work, too, and I could tell who cared. I enjoyed hearing about people's lives (Jasmin).

Deinstitutionalisation should have ensured quality care in the community but there is widespread agreement that this has not happened. The parents' narratives give rich and detailed examples about how the system is failing. Mike, Jen, and Liz all provided their views about the lack of effectiveness of community care:

How effective are services if someone has been going for years and still isn't making progress? (Mike)

I started with another mental health team, and they took me on. I started going to groups and went through all the levels. I kept going and going for years, and I went once a week and then thought that I wasn't getting anywhere there. The nurse counsellor was removed, and they got a social worker in. I needed a counsellor once a week and I got her once a month. I saw the doctor once a month and a counsellor once a month and that went on for months and months. Then I lost it in their office one day because I wasn't getting the help that I needed, and then they had a lady come out to the house to see me (Jen).

I got in touch with someone . . . like, the early childhood nurse, and she got in touch with the early intervention team - they were hopeless, totally hopeless. I waited for eight months to see them - nothing. They did come out and visit us and did the initial thing asking questions. That took four months (Liz).

Once one agency had accepted responsibility, others seemed to accept their position as case managers, but would then retract their support services. Liz explained this situation:

Like, before all that happened, we were seeing about two different people, and then after that everyone else thought that everyone else was supporting us, because then we didn't get anyone and I ended up with no support and it was worse. I couldn't believe it went from seeing, like, two people and then those people must have thought that I was seeing someone from the hospital, or whatever, but I ended up seeing no-one after that, and I had to really start again.

The discussions about the lack of generosity by professionals towards parents with mental illness were substantial. However, each parent had a different idea about why this situation was so; Liz provided her rationale of why service providers failed to meet the needs of their clients. She felt that it was partly due to her age but also revealed services with lack of awareness of the needs of parents with mental illness:

I never thought it would be a problem, but it is well, erm, to be taken seriously. No-one listened. And it had to bring me to a point of breakdown, you know, and then they still didn't listen, no-one was interested in how I was or how I was coping with the baby. . . . Like, doctors aren't aware, and I couldn't believe what they were telling me, oh, ok, that's simple. I'll just go for a walk, oh, great, no problem. Like, everyone was telling me, just to get over it. And I was so angry, you know, and it was getting so bad, and I kept getting told stuff, like, it was so simple to do. . . . No-one listened to me, and it had to bring me to a point of desperation.

It is important for doctors to be aware of the specific needs of parents, as research has shown that 40% of people with depressive illnesses will seek support from them (Henderson, Andrews, & Hall, 2000). The attitude of staff therefore has a huge impact on how people experience their journey through care to recovery. Some parents like Jen, provided examples of how this had affected their experiences:

The second time I went into hospital was when she [her daughter] was 11 months old, and the psychiatric nurse that interviewed me said, oh, you are all right; you are a pretty young blonde. It broke me, but I didn't get any help and didn't get any kindness. I just got the type of help people with depression got at that time. That was no kindness and no comforts - nothing. I would rather have died [than remain in psychiatric care]. It was the most shocking thing, but you just do it, you know how retarded people have their things, and they go to their workshops and do their stuff, but they suffer pain all the time, but still, they go and they do it. I kept seeing the psychiatrist once a month until I felt it wasn't helping me and then I just gave up seeing her. And before that, she was taking me off medication. I did get a rebound depression and then I got sick of her.

The parents' stories of dissatisfaction provide an expose of the state of statutory services; their experiences suggest that there appears to be lack of standard of care within mental health services. These narratives build on the stories provided by the submissions to the Senate Inquiry discussed in Chapter 5.

8.4.2 *A specific example of lack of generosity*

The most upsetting example of lack of generosity was told by one of the mothers. Although she is part of this study, this particular story is so sensitive that, I have not used her pseudonym. A name is not necessary to understand the essence of her story that speaks of a lack of care and generosity. It is also, a story of the effects of deinstitutionalisation whereby more people who once would have lived in long-term psychiatric care are now living in the community, forming families and becoming parents. This mother had a late induced abortion after the suicide of her partner who was also a long term mental health patient. At the time of the incident they had both been living in an institution. After his suicide a decision was made that she was not fit to parent alone, even with support and she felt that she had not consented to the subsequent procedure to remove her unborn child. From her story it appears that assumptions made about parents with mental illness are that they do not have the same rights as other parents - an argument of the Burdekin Report outlined in Chapter 4. This is her story:

We have an angel in the house; called Eric, he is . . . a terrible experience . . . I told my son when he was little about his brother. I said that he died when he was born, but he loves you. You are a big brother and he is very happy about that. He looks up to the stars and says, that's him up there . . .

You could tell he had mental illness [her partner] but you couldn't really tell that I had mental illness. He was amazing, he used to stick up on the walls this writing and he would like Russian psychiatric books and cut out pages and put them up. One day I asked him, why do you do that? He said those bits were about him. Then his father took him away and he killed himself. He took him [her partner] away and I just fell. He pushed me into the gravel and I was just crying. I couldn't believe it, that anyone could be like that, and he said, you are just creating a mutation. I was disturbed and the doctor said that I wasn't well enough to have a baby. So at 22 weeks they took the baby. They induced the baby, and I had it in the shower and I was holding a little boy. I think that they made me sign something, but I didn't really know what was going to happen. I think that they wrote that I was in a fit mental state, or something, but I wasn't. I was totally devastated. . . .

I was in the shower at the end. The nurses were, you know - people who do night duty, they are usually weird and they were really awful. I had moved around, the drip had come out and they said, For god's sake, will you stay bloody still! Then I was in the shower and I am holding this baby. I am screaming. I was there for half an hour. I had to put the baby in one of those pans, you know, and run up and say that the baby is in the bed-pan. So I ran away from the hospital. There was blood everywhere, I am hiding behind the lemon trees, and the police are going around looking for me. Then I saw my dad's car and I jumped at him and begged him to take me away. All my life just fell into a heap.

This incident remained hugely traumatic for this mother. It reflects arguments about the removal of children of parents with mental illness as a preferable situation to

allowing them with support to care for their children. Literature does suggest that removal is no longer the preferred option, what is clearly needed is more effective support for parents, especially for mentally ill parents. Little (2006) suggests that one option is to provide all parents with a universal program of support; then parents in more acute need, such as parents with mental illness would at least receive some level of service.

8.4.3 Generosity of clinicians

Trying to find someone to connect with who will try to understand their experiences created frustrations for most of the parents. Some, like Vinnie, had noticed that clinicians were being burnt out and moving on, which, in turn, created issues with a lack of ongoing relationships with any one person:

I was just getting down to the community team here, and I would just get used to one counsellor and then, you know, because of the health system, they just swap them around here and there and everywhere. I'd just get comfortable with one person and then he'd be off or she'd be off, and I used to really get the jack of doing that. It took a long time before I actually found someone to help me. She's helped, she has just hit the spot and just helped with a few little things, just to take things off and not be so hard on myself.

Reflecting on how things could have been different and staff more generous towards her treatment, Dani put her experience within the framework of her own practice as a nurse. Dani knew the impact that her illness was having on her family and tried to find a sympathetic ear, but instead found the wall of silence:

They just threw me down, and, like, there were men and women there, like, all these people and, like, bang, bang, bang, and they just went. And I thought, like, what have I got myself into? I was just a nurse, and I guess as nurses we are supposed to just care for them, but they were shockers, absolute shockers. I knew that they had an opinion about me and what I was going through, and it really worried me because I think, oh, yeah, it would be different if it was on the other foot and it was one of you. Unit 2 was definitely the worst. Like, I wasn't treated very nicely there, and I probably erased a lot of memory as to how bad it was. But I know in my heart that I am not telling you everything that happened to me in there, but I think that I have forgotten actually how bad it was. . . . I don't think that professional people who came across my sickness really understood what was driving a lot of my behaviour. And for them to teach me how to say to someone that I can't do it and not feeling guilty about all of that. Things that I wasn't doing.

The wall of silence Dani encountered signifies life within what Frank (2004) refers to as, 'The Tunnel', which is also associated with the notion of generosity. From the parents' experiences, perhaps a question needs to be asked: Is the lack of generosity related to the clinician or is it related to the working environment and to being worn

down by the system? Dani also attempted to answer this question from a professional perspective as a clinician. She noticed that the lack of dialogue was not limited to professional interaction but also to the stigma attached to the relationship of the staff to patients. She saw this as a lack of staff interaction and integration with patients:

It was interesting in the communal dining room, all the staff sit at one table and all the clients sit apart. I thought, wouldn't it be nice for one day that, like, a staff member could sit down and share breakfast with you. I did notice little things that could be so much better and it wouldn't take a lot of effort to learn more about the people you are caring for.

Dani's experience also reflects the views of Frank (2004, p. 28) who notes, "When hosts and guests meet face to face, each must decide in that moral moment that he or she will be in relationship to the other." Jo was able to reflect on this situation as both a medical professional and a parent. She was able to think about the impact her colleagues had on help-seeking behaviours and parents' access to services. Jo knew from her practice that some of her colleagues were not able to be generous towards parents with mental illness. As a GP she felt that this issue needed to be addressed through training but as a parent with mental illness she felt that the reality was less hopeful as she knew that she would never disclose her status in this second group:

I certainly think that the medical profession have a lot to answer for in terms of how much they don't really talk about it and, like, they kind of ask about it, but, you know, maybe in public hospital where it's a bit, like, common, but not like in the private hospital where everything is too nice to talk about. Whereas at least in the public hospital there is that kind of stereotype of, like, who gets what, and they think, like, everyone is, like, 18 and smokes and that kind of person. . . . A lot of the time you hear that a lot of people say they went to the doctor, and they said to her. . . . He put his hand on her arm and said, look, you are a first-time mum. . . . What is that supposed to do to help her? A lot of people in the health profession are kind of young and have never had kids, and they don't really understand where you are coming from. And there is this other kind of older men, who probably haven't been there or been involved in their own kids anyway, or involved a long time ago, and come from that generation where women were just, you know . . . it was all hormones.

Perhaps this signifies systemic issues with the mental health system. Some of the problems with the system are related to the policies, which define, design, and fund mental health services. A question remains about who actually fits the systems of care that are in place. Is there a specific type of person who can make the system work for them to assist their recovery and rehabilitation? Frank (2004) also refers to the 'monological medical style' where there is no communication between clinician and patient. This can be seen in Mike's attempts to both please his psychiatrist and fit into the system:

I am running out of stories, you know, like I don't like to think that in six weeks or when I see him that something significant has happened in my life. It's like he's waiting, you know, to see what has gone on. He never talks . . . he doesn't say a lot. I don't even know if he does talk - put 20 cents in the slot, you know, I said. I think he's just writing a book on the side, you know . . . There is no period in my life where something has never happened and it could be for the rest of my life because that's where it feels shit.

If there was limited interaction between the parents and their mental health clinicians, I wondered if they had ever been asked about being a parent or about their family. Evie answered this question:

It was all very separate. I found that this lot here, they treated the mental illness and that was sort of taken care of. This other lot - this lot here, they did the counselling and some of that counselling was about feeling or not feeling that I was a good parent. In those early days, it probably laid the foundations for recovery, but it wasn't really helping terribly.

Generosity does appear to be intrinsically linked to trust. Many of the parents did not have a relationship where trust was apparent. As a result, they were fearful of disclosure of their symptoms, fearful that the clinician was interacting based on their assumptions about parents with mental illness as opposed to knowing the parent and having a relationship with them and their family.

8.5 Examples of good mental health services

Some parents experiences of good mental health care or services. A feature of these more generous relationships appears to be trust that the clinician would provide them with time and understanding. Darren and Mike had both endured long searches to find a good clinician. Darren felt that it was his role as a father that had spurred him on to finding a person who could understand his issues and who would be interested in his role as a parent. Mike had also experienced an endless search for an understanding clinician:

I have a good psychiatrist but not local; I have to go there because there is no good psychiatrist on the Coast. My doctor in the city is just an excellent doctor and he has kept me out of hospital for the last nine years. I can't praise him highly enough - he is the last stop for many people (Darren).

The medical system is flat out, mate, on a shoestring budget. I have known the nicest chicks, just nurses, and I am like, man, how do you do this? They are basically doing it because they are just giving people and that's it. They are basically doing it off their own backs, but there is a cost, mate. They just get sucked dry, and they are probably the most crucial people - they are more important than the doctors themselves (Mike).

Ursula had lived in many different places but found that living in a rural community had been beneficial in terms of service provision. Her mental health worker had also lived and worked in the small community. She explained the benefits of rural services when she talked about her ‘cake manager’ as opposed to ‘case manager’. Ursula used the term ‘cake manager’ to explain generosity, in terms of time and support. She felt that living within the community meant that her ‘cake manager’ had to be accountable, as they went to the same hairdresser or cafe. Other people in the community would ask her ‘cake manager’ how she was doing, making her ethically responsible to the community for good quality care. Ursula had only experienced the ‘cake manager’ style of care when living interstate and reflected on the differences with her current experiences of care:

There's no psychiatric care on the outside or even within the hospital. I spent seven weeks trying to get to see a psychiatrist. I've rung up to try and see a psychiatrist, just to check medications, and its several weeks later, you know, before you get to see anyone. The hospital was excellent down there. They wouldn't put me into the psychiatric ward, and they would look after me in that little hospital.

From the parents’ narratives, lack of support has been seen to fall into several main domains: lack of support from family, from services, from friends, and through social isolation. This also reflects societal values that are embedded in the development and ongoing input into social capital, reciprocity, and caring attitudes of society. Jo suggested one option was to provide parents with “networks of support of people who understand what you are going through”.

However, a paradox is apparent throughout the narratives. Parents wanted services but there were none that met their needs. However, if services were provided, there was the distinct possibility that their fear of discovery would prevent them from feeling able to access them. Jane said that for her, an ideal service would be:

I need friends but I don't know how to make a friend. So when someone says, how can I help you? I say there is only one person who can help me - that is myself . . . But sometimes just being listened to is enough to make a difference, just asking the question and listening to what I am saying is enough.

Such an admission was frightening for this resilient group of people who generally found safety in their isolation. It does appear from the help-seeking behaviours of the parents however, that if more funding was provided for community organisations that parents would utilise these as a form of support more often than accessing statutory services. The parents rationalise such a decision as opting for services that

are safer and where they are more likely to find generosity and clinicians who have vision as opposed to those who inhabit ‘the tunnel’.

8.6 Chapter summary

This chapter has followed the journey of the parents who took part in this research project through their experiences of mental health services. Excerpts from the parents’ narratives have shown that for them, inpatient treatment was a time when their parental capacity was often put on hold while their experiences of parenthood were further fractured by the system’s neglect of their role within their families. The parents, therefore, adopted many strategies to ensure that either they did not access inpatient treatment or that they would only accept this type of care when their mental illness was very acute. Alongside inpatient admission and temporary loss of parenthood was the associated stigma, which parents explained as particularly problematic during psychiatric inpatient care. Stigma about mental illness prevented some parents from seeking treatment.

A further issue raised in this chapter is the lack of providers with an understanding of the needs of parents with mental illness and providers operating without generosity. This concurs with Maybery and Reupert (2006) who note that not only does lack of understanding by service providers impact negatively on parents with mental illness but it also makes obtaining treatment almost impossible. The parents’ stories also challenge other research, such as that of Parslow and Jorm (2000, p. 998), who suggest: “An individual’s propensity to use formal health services for mental health problems is likely to be related to that person’s willingness to adopt the sick role and help-seeking behaviour . . . others may use mental health services to enable them to achieve greater human potential.” The parents talked about wanting to access services but that the barrier to achieving this was not their willingness, or otherwise, to go to service providers but service providers failure to provide effective services. Those parents who had accessed and experienced statutory services also found services and clinicians themselves disabled by ‘the tunnel’ and also feeling completely hopeless.

Many parents sought treatment through their local GPs which they found to also be judgmental and inappropriate, with GPs incapable of bearing witness to their suffering. This situation is also concerning as, from their research, Parslow and Jorm

(2000) note that GPs were most likely to be the preferred provider of services to support people with mental illness living in the community.

This chapter has also provided stories from mothers who had experiences of inpatient care. For some mothers, affording the privilege of accessing a mother and baby unit provided some light in the darkness of 'the tunnel'. Private mother and baby units offered the mothers any opportunity to participate in treatment with their babies which allowed them to maintain their parenthood and attain the ideological status of 'a good enough parent. The parents' stories highlight the greater issue of a lack of services for parents, especially for fathers who want to be supported at times when their mental illness is acute. These narratives have highlighted lost chances not only for parents but also for services to support parents with mental illness and reduce the stress and isolation they faced.

The stories also provide support for the issues relating to mental health policy and the current structure of silos of services as discussed in Chapter 4. Many parents in this study found that they were not able to access services when they wanted to help or support, because they did not fit the required criteria. Some of the issues raised by the parents are related to a standard definition of outcomes in mental health care where the effect on a patient's health status becomes attributable to an intervention by a health professional or health service.

The next chapter, Chapter 9, will discuss issues related to parenthood, mental illness and employment as told by the parents in their stories. As the final chapter in Part II, Chapter 9 highlights some of the issues related to employment, and parenthood that became apparent within the narratives.

CHAPTER 9: PARENTHOOD, MENTAL ILLNESS AND EMPLOYMENT

9.1 Introduction

Gender has been a submerged theme throughout the preceding chapters in the voices of the parents. Their identity has often been placed within gendered notions of the role of mother or father. While the previous chapters have concentrated on parenthood rather than gender there came a point in the analysis where gender differences became paramount in the explanations of lived experience. This was particularly apparent in their attitude to employment. The attribution of the place and priority of a working identity was clearly different dependent on gender and interwoven with expectations based on traditional discourses about gender roles. It was also apparent that working roles mitigated the effects of mental illness and allowed each actor to opt to live on a stage where their professional identity masked that of their private identity as a parent with mental illness. Work, therefore, subjugated their mentally-ill self and allowed a normalised period each day when work became the prime focus. Again, based on a gendered analysis, the ability to assume the working role created different problems, which affected the private parental role. Therefore, as Johnston and Swanston report, several studies (e.g., Bassin, Honey, & Kaplan, 1994; Risman, 1998) have noted:

To explore ideologies of motherhood, it is useful to recognize that motherhood is not biologically determined or socially ascribed. Motherhood is a social and historical construction. (Johnston & Swanston, 2003, p. 21)

The gendered construction of parenthood affected the parents who participated in this study principally in relation to their needs and their desire to work. Parenthood is seen throughout the narratives to be a multidimensional concept that includes many roles; for most of the parents, this included the role of working parent. Allan notes some of the stereotypes relating to gender expectations of parental roles:

This role is socially constructed around a gendered perception of sex-role stereotypes . . . women become mothers in a variety of ways. They bear children, adopt them, foster them, and inherit them. Men also play the role of father and come into contact with children in the same variety of ways and are subject to socially constructed explanations of that role . . . however . . . it is clearly apparent that the parent held responsible for a child's actions and problems is her/his mother. (Allan, 2004, p. 57)

Within the workplace, the role of working parent with mental illness was difficult to manage. The control of knowledge about their mental illness was highly dependent on the culture of the working environment. Some of the parents appear to have been enabled through work; it provided a sanctuary for them. For some parents it allowed them to split their lives, adopting an alternative mask where mental illness was unknown. This was not true for all the parents; the difference appears to be constructed according to gender and the desire to maintain or retain a previous identity - one before mental illness and, sometimes, before parenthood.

9.2 Opportunity to reconstruct identity

Life before mental illness is often carved through work or professional life and the status gained. This link to a past life and identity before parenthood and mental illness has significant emotional ties. The centrality of doing paid work for self-identity distinguishes parents from other people with mental illness and other parents. Darren was the only father in this study who was able to talk positively about the reconstruction of a new identity after mental illness:

I am actually retraining myself - I was an electrician, but now I am training myself as a carpenter, at 37 years of age.

Generally, for the fathers, there was grief for the loss of their former self. This was in stark contrast to some of the mothers who saw huge potential in being able to use their experiences of mental illness in a positive way. Whilst Helen returned to teaching she also made an environmental shift, which enabled her to access an alternative community. She felt this helped her be herself without additional pressures; it also enhanced her self-esteem by providing opportunities to master skills, achieve goals, and help others. Jasmin also incorporated her illness experiences into her employment through undertaking tertiary education and enter the medical profession:

I wanted to go back to work. That was the only way I could get away. And so I went back to where I had worked before because there was light there and I was healing. . . . As a person you can change your destiny, and I am learning to think different things and I am learning to stand up for myself. But I found mental illness really frustrating (Helen).

During this illness I have realised that sometimes you can overload yourself and this may just come back on top of you. When I finished Uni last year, I was just working and looking after my daughter, and I have come back to myself and I love it (Jasmin).

Some parents were, therefore, able to provide a positive interpretation to their experience of mental illness, often through work, which gave them an alternative reality to their life at home. Darren had learnt this. Whilst he found it difficult to work, he had strategies for coping, which he shared:

Just don't give up, you can beat it. Just put your head down and when the days are hard, just wake up in the morning and breathe in and out. Then just take it easy and get out of bed. When you don't have to think about breathing, you know, it's good. And the girls have changed my life, and for all that we've been through, it's made me a better person to what I was. And, you know, it has been worth the trip so far.

Inherent in all the parents' stories, was the daily reality of not only juggling their role as parents with mental illness but also other challenges which were specifically related to their working lives.

9.3 Challenges

Obviously not all the parents had good stories to tell about work. One of the challenges for many parents was in the negotiation between being a parent with mental illness and working. Sam initially found these two roles difficult to balance but because her workplace was accommodating of her needs, Sam had managed to work out a way to meet all of her roles:

To start off with it was difficult. . . . It took a while to settle into. But now it works out really well and my hours are really good. I start at 7am and finish at 3pm. So I will be able to pick the kids up from school.

There were other issues related to the practical ability to carry out tasks that the parents had earlier been able to do without error. The narratives provided by the fathers were littered with stories of accidental injury they attributed to their mental illness affecting their concentration. However, this may be a reflection of the different types of occupations undertaken by the fathers who were all tradespersons. All of the fathers provided similar stories about poor concentration due to being tired which they suggested was due to the pressure of working, maintaining a mask within the work place, and trying to maintain an active role as father after the working day was done, as well as managing their mental illness. Darren, Mike, and Vinnie all spoke of situations where a loss of concentration either did lead to or could have led to a serious injury:

I lose my concentration because of the illness, and I did a stupid thing that could have cost me my life. And I was lucky enough that I didn't die. But I was quite ill for six to eight hours and it was our wedding anniversary. . . . It was a culmination of bad luck and bad timing. I was pretty close to death and it gave me a different perspective on life. And then I got pretty nervous at work after that. I got to the stage when I couldn't get my head around working by myself and I got quite anxious. I just shot my nerves to hell (Darren).

I put a jackhammer through a main line in the eastern suburbs, 11 000 vaults basically, and it shattered me (Mike).

I get real cranky and they [his family] would say, come on, Dad! But I would just want to go off and do my own thing and have no real interest in anything, and sit and watch the TV the whole weekend (Vinnie).

For the mothers, their reality was as difficult, just in different ways and less risky, mostly because their occupations were not manual. For Liz, the reality of being a working parent with mental illness was juggling the priorities in her life. Liz attributed part of her situation to societal change and expectations that mothers can work and parent:

Being at home it was difficult. . . . Four nights having to go to work and you've got to, erm; cope with a lot of crap, mostly abuse. And you have to stay calm and, you know, sometimes I haven't been able to. . . . I don't want to be there [at work] but I have to be for my finances. And I am doing something my mother and my mother-in-law didn't have to do, and go back to work, you know. And I am trying to look after my son during the day, and cook and clean and do everything else, and work. . . . It's like I have got three jobs and they didn't have to do all of that - yet I have to (Liz).

This imperative to work however, caused the mothers to feel that they were not coping with their mental illness and role as a working parent. As a consequence, Liz needed to take time off from work: "Like, at the moment, I have not been great, and I have had to rest, and I have used up all of my sick days, and then I am not getting paid for it and that hurts". Explanation for the difference in mothers' and fathers' approach to mental illness, parenthood, and work was simple, as Jane suggested, "Women are pretty resilient and they cope". Jane's suggestion is a reflection of the philosophy of most of the mothers who felt that as women they did not have a choice to parent or work, they had to both as their partners would rarely take the responsibility for the family that they accepted.

9.3.1 Financial challenges

Most of the parents faced the reality of needing to work; whilst work was often problematic, they needed to be able to sustain their family. The pressure of balancing work and mental health needs and providing financial support for the

family also increased the distress and led to poor decisions. Darren and Mike both provided examples of their experiences:

When the eldest was two or three, we were having many financial problems and we were renting a house. We were behind on the rent and I was on casual. It rained for two weeks straight and I hadn't had any work. We were living off the credit card and owed mum and dad money, because we had moved back to Queensland, and had freight fees and lots of debts. I hated owing money so I just took an overdose. . . . I did, I thought that they were better off without me. I was worth \$300 000 dead - it would have repaid the debts and paid off the house. When you are depressed, you think silly thoughts, and you let your mind run away with you. I wasn't in a place there where I was really happy. It was nothing to do with my marriage, but it was just that I wasn't providing for my children (Darren).

When I go down I just have no consistency in my life, I can't say, oh, right, darl - I'm not going to be able to work for four months (Mike).

However, the mothers were also forced through financial imperative to continue to work even when their children were young and their mental illness acute. Whilst some mothers had hoped not to have to return to work once they entered parenthood, the reality was often different and they faced the prospect of returning to work earlier than they had planned. Example of this was provided by Sarah and Liz:

I go to work because, when you have got bills to pay, mortgage to pay and food and my eldest son goes to day care . . . it just all adds up (Sarah).

It was really hard, but we had saved money, too, from when I was working before I went on maternity leave . . . But then we needed the money, like, we had to get the Salvation Army to help us out, which was good. But I had to go back to work, like, we had been planning on me not going back, but then I had to. And there have been so many times when I have broken down at work . . . and been in tears (Liz).

For single parents the pressure to be a working parent with mental illness was felt more acutely. As Nita said:

You have depression, you are on your own and bringing up a child, and there isn't money and it's all so difficult.

Employment was put at risk when time was needed for recuperation after a period of acute mental illness. Jen's explained this difficulty:

I was really ill, and I got 12 weeks off, and then after that they said that we can't wait for you anymore. And they said, that's it - when I was just starting to improve.

These narratives challenge research which suggests that people with mental illness are not represented in the workforce (Waghorn & Lloyd, 2005). The narratives support an argument that parents do not have this choice, that they are forced to

work in order to feed and clothe their families and whilst being driven to do this must put on hold the symptoms of their mental illness, however acute.

9.3.2 *Discriminatory attitudes*

The workplace itself is another area where rank is predictive of depression and linked to gender. Work characteristics, especially skill discretion and decision-making authority, are closely allied to employment and make the largest contribution in explaining differences in well-being and depression (Marmot, 1999). Positioning within the workplace, therefore, affords people more or less agency and is generally related to tertiary qualifications and occupancy of professional position.

Some parents in this study found it was impossible to continue in their chosen profession whilst balancing the competing demands of parenthood, mental illness, and work. Artazcoz, Borrell, Benach, Cortes, and Rohlfs (2004) found that there is significant meaning attached to the importance of employment status, especially for women with health issues. However, the process of sustaining and maintaining a career in their chosen field whilst also managing parenthood and mental illness provides additional complexities for the parents. This was explained by one parent who had let go of her dreams. Instead of using her degree, she continued to work as a checkout supervisor in her local supermarket. Her need to work was driven by the high costs of her medication and her family's needs. This situation whilst practical also brought problems as she encountered discrimination within the workplace, as she knew some people were aware of her mental illness:

It's \$60 a month and, yeah, they said I would only need to be on it for six months. And it's been now, like, four and a half years. But I do worry about making ends meet, when you have got bills to pay, mortgage and food. . . . There is a lady at work that doesn't like me, and she has caused a lot of problems. And I think that she has been the cause of a lot of things, now that I look back. . . . And I no longer work with her, because I went to see the manager and got moved because I couldn't work with her. But she is still trying to cause trouble, and I think . . . I just wonder why she is like this (Sarah).

Nagle, Cook, and Polantajko (2002) support this finding that occupational choices of people with mental illness are constrained and limited because of social and personal resources available to them. Sarah's issues were both personal and social; she had returned to her childhood home town after being diagnosed with mental illness in order to access family support but, as a result, fell victim to the public/private

dichotomy of being identified with the small community as a parent with mental illness.

Several other parents travelled some distance to work, which allowed them to separate work from home and, therefore, reduced the likelihood of their mental illness being discovered. The geographical issue of working away from home where people did not generally know about their private family life was not without problems. For instance, Mike said:

I separate work from home easily. But as I say, by the time I come home, I am just absolutely brain dead, and I think, well, ok, I have got to do this [go to work].

Many parents were aware that if they let their mask slip whilst at work, their status as a parent with mental illness might have been discovered. This could have different results. Vinnie and Darren, for example, explained their views on the stigma of mental illness. Darren even provided a justification for other people's attitude towards his position as a parent with mental illness:

It's still there, the stigma. Even if they give it a pretty name, I think that people with mental illness will always be shunned (Vinnie).

I was looking for work, and I was in between jobs, and my boss was negative to me a couple of times. And I probably take things on board a bit too much, when people speak to you. And I am probably more sensitive in my old age. I'm getting used to it. When I was younger, I used to be a lot fierier and I didn't take a lot of crap. Now I've got two kids and a mortgage to pay off; you can't have that attitude and you've got to be a bit more tongue-in-cheek, so I take on a lot of these negative comments (Darren).

The mothers also raised concerns about how they would negotiate their identities within the workplace. Many parents did not want to lose their employment or reduce their career options so they put everything into their work. This was especially evident if they were trying to maintain the mask of normality when their mental illness was acute. Dani and Jane were both concerned about their exposure and adopted strategies to deal with this. Dani had let her mask slip and her colleagues knew that she had mental illness, whereas Jane adopted a hidden position continuing her life the same as everyone else's. However, this hidden position put much pressure on her and led her to be selective in telling trusted people in the workplace about her mental illness:

I am looking forward to it [work]. I will probably start off doing one shift a week and see how that goes and if I am coping, then I can always increase that a little bit, as long as I don't overdo it. . . . I still worry about it now; going back . . . I will be

working with a lot of people that looked after me. My husband said, it's not like you had an affair with someone's husband, or you did something really bad, you just got burnt out and sick - like, it happens (Dani).

I went back to school and went back onto the rollercoaster . . . Look; I just turn it on as I get through the front gates. I just smile and I get on with it. Teaching is a bit like acting, you know, you can't let what is happening in your personal life get involved. I have a duty of care at school for a whole bunch of kids, but as soon as the kids are gone . . . I break down again . . . But don't all women do that.

I told my colleague, the teacher next to me, and she was really lovely. And she's a single mother as well, so she knows how hard it is - financially, mentally and physically. I usually talk to her about what's going on with me . . . She's the only person that I really talk to and she's just non-judgmental (Jane).

The parents' decisions to tell people about their illness were generally limited to confidants. Jane provided a comparison between her current situation and her previous workplace where she had encountered discrimination due to her mental illness:

I am lucky because I have got a really nice principal who's actually got clinical depression himself. But if I'd got a nasty principal, like that one I had two years ago, that would have gone in the little black book against my name.

These narratives raise the question: What is more disabling, to be a working parent with mental illness or to be a parent with mental illness who does not work? Galvin (2005, p. 32) draws on the views of others (for example, Jolly, 2003) to suggest: "There are those who argue that the assumption that all people could work if certain social barriers were removed can actually contribute to the oppression of some disabled people." The reality of being enabled to work is not easy and creates additional stressors for parents.

Dani, thought about her illness from a positive perspective hoping that now her mental illness was manageable, she would be able to transition back into the workforce:

I haven't worked for about 18 months, but I am going back to work again in two week's time. I think that has been an interesting time, but it has really thrown me. When I go back to work, I will have so much more insight into what people go through. I understand the mental torment that people go through, and to be a good listener and to be able to have those interpersonal skills, and to sit down with someone and give them the time.

Many of the parents were not able or confident to challenge the effect of stigma and discriminatory attitudes in the workplace as they were forced to work due to need for the income. This reality meant that most of the parents were forced to hide their status as a parent with mental illness due to assumptions they feared people would

make about them. However, this also compounds stigma and supports Corrigan and Watson (2002b) who suggest this is the paradox of self stigma, assuming everyone has entrenched notions about mental illness. In this situation this paradox limited the parents' options for support within the workplace.

9.4 Preserving past identity

The imperative of paid employment was particularly strong for the fathers. This appeared to be closely connected to the loss of self due to mental illness. The men talked about how they needed to work; they were also able to acknowledge the cost of working on their families and on their mental wellbeing. The fathers placed work as central to their identity as men. Mike felt that work was part of being a male, and Vinnie also explained the male role in his narrative. Vinnie even felt that without identity as a working father with mental illness, that his life would be worthless. They both accepted that as fathers they would continue to work even if it meant that there they had no energy for their family at the end of a working day. The fathers rationalised their attempts to reclaim at least some of their former identity in their narratives:

I was walking on a tightrope. The biggest thing for males is that it's ego, that's where it is hard, you know, with mental illness. I think it's linked with insecurity, but then these people have huge egos (Mike).

I was commuting down there for 12 years. And then when this happened, I just couldn't do it any more. With everything that has happened over the years, and how bad things have been, if I lose my job, I am useless. Basically, I thought I have to put 110% into work, my mind power into my job, and do everything, because if I lost my job, I reckon I would probably really go down the heap (Vinnie).

For the mothers, this imperative to have to resume a pre-parenthood, pre-mental illness working role was not so significant. Whilst they practically needed to work for the income, their identities were not so tied up in the need to continue to adopt the structured identity previously lived through work.

However, there were a few issues apparent due to the occupational choices of some of the mothers, there were not only societal expectations but also professional standards and expectations that they needed to reach. Jane and Jo both provided examples of these. Jane said that some of the societal expectations attached to her profession combined with legal obligations. She lived the paradox of being

responsible for reporting parents who were considered to be putting their children at risk whilst also being under investigation by DoCS herself. She said:

As a teacher, I have done DoCS reports in school. So you understand the system of disclosures and stuff, and then it is embarrassing. It feels embarrassing to be at the other side of it and to know that there are many worse cases than yours, but that DoCS isn't doing anything about them.

Jo provided an example of a professional highly skilled woman who had been stopped in her tracks by mental illness and her previous knowledge had been challenged by her new reality. Because of her position within the medical profession, she acknowledged that the truth about being a parent with mental illness would inform her practice:

It is very hard . . . You know, most of my friends don't have kids, and I was very much under the misapprehension that, you know, that all of these mothers who hang out at mothers' groups are just, you know, bludging, and, you know, should go back to their careers and, you know, like . . . I was just this absolutely misguided person. . . . There are certainly a few friends of mine who I can't talk to at all because I just don't want them to know . . . it would just be too hard to explain. . . .

However, she would need to subvert her changed self to maintain her professional image, providing an embodiment of the dilemma of resuming a working identity, she said;

I think it is kind of what people accept in life . . . I think that a lot of us are told that you can have your career and then you have your baby and then, you know, you take six weeks off, and they go to full-time daycare, and you go back to work and that is all completely do-able . . . You know, when it happens and it is so different and you feel so overwhelmed by . . . by looking after them, and it's not as easy as that.

Again, societal discourses are strong creating assumptions about the behaviour of people with mental illness. It was interesting that Jo had also made assumptions about other mothers, which had now been challenged. However, she envied the mothers who she felt seemed more able to take things easily, ensuring that their parental status was not interrupted by the resumption of their professional life, so that there was no undue impact on their mental illness.

9.5 Gatekeeping

The most observable gender difference between the parents was that the men all spoke of the place their wives occupied in their lives and how they took responsibility for the care of the children as well as their husband's mental health. The fathers

therefore had extra security because of their wives role as gatekeepers for their illness and for the welfare of their children. The men were, therefore, able to utilise the gatekeeping role their partners provided to avoid parenting when their mental illness was acute or when they returned exhausted from work. Their experiences were not in any way similar to those of the women, even women with partners. This reliance on the gatekeeper allowed the fathers to shift the responsibility of caring for their children and their family outside that of providing economically by going to work. Vinnie realised this position, and he described how his wife took on this gatekeeping role:

I would get very withdrawn and I would just sleep and generally just do nothing . . . [Before mental illness] I would go fishing on a weekend, but now my wife would not let me go out by myself in case something happens. . . . My wife says, you know, every six months and he's ready to go off the rails. And that's basically what it was . . . every six to seven months I would just fall in a heap and just be a real pain to be around. My wife says, oh, you know, dad has just had a rough time and things like that. And so, once she says that, it gets through to me that I need to do something (Vinnie).

Mike acknowledged that his wife was the gatekeeper for their family but was concerned that he did not want this role. He had not actually discussed with her the depth of despair this reversal of roles caused him. Again, this made him feel as if he was failing his family:

I have said to myself, I feel like just driving off this cliff. I have driven there in my mind. I would never hurt anyone, but I could just go straight through that pole, you know. I just think that it has happened, and I have got what I am left with. Basically, her being a woman [his wife] and her natural instinct is to look after the kids no matter what the cost is, you know. Because 80% of the time I am good, but there is also that 20% when there is this flashback, you know. She basically got to a point where she gave it one last chance, you know, and thought that this is the last bash, because you can't do it alone. And she knows that with the kids that it is hard, but she still loves me for who I am.

Mike was realistic about his wife's commitment to their family as he had friends with mental illness who had separated from their partners due to the additional pressure on the family:

I look at any parent who has broken up, because I don't know what the percentage is with parents, who stay together with children, and parents who split or couples where one has bipolar. But the percentage of couples who have broken up, and there is one partner out there surviving by themselves, it's like 90%, and they are gone within a year of diagnosis.

These narratives show both sides of the issue: the feelings of the fathers and the resilience of women who are wives to fathers with mental illness. There appears to

be a larger role for wives of fathers with mental illness than that for husbands of mothers with mental illness. In this sample, there were only mothers who had fractured relationships, and they attributed this to their mental illness and/or the pressures of parenthood. Another impact for the fathers with mental illness was that their wives often had to be flexible in relation to their paid work. For example, Darren explained:

I was lucky enough that my wife's boss . . . When I went back to work this year, I worked around her. And she wanted to cut her hours back, and he allowed her to do that and he's pretty good in that regards. He knows about my illness, as well, and I have always been pretty open about my illness.

Darren's story shows the family having to utilise protective factors to enhance resilience within the family at a time when his mental illness became very acute. Still, this was not generally realised by other members of the family:

I didn't really explain it [to the kids]. I just said Daddy is having some time off work for a while. And my wife went back to work full time, so I didn't really have to explain it . . . My wife and I just swapped roles.

Liz summed up the discussion on the difficulties of balancing parenting, mental illness, and work, arguing that gender disparities continue to disempower women:

I just want awareness out there. It is so hard for us . . . We do have to go to work and be a parent and live with our mental illness . . . you know. To look after our family, as well, and still do everything, as well, you know. And just deal with all of this crap . . . It is not equal. Life is not equal anymore, at all. . . . Once you become a parent, there are all of these other pressures, and I just want people to understand.

9.6 Chapter summary

This chapter has shown that work is important for two reasons: firstly, for financial reasons, and secondly, it allows the parents to reconstruct their identity. Whilst the need to work was a reality for most of the parents, this is significantly different to research by Hickie, Groom, McGorry, Davenport & Luscombe (2005, p.402) which suggests: "The rate of workforce participation in Australia among people with mental illness is low (29%) compared with people with physical disability (49%). Therefore, the parents in this study were distinctive in that most of them were in paid employment. Whilst work presented issues for the parents they continued to work for the various reasons presented in this chapter. Stress related to work however, was found to be important by Kennedy-Jones, Cooper and Fossey (2005), as, obviously, if work is stressful, it can negatively impact on health.

Gender is an issue that is also apparent in the parents' approaches to work. The three fathers in the study can be viewed from a traditional perspective. They had all attempted to resist being labelled as mentally ill not only from a medicalised discourse, but also within the work place in order to protect their identity. Their narratives explain that work provided them with an opportunity to overcome inadequacies, which they felt were associated with their mental illness diagnosis. Each father negotiated the balance between mental health and parenthood, some better than others. Each father actively engaged in complex strategies to ensure that he could continue to work and thereby maintain his identity as the provider for his family. In undertaking this stance, the fathers actively resisted stigmatised positions and identities. Each father positioned himself in a narrative account as a man with agency and choice, even where there was no choice in his private life of fatherhood and mental illness. Darren, Mike, and Vinnie are examples of men with mental illness who are also fathers; they experienced their mental illness in different ways to the mothers in this study. The issues the parents faced are summarised by Charmaz (1994):

Before men learn new ways of preserving self, many of them assume that they will recapture the past self, or explicitly aim to do so. Here, they aim to reclaim the same identities, the same lives that they had before illness. Nothing less will do. For these men, their 'real' selves are and must be only the past self (Charmz, 1991; Turner, 1976). They lapse into invalidism and despondency if they cannot recapture their past selves . . . Women, whose disease caused severe mental impairment, showed more resilience and resourcefulness than men in preserving aspects of self, even though women were less likely to have spouses to bolster their efforts . . . Women rarely tied their futures to recapturing their past selves. (p. 279)

This view is a little different from the work experiences of the mothers in this study. The women's narratives pivot on their breakdown, hospitalisation or treatment, and, more fundamentally, the breakdown of their ability to be a good mother to their children. They did not reconfigure their thinking in the same way as they had before, accepting their change in identity and letting go, mostly, of their professional identity. The women, in some cases, allowed their working identity to be consumed by their identity as a parent with mental illness. They placed work at a more practical level, as it was something that they needed to do for financial reasons as opposed to being linked to their sense of self. Whilst some of the women's experiences also show how work played a part in liberating them from mental illness, this was less apparent than for the fathers. The women, in direct contrast to the men, were able to see disruptions in their work careers as bringing opportunities for

their lives to be reconfigured and new career options to be explored. The new working identity was often termed as healing and, therefore, in line with Spear (2006, p.175), who notes:

Work may enhance self-esteem by providing opportunities to master skills, achieve goals, and help others. This is consistent with Fromm, who emphasized the value of living productively. If work provides meaning and purpose, then work can fulfill the need for self-actualization. Frankl believed that meaning comes through developing loving relationships, purposeful work and transforming unavoidable suffering into achievement and accomplishment.

This chapter has shown critical gender differences between the mothers and fathers who took part in this study in their approach to work and its significance in their lives. Furthermore, the parents' narratives have also shown how the drive to continue to hide behind a working mask often detracted from their ability to parent and impacted negatively on their parenthood.

The thesis now moves to a conclusion (Part IV), where the threads of each section are tied together. Chapter 10 discusses the findings of this research and will synthesise this with the, mostly, medicalised and institutional research generated about parents with mental illness. This final stage will also specifically discuss the contribution of this thesis to developing and extending knowledge about this silent group of people.

Chapter 10: IMPLICATIONS OF INSIGHTS INTO THE LIVES OF PARENTS WITH MENTAL ILLNESS

10.1 Introduction

This penultimate chapter contextualises this research in relation to the literature about parents with mental illness. This study differs from the current body of knowledge which is largely dominated by studies focusing on mothers with long-term acute psychiatric disorders or illnesses. This research presents mothers and fathers but discusses them as parents in an attempt to fill the deficit in knowledge about parents with mental illness. This stance is verified by Ackerson (2003, p.194) who suggests that “Most of the literature focuses almost exclusively on mothers. Very little literature on fathers has been published, and virtually none that examines parents as a group”. Another major difference is that this was a community-based study of mothers and fathers contrasting with previous highly medicalised studies. This study made great effort to find these marginalised parents who live their everyday lives in much the same way as other people, but who must also find space for their mental illness, as others do their physical illness. Not all of the parents who took part in the study had a formal diagnosis which differentiates it from other studies where participant samples are based on a mental illness diagnosis. Even if the parents had a diagnosis, they did not necessarily agree with it. They often resisted treatment related to the illness, choosing to adopt alternative methods of support unlike other reported research on groups of parents who have accepted their medical diagnosis and been involved in medicalised treatment systems.

There are a multitude of barriers that create an assault course for parents with mental illness to negotiate. The most apparent issues are those of stigma and risk which occur every day in their lives as parents. Countering the dominant discourses of danger and impairment is the only way to create the possibility of empowerment for the parents.

This study challenges notions of mental illness and parenthood by engaging with those who live lives where these are combined. As Frank (2002, p. 3) suggests this

engagement is crucial to developing deeper understandings about health and wellbeing: “To seize the opportunities offered by illness, we must live illness actively; we must think about it and talk about it.” The chapter examines the ideas of the parents through a model of understanding developed in this thesis which sees their journeys in five stages: firstly rejection, followed by resistance, which leads to resilience and responsibility, and, ultimately, the reward of relationships with their children.

10.2 Who are the parents?

Part III of this thesis presented the narrative accounts of the parents with mental illness, a population who were not easy to access. Previous studies have presented parents with mental illness based mostly on their access to public mental health services (for example, Kahng et al., 2008; Korhonen et al., 2008; Mowbray, et al., 2001). Dearth of literature about non-medicalised parents prevents service development and policy changes. As Keitly (2008, p. 31) suggests “stereotypes are often evoked in situations where there is a lack of information.” Several major issues have arisen in the course of this research which is significant to the development of knowledge about parents with mental illness. These issues relate to how parents with mental illness feel about their role as a parent and include lived experiences of stigma, labelling, deviance, and negotiation of the discourse of risk.

This section addresses the narratives provided by the parents which were grouped according to Frank’s (1995) narrative types. The data was analysed and encapsulated into four main themes. The first theme, ‘who are the parents’, provides information about the parents who participated in the research and who were not medicalised, did not adhere to strict treatment regimes, and largely lived normal lives. The second theme, the ‘good enough parent’, describes the label and position explained by the parents. It explores what is ‘good enough’, what it feels like to be under surveillance, and the risk discourse associated with being a parent with mental illness. The third theme explores parents’ ‘experiences of the mental health system’, provides an overview of the passage through mental illness, the exclusion of parenthood, experiences of inpatient care, and the long wait for ‘generosity’. Lastly, the theme of ‘parenthood, and employment’, discusses past identity and opportunities to reconstruct an identity as a parent with mental illness, employment and financial challenges, experiences of discriminatory attitudes, and gatekeeping

roles. None of the themes are separate, they are all interrelated and also the categorisations of illness narratives were also fluid throughout the stories.

It was a surprise that many of the parents in this research are well-educated, held down good jobs and are able to access treatment when the need arises. However, this difference may be explained by the identification of the population of parents with mental illness who utilised community and/or private mental health services. The parents in this study therefore provide challenges to other medicalised studies about parents with mental illness (for instance, Nicholson & Blanch, 1994; Nicholson, Nason, Calabresi, & Yando, 1999; Nicholson et al., 1998a, 1998b; Oyserman, Mowbray, Meares, & Firminger, 2000). This study differs from some of the taken-for-granted assumptions about mental illness and offers an alternative point of view about commonly beliefs concerning the demographics of this population. For example, Mowbray et al., (2000, p. 118) found that “nearly all individuals with long-term mental illness are poor”. This research has however found diversity and difference in this population. This study has shown that there is a shadow cohort of people who are not using statutory mental health services and who are not medically diagnosed as mentally ill but who nevertheless consider themselves mentally ill. The findings of this study suggest that parents accessing statutory services are perhaps in the minority while the sample and characteristics of the parents in this research are more reflective of the everyday communities of parents with mental illness. This study shows that people who are medically defined as mentally ill are not the total of those who define themselves as having a mental illness. This study provides insights into the lives of people who define themselves as mentally ill and from their narratives, it is reasonably clear that most of them are correct in their self diagnosis.

Transition to parenthood for most of the parents in this study marked the beginning of their experience of mental illness. It was also a time when the parents first experienced the concept of risk. Risk was evident throughout this study and seen in the powerful position adopted by government services called upon to assess the capacity of parents with mental illness to be parents. For parents who had not previously acknowledged the existence of symptoms that became attributed to mental illness, parenthood also provided a catalyst for previously unacknowledged yet manageable issues to no longer be manageable. Parents reflected it had been easier to hide their symptoms or explain them in another way before they became a parent. The journey through pregnancy was largely without comment except for one

parent who became catatonic. She explained that this was due to the cessation of her medication. All of the mothers made the decision to cease taking medication to reduce any risks to their unborn children. This pre-parenthood position was criticised by parents as being focused only on the baby and how it would be born rather than on the realities that they would face as new parents.

The parents talked about having certain expectations of parenthood. Some are realistic about what they are able to do and what they might expect in terms of changes to their lives. Others operate from an unrealistic media-driven image of the 'perfect parent'. La Rossa and Sinha (2006, p. 434) argue that "research on the social construction of the life course has empirically established that life course stages are not just culturally shaped but imaginatively built." When people become parents, life is no longer the same. This was the experience of the parents who found themselves on unfamiliar terrain, often reliant on social constructions, and gendered concepts of their role.

The parents talked about how the first weeks of parenthood are critical in defining the trajectory that they take. It was during these first few fraught weeks that they attempted to adapt to their new role. It was also during this time that early intervention could prevent the acceleration of symptoms and sustain the transition to parenthood. For instance, the parents understood that their symptoms are not merely attributable to sleep deprivation due to having a new baby but were more alarming. The narratives provide many examples, the mother so frightened about her feelings that she had planned how to leave her baby in the hospital and another mother not bonding with her child and feeling it would be better adopted. Similar experiences were found in a study by Parrott, Jacobs, and Roberts (2008) who identified these symptoms as "one of the major stressors for families where this transactional effect can be identified as that of loss, including the complex loss created by mental health problems because the person who has been 'lost' is still present in the family". Some parents had attempted to engage with services at this point but this had often led to an initial label of 'over' vigilant or anxious parent.

There was another loss identified in this research, that of the parent that they thought that they would be. The parents reconciled this lost expectation with the parenthood that they had experienced. Foster et al., (2005) suggest that expectations are created from assumptions and understandings which are subjective;

they argue that reality does not simply exist, it is constructed. This view suggests that parents develop their sense of what is real through conversation with, and observation of the parenthood of others. These perceptions frequently shift especially during the transitional period of new parenthood and the onset of mental illness. From such a perspective, the old self of the parents is still connected to the social world, but it is also in flux. Therefore, as they enter parenthood relationships change, and new, alien identities are formed. This is explained by the parents as belonging as much to the 'other' as to them, a process which Bohan (2002) also describes. These ideas are also discussed by La Rossa and Sinha (2006, p. 434) who suggest "actors will rely on cultural contexts as a resource for their biographical work, but the process by which they do so involves their selectively appropriating 'chunks of culture' from a supermarket of ideas to suit their rhetorical purposes."

These concepts bear witness to the explanations parents provide for the shifts in identity. Some of the shifts in identity are to that of parent, whilst others are more complex to that of parent and mental health client, both of which required certain acceptance. Inherent in this transition is an experience of loss which the parents identify as complex and multifaceted, as Jones et al., (2004) also noted. Both shifts in identity are impacted by societal discourses and other people's expectations that they impose on themselves whilst attempting to be accepted as both mental health client and good parent. This social construction of identity is often based on false interactions and the parents showed active resistance to the efforts of others to know them as real people. Similar to the findings of Davies and Allen (2007), the parents did not want to tell people how desperate they are feeling due to their fear about what might happen to them and their children. They could not associate their previous expectations of parenthood with the impact that mental illness had on this role. Many of the parents found themselves in a situation of being 'other' from their own expectations and identity.

In the failure to acknowledge the importance of understanding how they experience their lives, the parents are rejected not only by policy, but also by family and society. In some cases, it is clearly a stance adopted by those who do not wish to see the realities. Many parents suggested that it was those closest to them, their partners and families, who wished to believe what they wanted to believe as this abdicated them from any responsibility. This position shifts the blame onto the parents suggesting it is their personal failure rather than a societal failure.

10.2.1 *Intergenerational mental illness*

For over 50% of the parents there was a family connection or history of mental illness. This adds weight to the arguments that there is intergenerational transference of mental illness (Birtchnell, 1974; Cooklin, 2006). Some parents talked about their family backgrounds and experiences of abuse during childhood. Others, who did not have this history, identified systemic abuse from mental health services. Therefore, there are grounds for an argument similar to that of Erdmans and Black (2008) who suggest that if parents have repressed issues from their childhood then they will have significant issues later in life when these resurface.

During the interviews, as already stated, in their contact with mental health services, parents are not asked about their parental capacity nor whether abuse and neglect featured in their backgrounds, this is similar to findings of previous research (Dixon, Browne & Hamilton-Giachritsis, 2005). The parents reflected that the research interview was the first time many had the opportunity to tell their stories. This concurs with the findings of O'Brien, Henderson, and Bateman (2007) who argue that services need to reframe their practices in order to better identify those in greatest need. This study also found that there is a need to acknowledge the complexity of the lives of the parents living with unresolved trauma, similar to findings of Nehls and Sallman (2005).

The limited research on adult children of parents with mental illness means there is inconclusive evidence for the blame-ridden focus on parents with mental illness. Whilst Cowling, Luk, Mileshekin, and Birleson (2004) argue that children of parents with mental illness are at increased risk of developing a psychological disorder than children whose parents do not have mental illness. However, there are also other comorbid factors that have been identified and may impact on children's chances to develop normally (Cowling, Edan, Cuff, Armitage, & Herzberg, 2006). The parents in this research reject much of this blame-ridden positioning, for instance, issues of parentification only appeared in one mother's story. It is this responsibility that often justifies concerns or allegations of risk to children, but this was not apparent or widespread in this group of parents. This could be due to the demographics of the research participants who are more educated and drawn from community sources as opposed to those who access statutory mental health services.

Whether there is a genetic predisposition to mental illness continues to be debated (Manning & Gregoire, 2006). Accounts by parents in this research suggest the possibility of social transference of mental illness due to environmental factors through behaviour learned when growing up as a child of a parent with mental illness. Behaviours associated with mental illness are accepted as normal by the child, who takes on these as his or her own.

Foster (2005) found that up to 50% of children will experience a psychosocial problem or disorder attributable to their parents' mental illness. Foster fails to account for the normal adjustment of the other 50% of children. Therefore, as in this research, even the intergenerational transmission of mental illness is not significant enough to rationalise the concerns raised by statutory services about the risks for children of living with a parent with mental illness. Furthermore, it is possible to hypothesize that behaviours are learnt, due to the systemic neglect of these families; what is problematic is the lack of services which could lower these statistics. Some researchers continue to argue that mental health always raises difficult issues. For instance, Cooklin (2006, p. 33) suggests that "there may be significant under-reporting of abuse by children of mentally ill parents, even among those - relatively few - who are given an opportunity to talk about their experiences." Such a finding was unproven in this study concurring with other researchers who also argue for a more positive approach. For instance, Zeng-Yin Chen and Kaplan (2001) suggest that studies often focus on negative transference of parenting as opposed to investigating positive aspects of parenting. Whilst, some of the parents in this study talked about stigmatisation of their children due to their mental illness, this was dependent on age, understanding, and education about mental illness.

A counter position to the negative research findings on parents with mental illness would be to suggest that children can develop normally with a parent with mental illness, as the children of parents in this research appeared to be doing. This view also engages with the literature which suggests resilience provides an alternative option for families by utilising their inner resources (for example, Polkki, Ervast & Huupponen (2004). Indeed, the parents in this research are not ill all of the time; many of them are ill for only short periods of time and adopted strategies to suppress any symptoms as they did not want their children to be affected by these. Furthermore, many of their symptoms are cyclical and controllable not only through drug therapy but also through their understanding and knowledge of their condition.

Therefore, the few instances where children are removed from their parent's care should represent a last-case scenario as this has been shown to be detrimental to the parent's health and to have a negative impact on the child. Arguably separation causes more damage than if the children are living with a parent with mental illness who had appropriate parenting. This research agrees with Prior (2003) who states that care and protection of a child should be paramount; mental illness should not be used as justification to supersede parental responsibility for the care of children. If support is provided then removal of the child should not be the only option.

Another interesting mediating factor protecting children from negative transference of abusive backgrounds has been found by Serbin and Karp (2003) to be educational achievement. In this study, many of the parents had achieved tertiary studies and therefore their educational qualifications may have mediated their current status as parents with mental illness providing a buffer to their troubled backgrounds of abuse.

Of significant concern are the normalising attitudes experienced by many parents in the form of social inequalities whereby once they become visible as a parent with mental illness they are labelled as other than normal. This discourse is troubling for children living with a parent with mental illness. The parent's actions, therefore, in isolating the family show resilience and attempts to reject distinctions created by these labels. This position of marginalisation also shows parents attempting to reject the fate of becoming discredited by society. It therefore follows that the isolating position of these families is due to societal neglect rather than flawed parenthood. For one parent, the focus on negative aspects of parenthood left her feeling an imperfect parent and scarred for life. McConnell Gladstone et al. (2006, p. 2544) found such positioning immoral when applied to a child, ultimately "being identified as 'at risk' is a powerful label . . . their 'at risk' status follows them into adulthood."

10.2.2 Summary - Who are the parents?

This thesis has identified a population of parents with mental illness, to date, largely unreported. It has shown, through their narratives, that their lives are not dissimilar to many other people. Their characteristics, for example, age, employment and work mean that they are embedded within society mostly without recognition. The dominant ideological constructs of parenthood also shape the lives of the parents.

Many had silently integrated into their communities and wished to continue to maintain their anonymity about their role as a parent with mental illness as few could see any positive benefit from disclosing their status. However, inherent in their desire to remain unrecognised are various issues which will now be discussed.

10.3 'A good enough parent'

One issue to be considered is whose definition of 'a good enough parent' is authentic and how is parenthood shaped through these dominant discourses. Risk, stigma and labelling are apparent in notions of what is 'a good enough parent'. This argument is threaded through the parents' narratives and can be discussed in relation to moral responsibility, causal responsibility, and responsibility for self. These responsibilities are derived largely from historical influences and current mental health policies. The idea that parents have a moral imperative to care for their children was a dominant theme of the parents' narratives. This desire to fulfill their obligations was challenged by the lack of assistance parents received from mental health services, their interactions and experiences of mental health care, their relationships with family, the support of friends, and their difficulties in continuing to cope with their parental responsibilities.

The opportunity for new mothers to be deemed 'a good parent' was explained through the difficulties associated with breastfeeding their new babies whilst also experiencing acute mental health symptoms. Some parents tried to fulfill societal norms associated with good parenting even when this was detrimental to them. In continuing to try to maintain the status of 'good enough', decisions about medication are put aside in favour of fulfilling societal expectations and striving for the attainable goal of being labelled 'good enough'. Mental health clinicians are not knowledgeable about the risk of medication to lactation and, therefore, parents either choose not to engage with clinicians or not to take medications. Bortiz Wintz (2004) proposes that breastfeeding and medication can be managed and encouraged by clinicians. This study demonstrates that this did not often transpire. Instead, parents make decisions based on their aspirations to be the best parent that they can given their circumstances. This lack of regard about what parents need and ignorance about the significance of failure to breastfeed compounded the mothers' distress and deepened their mental health crisis because they felt themselves inadequate. Failing to continue to breastfeed for the appropriate period of time often led the parents to

feel stigmatised not only about their mental illness but also because they felt that they would be blamed for failing to fulfill natural expectations about ‘motherhood’.

There appears to be an assumption that mental illness prevents mothers knowing the difference between being a good and a bad parent; in this respect the study findings are comparable to the findings of Davies and Allen (2007). They found parents are willing to be open about the challenges of integrating their role of a parent with living with mental illness. Barriers appear to be created when parents attempt to process their issues with professionals, for example, “the failure of a GP to adequately acknowledge their expertise [that of the parent] regarding their own child may have greater significance than it does for a woman in good health, because of the threat posed to her identity as a mother” (Davies & Allen, 2007, p. 371). Parents, as in this study, acknowledged that there are times when life is difficult and “recognised those occasions when they had failed to meet this standard” of being ‘a good enough parent’ (Davies & Allen, 2007, p. 373).

Many of the parents did undoubtedly have a poor self-image. To some extent the argument that they imposed a stigmatising position on themselves is valid. Due to accusations premised on the risk discourse, the parents expected that they would be treated as ‘risky’ parents or poor parents before they even entered services. These beliefs resulted in a position of self-fulfilment because the parents are then treated as ‘risky’ or ‘not good enough’ and, subsequently, adopt this position. The issues raised are wider than the individual level. As Corrigan and Watson (2002) comment stigma ‘marks’ people who do not conform to socially determined norms. Self stigmatisation is a point where the parents finally internalise the publically held views about their lives and according to Rusch et al., (2005) they begin to experience decreased self-esteem and self-efficacy. It is often this self-stigmatising position that led the parents in this study to isolate themselves, thus further compounding their exclusion from social opportunities and inevitably relegating their family to a position of silence.

10.3.1 *Stigmatised parents*

Some of the parents were fearful of stigma prior to entering parenthood. These parents had already endured a life filled with mental illness and had battled the stigma, so they knew what might lie ahead. For others, the fight had not begun and

the stigma was an unwelcome opponent in their lives that challenged their limited resources. This experience is oppositional to parenthood being a normalising role. Research has shown parenthood should make people more acceptable and 'normal' thereby reducing the distance between people with and without mental illness. Nicholson et al., (1998a) suggest that if a child lives with a parent with mental illness this is often viewed as a disadvantage. Stigma is associated not only with the parent but also affects their children:

The consequences of being labelled ill and receiving treatment are often far greater for a person who is given a psychiatric diagnosis. Central to the attribution of a label of mental illness is a negation of 'self'. Since diagnosis involves a judgement about a person's conduct, there is always a risk of invalidating their whole identity. (Rogers & Pilgrim, 1993, p. 613)

Parents with mental illness are located in opposition to normal parents who fulfil societal expectations and are deemed to be 'good enough' when under surveillance by their peers as there are no noticeable marks of mental illness (Nicholson et al., 1998b). For example, the parents in this study talked about resuming life after inpatient care and gauging peoples' reactions to them if they are aware of their illness. For some parents, their concerns are valid. Comparable to arguments provided by Goffman (1963), parents felt that once their illness is disclosed people then see them differently. As a result, they live with the embarrassment of being different from what people expect. Some of the parents then challenge Goffman's notions suggesting that identity as a parent with mental illness is not always negative. A number of parents found relief in sharing the information about their illness. Their views concur with Corrigan and Watson's (2002b) suggestion that whilst the stigma of mental illness may result in significant loss in self-esteem for some, for others there may be positive outcomes and opportunities. Some parents had made connections with parents they had met in inpatient care and developed relationships with them. Therefore, stigma clearly impacts on parents in different ways due to its influential powers, and it is not always discrediting as explained by Goffman. Some impacts are positive and do not diminish the image of being a good parent. These findings are related to Little, Paul, Jordans, and Sayers' (2002, p.170) proposition that "identity is a philosophically complex subject, but there is some agreement that memory, embodiment and continuity are essential components. While the sense of personal identity is internal to the individual, a sense of that person's identity exists in the minds of others." It is however the construction of a self-stigmatised position that undoubtedly led the parents to feel a sense of decreased self-esteem and self-efficacy. Again, this return corresponds with Goffman's position and shows the

complexity of the lives of the parents with mental illness and the disadvantages in terms of their social positioning and isolation from the community.

Stigma is socially constructed, meaning that it is fed by media images which fuel expectations and images of who or what people who are parents with mental illness are like. For people with mental illness, stigma is a reality which has been seen to deprive them of certain opportunities (Corrigan & Watson, 2002a). For example, because they have heard friends', other mothers', or the public's beliefs about mental illness through the media they are led to believe that these labels are correct and that they are guilty by association (Hayward & Bright, 1997). Some of the discourses of risk can be viewed in the moral panics that have arisen around parents with mental illness. For instance, there have been many sensational media reports about parents with mental illness either killing their children or placing their children in significant danger. Such sensationalism is supported by systems. Deaths are investigated in New South Wales by the Ombudsman. Each year, the findings of such investigations are made known in a Child Death Report. It is interesting to note that the last report of reviewable child deaths (in 2007) made no mention of parental mental illness, in fact more deaths or risks for children are related to parents who had alcohol and/or drug issues. The parents' narratives about responsibility to their children are therefore supported but unacknowledged in the media or by Government. Some parents had adopted survival strategies as a form of resistance so that they are not viewed through lens of mental illness, thus maintaining the ideal of 'good enough parent'. For instance, the parents often over-compensated and are hyper-vigilant, trying to do their best and be their best at all times.

Active engagement with stigma can be seen in the parents' narratives through their use of resilience. Resilience was a strategy utilised by the parents to access support and live their lives. This strategy has also been noted by others (for example, Beardslee, Gladstone, Wright, & Cooper, 2003; Dyer & McGuinness, 1996). Resilience is shown by all the parents in a myriad of ways as they actively engaged with the challenges that risk presented in their parenthood. Another form of resilience was explained by the parents through the utilisation of their own resources as opposed to accessing services. This strategy kept them safe so that they did not need to access services or notify authorities even when their mental illness was acute. It could be questioned whether this is resistance or just merely a strategy for survival. In other situations this resilience would be praised, but because of the association with risk it

is likely to be condemned. It is also argued in this thesis that the lack of social tolerance for parents with mental illness is clearly apparent. Most parents fear being labelled as a bad parent. Most hope to write off moments of 'bad parenting' and like to view others as worse than they are. As bad parents are deemed to be risky or likely to put their children in situations of risk, most parents would prefer not to be placed in this position.

The parents, as already discussed, utilised significant resilience in their everyday lives; this allowed them to negate some of the concerns raised about their status as a parent with mental illness, offsetting the dominance of discourses of risk. Risk was a concept applied to their lives by agencies but, nevertheless, was incorporated into their daily routines. As outlined by Lupton (2003) risk is a fluid concept, due to the different types of risk. Lupton also proposes that risk changes over time and is dependent on policy, society, culture, religion and other variables, a finding comparable to this research. Again, concurring with Lupton, one of the most permeating risks is that of imagined risk. The most apparent and pervasive risks identified in this research are not the real risks that the parents felt at various times but are those that are imagined or perceived by others. Those that held power over the parents appeared to create more of a risk as their reactions created barriers to parents wanting to access services. A risk discussed by the parents was that associated with mandated reporting by mental health workers. This risk fails to be discussed or critiqued (Sawyer, 2005). As Melton notes:

Although researchers have seldom examined negative side effects beyond the formal child protection system, mandated reporting may have reverberating negative effects on the integrity of the broader service systems. It is plausible, for example, that health professionals' involvement in mandated reporting compromises their own or their clients' perception of them as helpers. (Melton, 2005, p. 15)

There are relatively few debates about how services assess risk and what risks they are assessing. According to Arad-Davidzon and Benbenishty (2008, p. 109), service providers "rely heavily on their discretion. Not surprisingly, they vary in their assessments of parental functioning and show wide ranging inconsistencies in their decisions". Assumptions related to risk seem to be subjective, driven by fear related to risks of acute, long-term mentally ill parents. The parents who participated in this research had ongoing mental illnesses which are cyclical and require medication. Their illnesses are generally controlled, as are the illnesses of parents living with disabilities such as epilepsy, diabetes or arthritis. These conditions also require

medication, monitoring and attention but parents with these disabilities do not fear stigma associated with the illness that may affect their lifestyle.

10.3.2 *Summary of this section*

Risk was evident throughout the parents' narratives about striving to be 'a good enough parent'. One of the major barriers to attaining this standard is the lack of appropriate services as noted in other studies (for example, Devlin & O'Brien, 1999). Furthermore, the risk discourse is also an explanation for the parent's experiences. Risk - as a discourse was applied to the parents by professionals and communities when their status became apparent. Most of the parents talked about risk directly attributable to personal risk but at certain times on their illness trajectory they also acknowledged that there might be risks to their children due to their mental illness. Again, most parents are aware that if their mental illness became known, this would result in increased surveillance. Many of the parents therefore, tried to conform to the dominant social discourse surrounding 'good parent' versus 'bad parent'. Sands (1995, p.91) also found that "mentally ill mothers did not describe themselves as mentally ill and preferred to speak about problems, stress or nerves". This, in part reflects the attempts of parents to steer themselves around the barriers created by the discourses that continue to be the dominant ideological form of social control for mentally ill patients who are parents. These issues position the mentally ill parent as a risk, as though all mentally ill parents are a risk. However, these propositions are not true and this study has found that parents whose mental illness is controlled and stable present no risk at all to their children.

Most parents provided with the opportunity, are able to name their issues or concerns and take responsibility for making changes. Programs that support parenting, if available and accessible, are generally welcomed as a positive step by the parents. Support has a positive effect on their mental health and on their children's wellbeing; some parents even suggested that it could increase their safety and that of their children. Parents continued to be afraid that if they did name their troubles there would always be the potential for losing their child due to child protection concerns: these findings are similar to other research, for example, Gillingham (2006). Whilst some parents disclosed their darkest fears during the interviews for this study, they also said that they would never normally share such

feelings, not even with those close to them let alone mental health service providers. The culture of blame is, therefore, a strong argument for silence.

10.4 Experiences of the mental health system

Personal responsibility for seeking treatment is often accepted by the parents. Inherent in treatment are numerous issues, for example appropriate places for support are limited so the parents were creative and flexible in their quest for help. Discourses of stigma and risk are deeply embedded in society but have been found to be specifically problematic for the parents within the mental health system. For example, once recognised as a parent clinicians' reactions to them are based on a lack of exposure to their needs in practice. The need for 'generosity' was shouted loudly by the parents concurring with Frank's proposal that generosity could change these perspectives of parents; he suggests that reactions of clinicians to parents with mental illness would also need to change:

Acting too fast for what the situation requires, we forget that action is a service, to others and to ourselves. We become absorbed in the part that some institution expects us to play and forget our fully human part in a larger community. (Frank, 2004, p. 139)

This lack of 'generosity' concurs with the parents' narratives and with the findings of Arad-Davidzon and Benbenishty (2008, p.110) who suggest "that the decisions child welfare professionals make are influenced by their personal attitudes, which are value-laden matters that may evoke very strong feelings". The culture of mental health services is orientated around assessing risk and harm. These subtleties of service culture create barriers to parental engagement. Herein lies a contradiction in services that should assist recovery but are ill equipped to support their recovery and resume their parenthood.

Assessment of risk is also suggested by the parents as problematic. Reporting harm is not only subjective but also driven by governmentality. Again, this limits the voluntary participation of parents due to fears that their parenting skills may also be examined, and that they will be deemed a bad parent or not good enough. Therefore, it is apparent that assessments of parents with mental illness are, based on perceived risk driven by notions that all parents with mental illness are a risk to their children. This is not true.

It is acknowledged that co-morbidity of some parents with mental illness and a history of alcohol or other drug use may provide a level of risk. Nevertheless, there is a strong argument from the parents in this research to counteract the COPMI (children of parents with mental illness) literature that suggests parents do not take control of their mental illness. These misconceptions related to the parents' rationale for their position on the margins of society as a constructive strategy of resistance. From this position, the parents are able to have some agency and control of their lives. The parents talked about this location during the interviews suggesting that it enabled them to safely assess risk; they are not formally doing this, but on a daily basis would engage in risk-minimising behaviours through the self monitoring of their mental health status. For example, the parents would frequently assess how they are feeling and what sort of a day they are having. Studies in the literature do not reflect this reported strength and resilience and also fail to acknowledge the parents' unique insight into their mental illness. The parents talked about the changes in their lives and knowing when they needed to access help. These findings contest research which suggests that parents fail to take responsibility but shows them as active participants in their illness. Their resistance towards medicalisation and surveillance appears to be perfectly rational given their stigmatised position.

This positive resistance supports utilising detrimental concepts for positive gain. As Davies and Allen's (2007, p. 378) research suggests, "Health professionals can use their disciplinary power to support women who are mothers and who have mental illness to manage the contradictory aspects of their dual identity." The parents in this study are realistic about the challenges of living with mental illness. They talked about their fears about mental illness, of something 'accidentally happening to them', of what might happen to their children in the future, and the fear that they might become mentally ill and not be able to care for their children. In other circumstances, voicing these fears and addressing them would be deemed to be positive, but under the gaze of mental illness these concerns, once vocalised, are also pathologised and deemed to be real risks as opposed to imaginary risks.

An unorthodox contention about the discourse of risk would be to suggest that it is embraced by parents with mental illness because it is another attempt to maximise their opportunity to be a good parent. Risk has been shown to be incorporated into practice and utilised in a positive fashion. For instance Davies and Allen (2007) argue that the risk of being stigmatised is outweighed by the provision of services and this

can be used positively. In this projection of findings, risk is a tangible, fluid concept not limited to policies. Risk is woven through all of the discussions in this chapter and, therefore, has to be incorporated into the lives of the parents and used wherever possible to their advantage.

10.4.1 *Resilience - finding appropriate places for support*

Given the rough terrain negotiated by parents with mental illness, their ability to continue to be 'good parents' should be praised. Some of the parents in this study normalised their experiences through attending consumer groups, which are, a place where they found respect. SANE (2005) and Bassett et al., (1999), suggest that consumer support groups are positive for parents and encourage the development of networks amongst parents with mental illness. This was experienced by some of the parents who joined such groups and were able to normalise their feelings about their children. Some parents had different experiences, suggesting that support groups are stigmatising as opposed to normalising. Other parents felt that there was a risk of stigma in attending support groups which is similar to the findings of the study by SANE Australia (2005) about the use of community support services. SANE (2005) found that 46% of respondents never used community services, 26% rarely used them for support, 14% would only utilise them sometimes, while the remainder would not use them or not very often which is similar to the help-seeking behaviours reported by the parents in this study.

The issue of the stigma associated with mental illness was explored by Lundberg, Hansson, Wentz and Bjorkman, (2007). They found that many former mental health patients felt that they are not accepted by most people as friends; they feel that they are not viewed as intelligent; they feel that society does not trust them; and they are concerned that they would not be employed because of their mental illness. Some of these findings are similar to those of this study. For example, parents who are or had been studying found their intelligence was questioned, while others did not disclose their mental illness to employers for fear of not being employed. Hayward and Bright (1997) argue that although there is evidence of increasingly positive attitudes from the public towards people with mental illness, the stigma also continues to be prevalent. A plethora of examples from the parents' narratives in this study provides evidence of the general stigma attached to mental illness. These

indicate a lack of acceptance by society enhanced by the casual use of labels such as crazy, mad, and so on.

This research provides an alternative viewpoint of parents with mental illness who are resisting medicalised models of service. Instead, they are operating on the periphery through utilising community mental health services, non-government organisations, or consumer-driven support groups. There is a dearth of comparative research to this study which examines the experiences of patients who avoid 'institutionalised' frameworks of mental illness. This study has provided narratives reflecting a group of parents who, in effect, are choosing to adopt a position of resistance. This also reflects the ongoing struggle to discover this hidden group of people and record their lived realities.

The parents with mental illness in this study lived their lives with little social support, and a lack of places to go for assistance. Frank (1995, p.113) suggests that even if the sick access health services that "the very poor and the very sick have . . . a marginal place in the case load of the professions, which prefer what can be fixed". This lack of support was also seen throughout this research and created issues for parents; their only source of help was their families. Where parents had a partner, for example, they are able to seek help in practical and routine duties such as caring for their children. Not all partners are supportive; some parents lived with partners who also had mental illness which increased the issues they faced and saw them negotiating their own and their partner's illness, and need for care and support. Furthermore, some parents had families who failed to recognise or acknowledge their mental illness. These parents found their relatives are afraid that they may pass on the mental illness or would 'catch' the mental illness themselves. A few of the parents rejected the risk of stigma instead choosing to be visible as a parent with mental illness. They felt that they could make a positive impact that would negate the stigma of mental illness and embraced every opportunity to talk to others about their illness. This was, perhaps, another example of stigma, although it was lived in different ways and often affected the treatment options that the parents would utilise when needed.

10.4.2 Pathways to care

Some parents had attempted to engage their obstetricians in the treatment planning for their mental illness but had been unsuccessful. As a result, they had received only tokenistic engagement or acknowledgment. Whilst the parents did not discuss a lack of satisfaction with their obstetricians, as clinicians, they also share a portion of blame in this chain of responsibility for failing to adequately support the parents. It could be argued that this failure was a starting point in the parents' experiences of negative reactions towards them as parents with mental illness. This concurs with Krumm and Becker (2006) who also found that negative responses from professionals towards parents with mental illness are not isolated. From the narratives of parents, it appears that within the pre-natal private system the responsibility to plan and care for parents who disclosed mental illness was abdicated to other providers who subsequently became involved when the mental illness became acute, usually after the birth of the child. However, in the statutory maternity services, parents who should have been routinely screened for depression did not report any positive assistance or early intervention.

As Krumm and Becker (2006) note, there are still not enough studies that examine the relationship between motherhood and mental illness and the use of mental health services. The parents in this study are often motivated through their fear of public mental health services to find a place where they can feel comfortable to express themselves and their fears about being a parent with mental illness. The parents are keen for their care and treatment to be a part of their experience of living within the community. The parents explained that most of their energy was focused on living and recovery as opposed to having their lives defined by mental illness. The parents also lived with their illness in ways that would ensure that their families are not disadvantaged. There is evidence of normality for parents with mental illness that is similar to, rather than different from the lives of 'normal' parents. It is society that positions parents with mental illness as disadvantaged, and, therefore, provides a rationale for disempowering and silencing them. Furthermore, if they are not visible, society does not have to deal with their needs. Nevertheless, as Krumm and Becker (2006) state, this leads to a blame mentality, which means that parents are constantly monitored and suspected of abuse. Placing blame on parents and, as a result, blaming them for failing to fulfil ideologies of 'good enough parent', therefore, reduces their entitlement to receive support. Parents with mental illness

are demonised through fear. However, there is no real difference, no particular characteristics that shape or identify them in a different way from the rest of the population. All parents have the potential to become mentally ill but do not need to be pathologised or viewed under rigid medicalised models of diagnosis. Parents with mental illness are not sick all the time, and furthermore, they do not use their illness to get services but to access help when it is most needed.

Parents in this research are responsible and did access treatment and, thereby, ensure the wellbeing and safety of their children. The risk for parents with mental illness appears to be related to society's attitudes towards them. Sheenan and Levine (2005) argue that when mental illness begins to interfere with the parent's capacity to care for their children, they are likely to move between health and social care services. However, these services generally work in silos accepting no responsibility for a while family. For instance, one service will prioritise the need of the child, whilst the other will work only with the parent. As a result, any assessment will be subjective and exclusionary with limited communication between the two systems and thus, in effect, impacting negatively on the parent-child relationship. This research often provided the first opportunity for the participants to speak about their lived experiences of being a parent with mental illness.

10.4.3 *Diagnosis*

Most of the parents are reliant on their own ability to find services that will meet their needs. Given that at the time of the interviews, many had significant issues due to their mental illness, but are reluctant to accept a diagnosis, this is a significant concern. Parents attempting to access statutory mental health services must be diagnosed and, therefore, labelled with a DSM-IVR mental illness.

As described in earlier chapters, some parents had a mental illness diagnosis prior to becoming a parent, whilst others only encountered mental illness after parenthood. There is an apparent distinction, though, between parents initially diagnosed as post-natally depressed (PND) compared to other mental illnesses. The parents who are diagnosed with PND after the birth of a child explained that this was less stigmatising than mental illness and more accepted by their friends and peers as a part of parenthood. The comfort of this label and the lack of treatment and surveillance suited some of the parents who still retained this label even though their children are

now at school or it was evident that they no longer had PND. These views are correspond with a study on different types of mental illness. Man and Himelein (2004) found that views of self are on a continuum whereby schizophrenia, for example, was more stigmatised than depression; stigma could, therefore, be experienced by degrees. Thus the individual's perception of the stigma would be relative to his or her diagnosis (Link & Phelan, 2001).

The location of services creates barriers to access and the parents' active avoidance of stigma can be seen in understanding their pathways to care. Dumbrell (2007), for example, suggests the place of services has implications for engagement and the power that these services have to impose regulatory actions on people is also important in building and maintaining these barriers. Some of the parents felt safer within private mental health services, which accounted for 50% of the parents in this study. Their gateway to private mental health care was often through their GP with whom they had established relationships. This conduit was not devoid of issues. Whilst some parents talked about how their GP was a better option than other options but that the GP was often out of touch. This concurs with Lester and Tritter (2005, p. 657) who found that people with mental illness "don't feel right to go to the doctor" because they don't feel that their GP will be able to deal with their issues. On the other hand, Steel et al. (2006, p. 352) found that "GPs continue to play a central role in the pathways to mental health care. Supporting the capacity of GPs to make informed judgements about timely referral therefore would seem to be an important ongoing priority."

This study concurs with Angermeyer, Matschinger and Riedel-Heller (1999) who found GPs to be a favoured route to treatment. Although in order to progress care, when mental illness is acute, specialist mental health services are often required. It is often at the point in treatment that parents are most fearful of the discovery of their parental status. However, when entering statutory services, the parents were often not asked about their children but were continually fearful that anything that they did was viewed through a stigmatised lens; even behaviours that are not risky to their children are reinterpreted as risky due to the workers' perceptions of imagined risk, which concurs with Lupton's (2003) theory of risk. Therefore, the determination of 'good enough parent' is beyond the reach of even the perfect parent. 'Good enough', once under the glare of mandated reporting, is driven by ideology. Therefore, who determines what is 'good enough' and how it is determined cannot

be challenged. It is this ideology, according to Gillingham and Bromfield (2008) that also creates a risk as clinicians fail to properly assess risk due to their immersion in a culture of blame.

The nature and practice of assessment is raised by the parents as requiring attention. Clinicians, undertaking intake assessment do not get an opportunity to see the parents in their parental capacity and therefore face difficulties when assessing the parents risk to their children. It is this lack of visibility which according to Gillingham (2006) may be significant in predicting future harms. This was often experienced by the parents who talked about the assessment they had received. In another study, Bournsnel, Lee and Phelan (2005) found that prior to the one-year pilot of the Parent Link Project, undertaken by NSW Health, 95% of clients had not had discussions about parenting and 54% had not received a home visit from mental health services. This dearth of generosity permeates mental health services involving all professionals including psychiatrists. Other examples in this study, of deficient generosity are seen in the lack of engagement, lack of understanding, and lack of knowledge about the parents' concerns about their mental illness. The parents suggested the major failing inherent in mental health services was ignorance. This is comparable to Craig (2003, p. 7) who suggests, "There is clearly much to be done in understanding how mental illness affects women who have young children. The research to date is generally inconclusive, contradictory, or of such poor design that generalizations cannot be drawn." The incongruity in services was partly due to geographic location and sometimes the difference in being able to access public or private mental health systems.

10.4.4 *Generosity and inequity*

The concept of generosity is most apparent in the significant differences between public and private mental health services. The discrepancies are seen not only in the location and resources of the services but also in the generosity shown by the clinicians within those services. These services are not identified in the research literature on parents with mental illness. However, the parents in this study felt that it was the service philosophy of generosity that created the difference between good and bad services. It seems odd that private services are able to acknowledge not only the presence of children in the lives of the parents but also their role as a parent and, therefore, integrate children into treatment, recovery and rehabilitation. The

parents' narratives reveal that children are often the reason that they have the desire or determination to carry on; a reason to live and not to suicide. Children enable them to function on a daily basis; children get them through the tough times, and challenge them to be normal when they do not feel that they can be. Children provide the parents with unconditional love; children make them proud and give them a reason to face each new day and each challenge associated with their mental illness.

This is a counter position to blame-ridden research which suggests, "Children of people with mental illness may be viewed as contaminated by their parents . . . this kind of assumption robs people with mental illness of a key part of what it means to be human" (Corrigan & Miller, 2004, p. 538). The rationales, revealed in the narratives of the parents, for allowing parents with mental illness to continue to parent are important and need to be incorporated into mental health services. This more humanising approach is also important given that other research has found there may be negative impacts if children and their parents are separated.

A large number of women with mental illnesses are permanently separated from their children. Other researchers have argued that lack of interagency communication and collaboration limits the chances of positive outcomes when children of mentally ill mothers are involved in the child protection system. (Craig, 2003, p. 17)

Responsibility for service standards lies with government, and its regulations should be provided through evaluation of national mental health policies. In practice, due to limited funding, the enactment of policy into practice is difficult for area mental health services. Many criticisms are raised throughout the parents' narratives and also in the submissions to the Senate Inquiry about the poor state of mental health services in Australia. Taking account of the circumstances within mental health services in the area in which this research took place, and the amalgamation of health service areas resulting in displaced workers, dismantled teams, and disintegrating systems, it is not surprising that parents who had experiences of statutory of mental health services reflected that it was not just the people who are the problem but it is also the system.

It appears that generosity is eroded by the fragmentation of services effectively creating silos which limit both responsibility and collaboration. Again, these findings are similar to suggestions made by Frank (2005, p.15) who suggests that: "demoralized medicine refers to relationships that have ceased to be generous, either to patients or to professionals." This discourse extends beyond the health

sector into other government services; for example, when parents become identified as a parent with mental illness additional issues are placed on them due to the impact of the DoCS system which further segments the family pie. However, due to the fragmentation of family members between the services who may subsequently become involved with a family is a desperate need for collaboration and sharing of information.

What is more concerning is that risk management is more dominant than client-centred practice. Policy is accountable for case managers becoming 'risk managers' (Green, 2007) and lack of attention in policy to fathers perpetuate myths about women as primary carers (White, 2006). This confirms Slack and Webber (2008) suggestions that some mental health professionals do not feel that the children of parents with mental illness are their problem or their responsibility, so will not engage parents in discussions about their children. In all of this confusion, the need for appropriate provision of services for parents with mental illness is also overlooked or provided inappropriately in shorter interventions as opposed to long-term programs. Lederer and McHugh (2006) disseminated their findings about the NEWPIN model of working with parents with mental illness and their children. The strength of this model is in the long-term engagement and support of families with mental illness. Due to its success, this is now an international program although it is limited to non government services who often operate services on limited funding without opportunities to evaluate the outcomes of their interventions.

10.4.5 Responsibility for bad service - lack of generosity

Experiences of bad services are far more prevalent than stories of good services. A scarcity of generosity is reported through the approach of clinician's monological style. The parents felt that once diagnosed they become positioned under the diagnostic label with the associated expectations this created. Frank suggests that such practice is common in a medical system devoid of generosity which, in effect, silences parents:

Medical case reports - charts and presentations in rounds - aspire to monological unity. The speaking or writing voice denies that the reality it expresses makes sense only at the level of a specific consciousness . . . The monological voice speaks from beyond such limitation, and this claims authority. Monologue silences other voices. (Frank, 2004, p. 109)

If mental illness becomes acute, inpatient care is often the only option. Entering inpatient care in itself creates a marginalised position for parents and a position where they temporarily suspend their active participation with their family. Davies and Allen (2007, p. 361) note that inpatient care “can cause women to feel a failure and make them vulnerable to experiencing depression and anxiety.” This compounds the severity of the symptoms and has implications for recovery and rehabilitation, because, if separated from children, the parents become desperate and sometimes tragically feel that their lives are no longer worth living. One parent in this study linked her suicidality directly to these forced separations and feelings that her life was not worth living without her child as an active part of her life. In an ideal world there would be good relationships between clinical staff and parents with mental illness. As Priebe and McCabe (2006) suggest, it is the quality of the relationship during mental health care and treatment that is crucial to rehabilitation. The parents in this study had limited experience of good relationships with clinicians.

Arguments for clinicians failing to engage with parents with mental illness cannot be continued, given that Singleton (2007) proposes that 50% of the people admitted to mental health services are parents of dependent children. However, the parents are united in their assertion that clinicians did not consider their role as a parent. Again, this finding is related to Frank’s (2005, p.27) suggestion that: “Institutional medicine provides multiple alibis for not entering into relations of care”. Responsibility abdicated by policy devoid of parenthood cannot hope services are interested in parents when they are not funded or directed to do this work. Singleton (2007) also found in her research in the UK that only 25% of mothers admitted to mental health services were asked about their children although this percentage is higher than reported in this study. Given the prevalence of mental illness in parents with dependent children it is difficult to understand why services do not remove barriers to access that would maximise service uptake. If services are able to reorient, a better quality of service would be possible. Some research has suggested that ‘lower income mothers’ fail to engage with mental health services for fear of being labelled (Anderson, Robins, Greeno, Cahalane, Carr Copeland, & Andrews, 2006). The findings in this research expand this generalisation as not all mothers, who participated in this research fit the label of ‘lower income mothers’.

Whilst, parental status is not routinely identified by the mental health system, parents are resistant to identification; this is a paradoxical issue that features both a

lack of help and also a lack of understanding. Therefore, disparities in services have developed with limited support being provided by non-government organisations who are trying to fill the gap left by the public mental health system (Slack & Webber, 2008). This has resulted in a systemic failure of responsibility by government mental health services. A solution could be to engage in conversations with parents with mental illness who are living everyday lives and to begin to understand their needs. Until policy is informed by the experiences of parents with mental illness as opposed to designing programs and services that do not seek the opinions of this group of potential clients then mental health services will continue to be a failing and tokenistic attempt at service provision.

Parents who resist identifying themselves as parents with mental illness could also be protecting their families from the stigma they perceive may be allocated to them should their own mental illness become apparent. Hinshaw (2005) agrees, and suggests that this can occur on multiple levels, resulting not only in stigma but also prejudice and discrimination. Therefore, the resistance in parents' concealment of their real selves is an effort to protect the safety of their families rather than failure to seek treatment. Diaz-Caneja and Johnson (2004) suggest that parenting responsibilities create issues in service engagement because services fail to offer practical support to parents and, therefore, are only utilised in a crisis. It is essential, therefore, to integrate parents' needs into other services where judgments also need to be made based on thorough assessment of the parents' lives rather than purely visible issues

In the main, the parents in this study are vocal in their criticism of the lack of co-ordination between the inpatient care system and the community in public mental health services. Treatment was a bad experience, which, for most parents, resulted in fractured parenting. Parental status is momentarily lost and mental health patient status became an overwhelming identity. Stigma is strongly felt by parents during these acute phases of their lives. Treatment of an appropriate nature is scarce as there are only a limited number of mother and baby units and even fewer spaces available for parents especially where the parent was a father. Most mother and baby units are run by private mental health services, limiting access for some parents. Consequently, the parents' narratives are often filled with lost opportunities of being able to access support services.

10.4.6 Staff

Most of the parents' criticism of public mental health services is that they are highly stigmatised environments inhabited by staff locked deeply in 'the tunnel'. The parents provided a plethora of examples of bad care which made them fearful of ever entering treatment again. This problem is also explored by Nordt, Rossler, and Lauber (2006, p. 713) who found evidence of disturbingly similar attitudes. They suggest that mental health professionals often compound and perpetuate poor practice: "If mental health professionals are used as a reference group of how far the social distance towards persons with mental illness can be reduced in the general public, nothing could be improved." In another study, Tipper, Mountain, Lorimer, and McIntosh (2006, p. 81) found that "support workers had personal knowledge of mental illness and may have held these opinions before taking up work." The workers are, therefore, operating from a stigmatising perspective and providing care which is not of a professional standard imagined in mental health policies. Hugo (2001, p. 419) also found some attribution of stigma in "the attitudes of mental health professionals towards people who experience mental illness . . . and is often experienced by consumers as stigma and discrimination." Hugo suggests that this is often worse than other types of stigma as "this may impact on the expectations" that consumers have of services (p. 424). Jorm, Korten, Jacomb, Christensen, and Henderson (1999) also suggest that discrimination is widespread in mental health professionals' attitudes towards people with mental illness compared to that of the general public. They argue that professionals are more aware that mental illness would be long term and are not optimistic about good outcomes. These findings are very concerning and can be reflected in those of Burdekin, who, over 20 years ago, showed systemic stigma, which was, arguably, abusive, was firmly entrenched within the mental health system.

Mental health services are failing to ensure clinicians have the skills to work with parents with mental illness. Frank (2004, p. 140) says that the capacity of staff for "action, perception, and desire" is dependent on training. In a similar vein, Mason, Subedi, and Davis (2007) state that if there are effective services and support for parents with mental illness, there is no reason why they cannot function effectively as a family. For this to happen, clinicians must adopt of family-centric practice. Such practice is not widespread and clinicians often fail to see their patients in the context of their family. There do not appear to be any specific impediments to giving

feedback to service providers. One option could be utilised through the use of consumer consultants (also suggested by McCann, Clark, Baird & Lu, 2008); but as this does not happen, service providers remain largely unchallenged in their practice. There are many excuses for bad service, including lack of funding, lack of time, services operating from silos, and those that reflect the ideology of deinstitutionalisation.

One of the rationales for not working with parents with mental illness is the fragmented responsibility and the rhetoric that suggests their needs are complex, instead of looking for interventions that have been suggested as successful strategies. Slack and Webber (2008, p. 81) argue that “one barrier to working with parents with mental illness is time”. They also identify other barriers, such as “knowledge boundaries” and apathy, in relation to engaging with the parents’ children. “It is apparent that the needs of service users’ children are not recognised or thought relevant by adult mental health professionals, while mental-health services lack the structures and policies to record their existence thus rendering the children ‘invisible’” (Slack & Webber, 2008, p. 79). These explanations of continued failure do not receive the same priority as that apportioned to parents with mental illness who are criticised for failing to engage with services, when in reality services fail to engage with parents. The best result for both would be to understand what is needed and how best services should be provided. Until this point is reached, and policies are enacted to ensure the direction of services, possibility of change is hopeless. Change is also reliant on the acknowledgment of the parenthood of people with mental illness as an appropriate role to support.

Mental health clinicians and services need to become more aware of parents with mental illness. This is juxtaposed with parents not wanting to identify themselves as in need of services because of the stigmatising gaze of authorities. These assumptions appear to be based on socioeconomic positioning which results in some parents with mental illness being more easily monitored by authorities than others. Korhonen, Vehvilainen-Julkunen, and Pietila (2008) evaluated child-focused family nursing in psychiatric units and found that child focused working was not a routine part of mental health practice. This concurs with earlier suggestions about the lack of generosity of clinicians willing to work within a family-centric model. Researchers (for example, Slack & Webber, 2008; Korhonen, et al., 2008) suggest that there is a need for more education for mental health staff. A starting point would be to

operate from a perspective of generosity which views everyone as capable. “Generosity in this new century begins by giving ourselves to dialogue, to alterity, and to justice. Generosity is giving ourselves to the suffering visible in the face and giving ourselves, no less to joy” (Frank, 2004, p. 143).

10.4.7 *Summary of this section*

Services often lack practical generosity such as time, space, environment, location, and accessibility. However, the lack of engagement with parents is, therefore, related to systemic and structural issues. These can be linked back to a failure of generosity in mental health policies to create pathways to care. The integrity in the approach of mental health services to parents with mental illness is, therefore, questioned throughout this research. Further issues of power and control are embedded within the mental health system. Mental health service providers and staff remain locked in a tunnel where generosity fails and moral responsibility is denied. The parents carry much grief about their experiences of the mental health system which is provided in the examples of systemic abuse outlined in this research which results in them never wanting to return to psychiatric care.

Blame is evident in the parents’ reflections of services that failed to provide support; this failure is also transferred to the workers within those services. Most services failed to engage with parents in their homes, a view which would allow them to be active agents in their own emancipation. As Parrott et al., (2008, p.7) note, “Most parents parent their children effectively”; this ability is not often recognised in parents with mental illness. Munro (2005, p. 379) suggests this lack of recognition can be attributed to the fact that “blame is a major feature of professional life these days”. Therefore, whether it is the parent who is trying to avoid surveillance or the worker who is trying to assess their risk, they are both equally liable to be blamed if something goes wrong that puts a child at risk. This approach accepts that risk is apparent and fails to acknowledge the resilience of both parent and worker who continue to operate without support and acknowledgment or exerting significant energy into the maintenance of this position.

10.5 Parenthood, mental illness and employment

This thesis has considered the issues of negotiating employment alongside maintaining parenthood and living with mental illness. Gender is apparent in discussions about employment, but this was not fully explored as it was felt that the focus needed to remain on the concept of parenthood. Ramsay, Welch, and Youard (2001), considered the issue of gender in relation to experiences of mental illness. They argue that gender affects both the presentation and course of mental illness. Other studies suggest that women are also more likely to be diagnosed with a mental illness (NSW Health, 2000). Women who are mothers, therefore, are targeted by researchers seeking to understand their experiences of parenthood. As already discussed, there is an almost total disregard of the experiences of fathers (Evenson et al., 2007). One of the most outstanding differences in relation to gender in this research was the way that men told their stories. Mothers focused on minimising risks in their lives to achieve the status of ‘good enough parent’ whereas fathers are often risk-takers. Fathers viewed risk-taking as related to the ‘male’ ego and, therefore, felt this was justified and accepted by society. Furthermore, none of the fathers in this study ever imagined being the sole carer of their children. Even if they separated with their partners, they accepted that they would not have custody of their children. On the other hand, the mothers felt that they could not live without their children in their daily lives.

10.5.1 *Meanings associated with employment*

Limitations within the literature are also applicable to the discussion about parents with mental illness and the issue of employment. There is limited reference to the complexities of working, raising a family, and living with mental illness. This requires multi-faceted organisation of personal lives. Whilst the literature discussed here is relevant to people with mental illness and work, it is not specific to issues associated with parenthood. Most of the parents in this study did work; this study, therefore, challenges assumptions about mental illness and employment. This might be because the sample in this research is community-based as opposed to samples in long-term psychiatric treatment, which statistics are mostly based on. This has led to certain beliefs that are challenged in this study. “By not appearing within employment settings, it is mistakenly believed that people with mental illness are too

incapacitated to work” (Waghorn & Lloyd, 2005, p. 22). It is generally accepted that mental illness is a barrier to employment. For instance, SANE (2007) found 75-78% of people with psychotic disorders are unemployed in Australia. “People with mental illness would be better served if public mental health services adopted recovery-oriented practices beyond a strict bio-medical approach” (SANE, 2007, p.2). This position is also accepted as indirectly contributing to stigma (Waghorn & Lloyd, 2005, p. 4). On the other hand, as Corrigan and Miller (2004) suggest, work can also be a site where stigma can be reduced. This occurs when people are aware of colleagues with mental illness and experience working alongside them. Mental illness then becomes normalised and stigma is subsequently reduced. SANE (2006) also suggests that “employment brings not only an income, but also the dignity of having a recognised, valued place in society.” In comparison to the SANE (2006) study, this research did not find evidence of parents’ disclosures of their mental illness within the workplace. Arguably, this lack of disclosure results in a lack of support and flexibility for the parents; most felt that if their status is known, this would result in some form of stigmatisation when they just needed to feel competent in their work.

10.5.2 Impact of gender on employment

Whilst motivation to work was largely driven by economic reasons, work did provide a place where the parents in this study continued to operate under the mask of invisibility. There are, however, different motivations to work apparent in the gender of the parent. Most of the women had continued to work in their chosen professions whilst a couple had been limited in choice due to their mental illness. Nagle, Cook, and Polatajko (2002) also found the parents’ ability to work was affected by availability, and personal and economic resources. In this study, childcare was also a major issue for mothers. This was different for fathers who felt constrained by their mental illness resulting in the loss of identity as the family provider.

Employment is generally regarded as positive for people with mental illness (Kennedy-Jones et al., 2005). For the fathers in this study employment mitigated the impact of their mental illness; it also allowed several mothers also to function and enjoy their professional status. This is in keeping with other research which suggests committing to multiple identity roles enhances the capacity of people with mental illness and provides satisfaction as well as an income, activity and meaning to their

lives (Elgar & Chester, 2007). It does not explain gender discrepancies. Existing research focused on mothers with severe mental illness fails to account for the population of parents with mental illness such as this cohort who often had to work due to financial pressures. The working lives of the parents, whilst still very challenging, provided social interaction, thereby reducing the isolation of their private lives. This finding harmonises with other research findings that work is an important factor for people with mental illness (for example, Gould, 2006). Weich, Nazareth, Morgan, and King (2007) suggest that educational qualifications also impacts on parents' help-seeking behaviours, those without tertiary qualification are less likely to seek psychiatric treatment. Corresponding to this finding, this research suggests that perhaps those with tertiary qualifications are more likely to be able to afford private mental health treatment. This is a different population group to those considered in other studies of mental illness and employment. For example, the Australian Bureau of Statistics (ABS, 2006) found that adults living in socio-economically deprived areas had a higher prevalence of mental illness. Associated factors included low rates of pay, casual work, unemployment, and living in poverty. They also found in their study that that more of this group are likely to be women with children.

The parents in this study experienced dilemmas around the purpose and logic of working. Gender appeared to affect the way mothers and fathers rationalised these differently according to the need to work and the need to provide for their family. This is not to suggest that fathers and mothers are oppositional, but rather they have different needs. Furthermore, many of the parents in relationships operated in 'traditional' family situations. In continuing to identify the issues related to parenthood, it is possible to continue to argue for parents with mental illness as a homogenous group; even though they are clearly not, this approach will give them more power and advocacy potential.

As mothers, the women in this study also engaged in more unpaid work than the fathers. On the other hand, perhaps the fathers did not talk about unpaid work in the context of the challenges in maintaining equilibrium in their lives. For the mothers, cooking, cleaning, feeding the children and other practical household routines are another burden in their daily lives. The fathers did not see this as an issue as with the support of partners who 'gate kept' their silence, they are protected in their need to rest and recuperate. In contrast to the fathers, the mothers are more likely

to parent alone and do not get this respite. As part of the traditional roles in relationships and marriages, even where parents lived with partners who also had mental illness, the burden of responsibility is held by the mothers. It was in the context of these issues, that the mothers experienced stress. Kahng et al., (2008, p. 165) also found “parenting stress was higher for mothers with more daily hassles and less support, suggesting that contextual risks add to mental health problems in increasing parent stress.”

10.5.3 *Summary of this section*

Research continues to place women in an unequal position in society. One of these structural determinants is that women are more likely to be diagnosed with mental illness. Postulating further, many women diagnosed with mental illness are likely to be mothers and a large percentage will be single and parenting alone. There is a myriad of social and ethical failures in their positioning. These failures need to be addressed including an acknowledgment that the motivation for women to be in employment is generally limited to wanting to provide for their children. This motivation is no different from that of men, except that women are often parenting alone.

Combining work, parenthood, and mental illness is a reality for many people. An important issue is the perception that everyone with a mental illness is incapacitated for a long period of their lifetime. This thesis has shown that this is not so and many of parents with mental illness interact with their communities, of which we are a part, on a daily basis. Therefore, in returning to the starting point of this thesis, the failure of society to document the everyday normality and reality of parents with mental illness is, creating barriers and limiting mental health policy from reflecting the realities of our society.

10.6 Analysis of mental health policies

The terrain of mental health and illness in Australia has changed drastically over the last fifty years. The transition in services and the resulting mental health policy developments in Australia to a national approach to mental health service provision have been explored in earlier chapters. However, it argued that the policies reinforce societal discourses about parenthood and have significant power over the

lives of parents with mental illness. Furthermore, because policies are backed by legislative measures they hold power (for example, care orders, interim, temporary disruptions to parenthood gained through access to judicial power). Issues inherent in the gap between policy and practice which have been analysed have shown the discrepancy between political ideals, reality, and practice as outlined by the parents. Frank also suggests that policies generate power, which regulates treatment and expectations of health and illness which then define how services operate: “Generosity is constrained by regulation, or people *feel* constrained which produces the same effect” (Frank, 2004, p. 124).

The discussion of policies (at all levels), links the current position of parents to issues related to the historical treatment of people with ‘diagnosed’ mental illnesses. In the past, the mentally ill were considered disabled and prohibited from full participation in society. However, despite environmental shifts in living arrangements for people with mental illness little has changed in terms of societal acceptance of the mentally ill. Policies relevant to parents with mental illness have been identified as embedded within a moral discourse and an individualistic, blaming approach. This subjective positioning continues to fail to be challenged (Rusch et al., 2005). Furthermore, policy is only applicable to people who are diagnosed and medically treatable under a defined criteria inherent in the DSM-IVR.

The political discourse has been shown to be supported by a moral responsibility perspective (Wyness, 1997) justifying, societal involvement in the lives of parents with mental illness for the sake of the ‘good of the child’ (Gillingham & Bromfield, 2008; Hansen & Ainsworth, 2007). This societal moral responsibility becomes a basis for the risk discourse now impacting on parents with mental illness. Ribbens, McCarthy, Edwards and Gillies (2000) corroborate the idea that parenthood is viewed as a moral task and that the family is a central arena in which moral identities are formed. As a result, despite the individualisation of parenthood, there is also evidence of standardisation in the form of a moral imperative which has become the foundation of parental caregiving. Therefore, parents are expected to take responsibility for their child unless they are deemed as ‘other’. This positions parents against parents, or parents with mental illness as ‘other’ and associated with risk. Once a ‘risk’ to their child, the parent becomes the responsibility of government and justification for regulation.

This individualistic morally-driven model of responsibility apparent in current mental health policies has been driven by deinstitutionalisation. Richmond and Savy (2005) apportion further blame to academics who, they suggest, have been complicit in failing to examine deinstitutionalisation as a contemporary response to mental illness. Any discussion of mental illness is, therefore, heavily blame ridden.

10.6.1 Policies supporting stigma

It is interesting that there is no one who is willing to be held responsible for the failure of policies. Rather, according to Frank (2004, p. 127), policies are the responsibility of no one person since '*artificial*' persons create them. As a consequence the harm actually done by bad policies is instead attributed to the victims of these policies. Any blame is, therefore, levelled at individual parents with mental illness who are powerless to respond to their critics. Frank's theory can be applied to parents with mental illness and provides an argument for shifting the blame from parents to policy makers who fail to accept professional and corporate moral responsibility. Such failure subsequently results in no one accepting or implementing policies.

Whilst there are now comprehensive national mental health policies, which have been reviewed and critiqued in Chapter 4, it appears that the rhetoric about and lack of care for people with mental illness has not changed (Henderson, 2004). Deinstitutionalisation shifted mental health care from a state concern within the environment of the asylum where a measure of safety was granted for everyone at the cost of their liberty. Deinstitutionalisation resulted in a reduction of long-term psychiatric inpatient care. Parenthood, previously regulated in institutions, was no longer regulated. As a result, during the last thirty years, further issues have arisen and discussions have been generated about the growing population of parents with mental illness. However, the analysis of policies in this thesis shows a failure to integrate the needs of this population into practice. An exception is the Promotion, Prevention and Early Intervention policy, which determined that prevention prior to deterioration in mental health should be implemented into practice wherever possible. In reality, however, services are not funded to provide preventative services and it is argued policy makers are simply, doing their duty and writing policies to meet the needs of government. This is evidenced in this research study through the narrative accounts of the parents whereby gaps between policies, research, and practice have been identified.

10.6.2 *Deinstitutionalisation - failure of policies to acknowledge parenthood*

This thesis argues that in the process of deinstitutionalisation, policies failed to institute measures to support the transition from long-term care into the community. Policies failed to be accompanied by funding to provide appropriate public education about mental illness that might have challenged long held misconceptions about mental illness. Policies define what is normal and, therefore, what is not normal. Deinstitutionalisation, in effect, created a fragmentation of normality. For example, communities of people with mental illness are broken apart during deinstitutionalisation. This led to social isolation without adequate aid for the development of alternative supportive communities. This highlights a gap in the rhetoric of deinstitutionalisation. Failure to institute supportive integration led to an increase in otherness and stigma which are already embedded within society. The institutionalisation of mental illness meant that communities were 'protected' from the long-term mentally ill who were placed in 'asylums'. Instead, the economic rationalistic response was to replace support, safety, and 'belonging' with medication. As the use of medication developed, this provided increasing opportunities for people with mental illness to live 'normally'. The reality of this for the parents who took part in the study was said to be incredibly isolating.

As more people with mental illness began to live in the community, research addressed their stigmatised position. Gaebel, Ziske and Baumann (2006), for example, suggest that the stigma of mental illness is an additional burden for the mentally ill. It is apparent that there is an interaction between stigma and disability which appears to be two-way. For example, mental illness has been seen to affect the disabilities of people with mental illness, and - vice versa - the disabilities of people with mental illness influence lay perceptions and, therefore, the stigmatisation of people with mental illness. As Goffman (1963) suggests, the cues which signal stigma may not be readily apparent. Distinguishing discredited from discreditable kinds of stigma, such as parents with mental illness, may be difficult. Parents might hide their mental illness in order to avoid detection and alerting society to an apparent mark that will identify them as part of a stigmatised group. In this light, parents with mental illness can be seen as belonging to the discreditable stigmatised group. They do not become stigmatised until they are conferred with the label of mental illness through psychiatric diagnosis, social skills deficit, or bearing

the physical appearance of symptomology sometimes related to side effects of psychiatric medications. In this study, the parents' expectations reflected this process as they feared perceived attitudes towards their mental illness and the resultant stigma. However, they had not often actually experienced any adverse comments because they continued to self-stigmatise through fear and distrust of what might happen if they are revealed as their true selves. Policies have failed to address or challenge stigma in any effective way despite the idiom and rhetoric within policy trajectories.

The intersection and alignment of institutional and experts' objectives result in advising and regulating parenthood (Henderson, 2005). Parents who took part in this study talked about their fear of the risk mentality and the surveillance which would result in judgment of their parenthood. This risk discourse (see for example, Davies & Allen, 2007; Hugo, 2001; Manning & Gregoire, 2006) is assisted by government policies and investigations into practice. Examples of these can be seen in the reports of child death reviews. Even these investigations, however, have only recently come under surveillance themselves. Munro (2005) suggests that the responsibility of the system to provide services such as those needed to support parents with mental illness should itself be reported on more often as it is a crucial link in the often deadly effects of systemic failings: "The history of child welfare is littered with tragic stories of children suffering prolonged abuse and then being killed by a parent" (p.376). Munro's argument is important as it opens debates about child deaths being unfairly attributed to parental illness as opposed to a reflection of a system unable to deal with the complexities of society and safeguard the lives of children whose 'welfare' has been undertaken by the state. This position is sustained by other recent arguments (for example, Gillingham & Bromfield, 2008; Hansen & Ainsworth, 2007) which are critical about the monitoring and reporting systems for child protection concerns often enacted when a parent is identified as having mental illness.

It is proposed that the 'risk' attributed to parents with mental illness can be derived from wider discourses in the treatment of mental illness historically and sustained in current policies. Following Foucault, Lupton (1999, p. 87) suggests that "risk may be understood as a governmental strategy of regulatory power by which populations and individuals are monitored and managed. Risk is problematic, rendered calculable and governable." Therefore, as Green (2007, p. 395) notes, risk becomes identifiable,

controllable and a “growing political imperative for most governments, their contracted agencies, and business corporations”. The major discourses of risk surrounding parents with mental illness suggest that parents are to blame and that it is their responsibility to ensure the health of their child. If their mental illness affects their family, they are answerable for their child’s distress, rather than the society which stigmatises them and the health system which fails to provide the preventative services they need.

10.6.3 *Advocating changes to policy*

It is evident from the data that policy changes are necessary if parents with mental illness are to be encouraged to integrate into society. Several major barriers have been uncovered to assisting in the emancipation of parents with mental illness in policy. Firstly, the language of mental health is oriented around concepts of ‘responsibility’; if this language is the only one that is used in policies then the marginalised position of parents with mental illness is reinforced. However, this research suggests that what is needed is to push beyond such concepts and question how these discourses can better describe the experience of being a parent with mental illness.

Secondly, there is a need for recognition of parents with mental illness in policies. Without adequate acknowledgment in mental health policies there is no recourse for services’ continued failure to provide for the parents’ needs. In effect, policies condemn parents for failings which should be ascribed to services, policies continue to perpetuate the “ignorance or misunderstanding regarding parenting and mental illness” (Nicholson & Biebel, 2002, p. 169) and to defend staff who are inadequately trained to work with parents with mental illness. Akister and Johnson (2002) advise that there are many strategies which can be used to promote positive parenting for parents with mental illness and these should be incorporated into policies. Although limited in Australia, examples of programs that do work include Crossing Bridges Down Under program and NEWPIN service model. Targeted parenting programs if integrated into policies provide the opportunity to successfully assist these groups identified ‘at risk’. Furthermore, according to Little (2007), if these services are provided through population health policies these ‘thick’ parenting support programs have been found to be less stigmatising. Such an approach when they are consistent with policy and offered at a population level seems a simple solution.

The only example of policy innovation in Australia can be seen in the PPEI. This policy provides an opportunity for services to encourage families with mental illness and parents who, if provided with services, would be identified as needing to become 'better parents'. This orientation, however, continues to be disempowering as it suggests that from the outset parents with mental illness are not good enough parents. Not only does such a perspective denigrate their abilities as parents but it also constructs them as 'other' from good enough parents or oppositional to parents who do not have mental illness. This was apparent in the narratives of the parents who took part in this study. The narratives also illustrate the paradox for parents who want services but encounter barriers due to the fear of a diagnosis which will result in stigma and labelling, as well as a lack of personal control over the outcomes of the support they receive.

Many of the parents in this research study are never identified in practice even when accessing services. Therefore, even if such strategies are to be adapted to support parents with mental illness, the issues related to 'hidden' or 'silent parents' remain a barrier to service uptake. Murphy (2003) suggests that there is a paradox at the heart of the relationship between the state and the family in contemporary liberal states. Whilst in principle, there is commitment to limiting the role of the state and respect for the autonomy and privacy of individuals and families, there are concerns inherent in policy which contradict such notions through the regulation of social and economic life. Policies, therefore, foster desired values, including wealth, health, and other kinds of wellbeing, and continue to encourage dominant ideologies about parenthood. If the state does not want to take on the role of parent, then it should clearly assign policies and funding so that parents can be acknowledged, supported, and praised for their dedication to their children even when their mental illness is acute. It is clear from this research that parents with mental illness are capable of parenting without the intrusion of the state. With less regulation, services would not be such a threatening prospect and would more likely become a haven for parents to turn to in times of adversity.

Current mental health policies encourage the incorporation of the patient experience. Despite the stated government policies, the extent to which parents with mental illness are able to be active participants in their mental health care remains limited and they are consequently, deprived of opportunities to challenge

barriers to service provision. For instance, lack of power is especially evident during inpatient care where parents are treated as ‘patients’ under a disempowering medical model as opposed to ‘a parent’ with resilient qualities (Slack & Webber, 2008). It is argued that mental health policies should demand services be challenged to see the whole person. In failing to acknowledge parenthood in policy, mental health services continue to fail to acknowledge and identify parents. If the same principles that govern the accountability of parents for their parenting skills are applied to clinicians, then their professional capacity should be questioned. However, as has already been discussed, research in this area is sparse and there is lack of opportunity to extend the participation of parents within mental health research (Cowling, et al., 2006). Therefore, the evidence that could provide effective answers is limited as are the opportunities for parents to help reshape clinical practice. As Cowling and her colleagues (2006, p. 407) have noted, “a major barrier to consumer involvement was the attitude of service providers . . . carers described very little opportunity for participation at any level.” The ability to participate at a consumer level was not explored by most parents in this study. The parents talked about bad experiences that led to reluctance to return to mental health services. They would not wish to participate in policy work, such as acting as consumer consultants. Their views are reflective of many people who experience mental health treatment. However, one parent had sought opportunities wherever possible to campaign for other parents who are also caught in the mental health system. She felt that being listened to provided further opportunities for parents to have their say about their experiences. This experience is unusual, and, in keeping with other research, it has been found that consumer representation is a ‘myth’ (Happell & Roper, 2006). To date, there is no outcome in terms of parents with mental illness effecting changes to policy but this is always possible in the future. As a result, parents continue to remain silent about their needs and in spite of the opportunity they have to advocate changes to policy concerns for their personal safety prohibit participation. These issues therefore, prevent parents from openly discussing or raising their needs at the policy level.

Thirdly, there is a need to challenge barriers to service access and resolve the inconsistencies in service provision. A renowned failing of mental health policies is that they focus service provision on those in acute need. Many of the parents in this research are not in constant need of services so are, apparently, overlooked by service providers as a priority. The ‘targeted’ approach is medically focused and not a considered use of valuable resources. This idea is discussed by Palmer and Short

(1997) who apply the law of diminishing returns to disease prevention. They argue that increased resources devoted to treatment produce progressively smaller increases in health status. Policy reflects cultural norms which in turn affect clinical practices. As Lefley (2000, p. 229) notes, “in these areas, culture, to a large extent, determines the parameters and concordance of the perspectives of patients, families, professionals, and outside advocates.” Parents with mental illness can promote the need for mental health services to shift the focus from 'curative', bio-medical models of service provision to community-based, user-friendly services (Baum, 1998). Furthermore, from an economic perspective, this argument is also strong as prevention that focuses on controlling the origins of illness is not only cheaper, but more humane and, ultimately, more effective than treatment intervention after an illness has occurred.

10.6.4 *Mental Health Senate Inquiry*

Continuing on in the vein of the above discussion is the reality of poor resourcing of mental health services as discussed in many of the submissions to the Senate Inquiry into mental health services. There are many examples of services failing to provide to their communities. Acute mental health services and policy declarations are in contention as individualised responsibility for mental illness is in opposition to public responsibility for the parenthood of children of parents with mental illness. McConnell Gladstone et al. (2006, p. 2456) suggest that “the children of mentally ill parents, like children in many contexts are often ‘invisible’ within the social processes that shape their lives.” Furthermore this subjective positioning is favoured by politicians who argue that they “serve as a basis for examining whose interest is being served by the social policies and institutional arrangements currently provided for children” (p. 2456). Part of this issue is explained by Lauder, Kroll and Jones (2007) who argue that linking the social world and the health system together will not reduce the social, physical, and economic influences on mental health policies. There is even less certainty, given these factors, that policies and mental health services can be directed to meet the needs of the parents with mental illness as these continue to be hidden.

10.6.5 Summary of this section

The overview of national mental health policies and analysis of the Senate Inquiry submissions have been combined to highlight glaring chasms in services, lack of funding, and lack of promotion of prevention and early intervention programs that can provide good quality community support and care. There have been no significant changes in national mental health policies since their inception in the 1990s apart from wording and slight emphasis of focus; however the overall aim of policies continues to be to provide for those in acute need. This opinion is shared by Collinson and Copolov (2004, p. 34) who state:

After many years in the background of Australian government policy and planning, mental health is now recognized as a major public health problem. A coordinated approach is now regarded if the mental health issues facing Australia are to be addressed in a manner that has long lasting benefits to its citizens.

Whilst policy may be a way forward to support parents with mental illness, it is a deeply politicised minefield. For instance, issues about adequate funds allocated for and to services within mental health arena are already significant. The needs of parents must be balanced against competing demands on government for general health and mental health services. The lack of awareness is further impacted by the lack of advocates for parents with mental illness. People willing to be considered an example are placed under the spotlight of the risk discourse. These discussions clearly show the dearth of public support for policy and subsequent lack of care for parents with mental illness. Furthermore, any debate about service provision is nested within contradictions and notions of ‘a good enough parent’. These debates perpetuate the issues of silence and lack of awareness faced by parents with mental illness.

This thesis has suggested that mental health policies are based on the medical model although operating through a public (or population) health model where universal access to services is the goal. However, this outcome is clearly flawed when applied to the Australian context where the provision of services to parents with mental illness is led by policies focusing on services for those whose need is most acute. The principles of the national mental health policies and the vision of community living for and acceptance of people with mental illness are clearly not matched by the reality expressed in the parents’ narratives. There is a deficit in policies to effect real change to the frameworks that can reduce, challenge, and provide alternatives

to the stigma of mental illness. The parents who participated in this research found that an inclusive community does not exist. Instead, this is a utopian vision premised on the notion of a community where all members are valued, irrespective of their differences. Furthermore, the process of deinstitutionalisation was driven by the assumption that if people with mental illness lived in the community, they would gain social acceptance. This assumption lacked attention to different dominant social norms played out in socially valued roles.

If policy is not driving the development of mental health services, then services themselves will not meet the needs of the population identified as needing to access these services. Parents with mental illness, nevertheless, in committing to parenthood, are morally obligated to be well, to parent well and to raise children who are normal, good citizens. Perhaps if moral obligation was shared by all, then the *artificial* persons who shape meaningless policies would also find purpose (Frank, 2004).

10.7 Chapter summary

This chapter has drawn together the data collected in this research with the findings arising from the data and the new information that has been generated in this thesis. The final chapter will now outline the recommendations arising from this research and make suggestions about the need for further research in this area.

CHAPTER 11: ENDING THE SILENCE

11.1 Finding the voices . . .

In the penultimate chapter of this thesis the findings arising from this research were discussed. This last chapter will now outline the resulting recommendations derived from this brave group of parents with mental illness whose voices, until now have been silenced. These recommendations fall into three areas; recommendations for practice, recommendations for policy and lastly recommendations arising from the parents' suggestions.

11.1.1 Recommendations arising from this research

In this final chapter recommendations arising from this research are discussed. These recommendations fall into three areas; recommendations for practice, recommendations for policy and lastly recommendations arising from the parents' suggestions. The following case study is provided to outline these recommendations.

Case Study showing recommendations:

Evie's story could have been different if she had been provided with support for mental illness when she first became unwell which was shortly after the birth of her son. The situation that unfolded in Evie's life shows a myriad of points of intervention and opportunities for support which exemplify the recommendations of this thesis.

At the beginning when she first noticed symptoms of mental illness Evie needed someone to bear witness to her suffering. She needed a generous ear; a person who had the expertise to know that what she was suffering was more than an over anxious new mother. If community support services and her midwives had made the necessary recommendations to services Evie may not have become so desperate and her symptoms may have been manageable given the right medications. If the clinicians had connected with Evie they may have realised the importance of her parenthood and her need to breastfeed her son and provided options for her to be able to do this. Had Evie been provided with support she may not have become so

isolated and so desperate ultimately circumventing the need for acute psychiatric care. Even if psychiatric care was the only option, admission with her son would have ensured that her early experiences of parenthood would not have been fractured. At this point in her story her son would not have been placed in foster care and the symptoms of her mental illness would not have been exacerbated by the separation from her child. Her subsequent suicide attempts would not have happened as they were part of her desperation and feelings of guilt due to the separation with her son. Her role as a single mother, if supported by community mental health services may have led to earlier and supported discharge from psychiatric care. Her experiences of care could have been different if clinicians had engaged with her as a parent and asked her about her fear over not being able to parent her son. If she had been provided with generosity she might have had a shorter stay in psychiatric care and may have been able to maintain both her job and her house, but given her circumstances she lost her life including her parental status. If there had been more knowledge about parents with mental illness clinicians may have provided options to support a reconnection between mother and child. The risk discourse related to parents with mental illness would not have been the total focus of treatments as there would be more understanding of the need for relationships between mother and son. If clinicians involved in this case had the support of policy they may have had options to support this family, including appropriate support programs to ensure continuity of parenthood. If the system was more flexible Evie may have been reunited with her son in the subsequent years as she learnt to manage her mental illness, instead of the permanent removal of her parental status and a life of missed opportunities for both mother and son. The lack of support for other mothers, like Evie, suggests that much work is needed to support other parents with mental illness.

Recommendations for practice:

1. Parents must be seen in the context of their lives and parental responsibilities incorporated into treatment, for example parents should be supported in their own homes, with their children whenever possible and practicable
2. Parents must be seen as parents not patients.
3. New professional perspectives are needed which allow for and respect the place of parenthood in the lives of parents with mental illness.

4. Professional performance of mental health clinicians should be strengthened through access to training, supervision and support in order to reduce systemic failings.
5. Increased pathways to services are essential in the provision of timely mental health care. Attention to location of services in the community and access to those services is required.
6. Participation of family and carers in mental health care and treatment is essential in order to challenge the culture embedded within services.
7. Better communication is required between service providers and families to overcome issues identified in silos of service models.

Recommendations for Policy:

1. Specific policy is needed to address the needs of parents with mental illness.
2. Policy must support long term work with parents with mental illness and their families.
3. Policy needs to support wider definitions of parenthood, especially the role of fathers in parenting their children.
4. Policy ought to drive research and evaluation of service models for parents with mental illness in order to develop best practice approaches for these populations.
5. Policy must normalise mental illness and address the stigmatised position of parents with mental illness in the community.

Recommendations from the parents:

1. Increased media awareness about the lives of parents with mental illness.
2. Positive media needed promoting and normalising mental illness.
3. Services to be made available that will not judge parents or place them under a risk discourse.
4. Easier access to services and services that will support parents and their families' long term.
5. Services must provide space for parents to receive inpatient treatment with their children and adequate facilities for children to maintain relationships with parents even when mental illness is acute.
6. Generosity needs to be a key concept of mental health policy.

11.1.2 Suggestions for further research

Future research in this area is urgently needed to further explore the lives of parents with mental illness who do not access formal services as this is a little studied group that is difficult to access. Whilst this present research uncovered a population of parents previously unknown it would be useful to expand the sample size in order to further explore this research area. Future research may also collaborate with mental health services to find out how parents currently receiving mental health services are coping with their experience of fractured parenthood. Other research could also interview service providers in order to understand their experiences of working with parents with mental illness in order to overcome the identified barriers to participation and engagement with services.

In terms of other future directions it would be useful to establish a longitudinal study following some of the parents over a longer period of time to see how they develop as parents with mental illness. Such a longitudinal study with parents with mental illness has never been undertaken; however given the dearth of any significant research studies this is not surprising.

11.2 Concluding comments

The extent of the participation and engagement of parents has been surprising and humbling. It was a privilege to record their narratives and to listen to their openness about issues and challenges related to parenthood. This research suggests that it is perhaps not treatment but a philosophy or commitment to providing support that is needed, one that operates from a respectful and non-judgmental position. This analysis of the lives of the silent parents has been generated using the key concept of 'generosity' which should be relayed to policy makers and incorporated into service provision. Information about parenthood experiences from the parents living in the community highlights and normalises many of the discourses about parents with mental illness, which are viewed through the gaze of risk posed by their mental illness, and the risk that they pose to their children as a parent with mental illness.

The two major concepts which have been discussed are parenthood and mental illness. They are both laden with assumptions and expectations. The role of parent has a number of societal expectations, and the notion of mental illness is associated with cultural conceptions about health and illness. Throughout this thesis, attempts have been made to separate the issues to ascertain how parents with mental illness negotiate their lives, to uncover the barriers they face, and to make suggestions about how life could be different for them. At the onset of this research, there was an awareness that parents with mental illness live under a veil of scrutiny from their family, friends, and community, apart from agencies and those in power who shape mental health policies. Under these conditions, it is not easy for parents to make choices about their lives and the lives of their children. Such scrutiny limits their options and determines the conditions within which they live. Their lives are impacted by understandings, notions and discourses related to mental health, parenthood, family, economics, geography, education, religion, and many other concepts, which all come together to shape the dominant ideological values of our society.

The major issue is that without generosity in policy there will be no incorporation of the needs of parents with mental illness. Without a greater acceptance that mental health affects many parents, not just those who are diagnosed with a long-term acute mental illness, there will be no recognition that many 'normal' people also suffer from episodes of mental ill health. Many of these parents continue to

undertake their everyday lives whilst also negotiating mental illness and fear disclosure of their status due to fear about stigma. Lack of community-based research into mental health fails to challenge stigmatising attitudes and misconceptions about parents with mental illness. Lack of their voices ensures that risk continues to be the dominant approach to clinical practice and fails to recognise the love of parents with mental illness for their children. Despite the arguments that parents with mental illness are a 'risk' to their children this research has provided a counter argument that any risk can and should be managed, this would be beneficial both for the parent and their children. Maintaining everyday life whilst living with mental illness is a position that needs to be incorporated into service provision and backed by government. However, until more research provides evidence of the needs, many of the parents, like those in this research will continue to be silenced.

This thesis has brought the narratives of parents from chaos to coping and in doing so has shown how parents learn to live and love despite mental illness.

Part V:

Supporting Information

Appendix 1

List of non government mental health support agencies

- Central Coast ARAFMI
- LifeLine
- New Horizons
- Life Without Barriers
- St Vincent De Paul
- Pacific Link
- Samaritans
- Women's Health Centre
- Central Coast Disability Network
- Schizophrenia Fellowship

Appendix 2

List of codes for thematic analysis

1.Support	<ol style="list-style-type: none"> 1. Family 2. Partner 3. Children 4. From other people with mental illness 5. From employers 6. From psychiatrists/mental health professionals or other health professionals 7. Changing support needs 8. Community support 9. Support organisations 10. Support from religion or church 11. Needs of support – services etc 12. Financial support 13. Surveillance – feeling that support is checking on them
2. Stigma	<ol style="list-style-type: none"> 1. Related to family 2. Stigma from family 3. Lack of recognition 4. Trying to overcome stigma 5. Living with stigma 6. How stigma feels 7. What society thinks about stigma 8. Work and stigma 9. Need for education to reduce stigma 10. Understanding mental illness 11. Blame or shame feelings
3.Effect of mental illness on parenthood	<ol style="list-style-type: none"> 1. Transition to parenthood – how it felt and how it was 2. Experience of being a parent with mental illness – daily life 3. Practical issues related to mental illness 4. Concern about mental illness and children 5. Guilt, grief and loss issues 6. Fear of losing children 7. Being a good parent 8. Gender related issues
4.Issues with mental health services	<ol style="list-style-type: none"> 1. Being excluded from mental health services 2. Services not acknowledging parenthood 3. Inpatient treatment – experience of 4. Feelings about inpatient treatment 5. Lack of care and generosity – what it felt like 6. Good care – mental health care & services 7. Bad care – mental health care & services 8. Private mental health care & services 9. How things could be different – ideas and suggestions 10. Discharge from mental health services – no support 11. Discharge – support from services 12. Accessing mental health services – what it is like and how it feels 13. No services – what it feels like 14. Lack of training of mental health professionals 15. Diagnosis – being unwell
5.Medication	<ol style="list-style-type: none"> 1. Taking medication – how why and when 2. Benefits of taking medication 3. Negatives of medication 4. Changes in medication 5. Prescribing medications – interactions with doctors 6. Information about medications
6.Living with mental illness	<ol style="list-style-type: none"> 1. Work and employment 2. Reflections on mental illness 3. Religion 4. Daily life – practical things 5. Becoming unwell – insight and reflections 6. Economic and financial issues 7. Comorbid issues 8. Partner/family support 9. Identity change – how it feels 10. Loss of identity – loss of old self 11. Feelings about medication

7. History of mental illness	<ol style="list-style-type: none">1. Growing up with mental illness2. Comorbidity – AOD use3. Previous episodes of mental illness (before parenthood)4. Abuse during childhood – specific issues5. Life before mental illness – how it was different6. Diagnosis – history of becoming unwell7. How it felt to be unwell before diagnosis8. Process of diagnosis9. Relationship breakdowns related to mental illness
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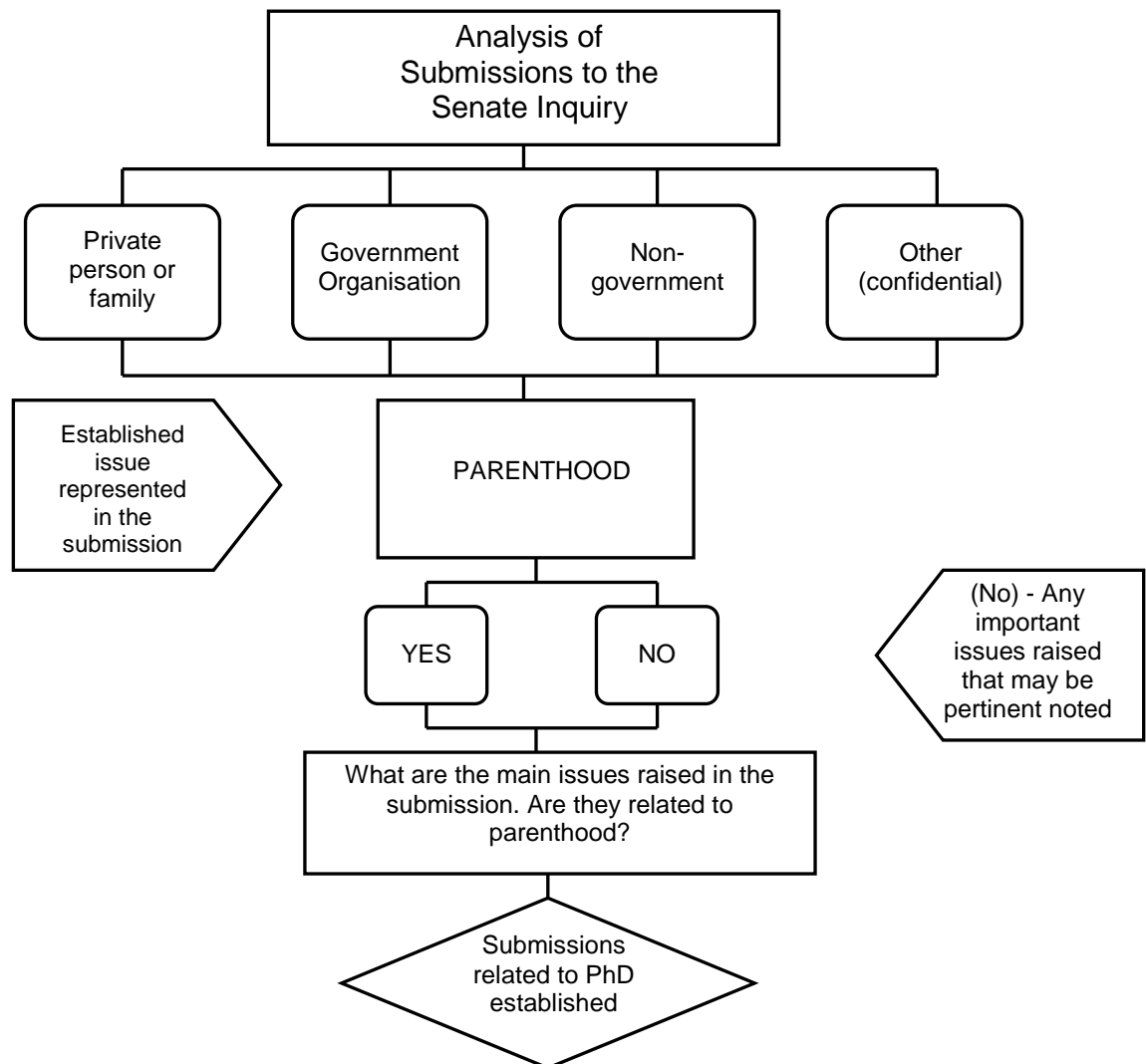
Appendix 3

Terms of Reference for the Senate Inquiry into Mental Health Services

1. the extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved the aims and objectives, and the barriers to progress;
2. the adequacy of various modes of care for people with a mental illness, in particular, prevention, early intervention, acute care, community care, after hours crisis services and respite care;
3. opportunities for improving coordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care;
4. the appropriate role of the private and non-government sectors;
5. the extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes;
6. the special needs of groups such as children, adolescents, the aged, Indigenous Australians, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence;
7. the role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness;
8. the role of primary health care in promotion, prevention, early detection and chronic care management;
opportunities for reducing the effects of iatrogenesis and promoting recovery-focused care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated;
9. the overrepresentation of people with a mental illness in the criminal justice system and in custody, the extent to which these environments give rise to mental illness, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people;
10. the practice of detention and seclusion within mental health facilities and the extent to which it is compatible with human rights instruments, humane treatment and care standards, and proven practice in promoting engagement and minimising treatment refusal and coercion;
11. the adequacy of education in de-stigmatising mental illness and disorders and in providing support service information to people affected by mental illness and their families and carers;
12. the proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness;
13. the current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated;
14. the adequacy of data collection, outcome measures and quality control for monitoring and evaluating mental health services at all levels of government and opportunities to link funding with compliance with national standards; and
15. the potential for new modes of delivery of mental health care, including e-technology.

Appendix 4

Diagram of procedure for Senate Submissions



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