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"In Her Shoes"
The Experience Of Mothers
Living With Mental Illness

**A Thesis presented in partial fulfilment of the requirements for the
degree of**

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ABSTRACT

This thesis presents a study of the views and experiences of a small group of New Zealand mothers living with mental illness. It is a qualitative study, the purpose of which is to explore the interface between parenting and mental illness through in-depth interviews and to draw suggestions from these experiences for service development. Utilising a perspective which is influenced by a combination of recovery, feminist and Kaupapa Maori research philosophies, the intent of the study is to hear and reflect upon these stories through a collaborative process.

The findings reveal similar themes to those from international studies. The participants emphasize the value of motherhood, seeing parenting as a tool for recovery and a way to increase self-esteem. Stigma and discrimination, especially self stigma, the internalised sets of beliefs about people experiencing mental illness, still affect women's lives, leading most of the participants to experience a pervasive fear around the loss of their children on account of their mental illness. Finally, mothers spoke of the stresses brought about by living in an environment often characterised by poverty and isolation.

The main recommendations are for family-focused, community-based services which utilise early intervention approaches. The need for more extensive, flexible, practical support services and support for family/whanau are also highlighted. The role of trauma in the lives of the mothers interviewed and the need for access to appropriate treatment is emphasized. Finally, the lack of concrete data related to the numbers of parents living with mental illness is underlined and it is suggested that the latest mental health information system incorporate details about parenting arrangements.

The findings of the research raise issues about the ability of present-day mental health services to fully meet the needs of families living with mental illness. Furthermore, it is argued that the compartmentalisation of mental health and child welfare services leads to a lack of a cohesive approach to the complexity of the lives of both parents and children in families with mental illness.

In spite of less than optimum services, the strength and resilience of the mothers interviewed is a demonstration of the success of the recovery philosophy.

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To my family, especially my mother, and my friends for being there when I needed you.

In memory of my father, Baden Watkins (1929 – 1998)

GLOSSARY

A number of terms are used interchangeably in this document to describe people with experience of mental illness. Among people with experience of mental illness there is no consensus on a preferred term. Here are some which are used in this study: consumer, service user, tangata whaiora (a Maori term which translates as “people seeking well-being”), people living with mental illness, people experiencing mental illness, client and patient.

A.C.C.	Accident Compensation Corporation of New Zealand
Aotearoa New Zealand	Bicultural term for New Zealand
Aroha	Love
CAMHS	Child & Adolescent Mental Health Services
COPMI/COPMIA	Children of Parents with Mental Illness/Children of Parents with Mental Illness & Addiction.
CYFS	Child, Youth & Family Service
D.E.S.N.O.S.	Disorder of extreme stress not otherwise specified
Hapu	Sub tribe
Hauora	Health
Hinengaro	Mind
Hui	Meeting
Iwi	Tribe, people
Kai	Food
Kaiwhakahaere	Manager, leader
Karakia	Prayer
Karanga	Call
Kaumatua/kuia	Elders
Kaupapa	Policy
Kaupapa Maori	Policy/procedure from Maori perspective/Maori philosophy
Kawa	Protocols, process
Koha	Gift

Mana	Authority, power, respect
Mauri Ora	Essence of life
Marae	The meeting place of the whanau/hapu, where decision-making and other family and community events occur
Matauranga Maori	Traditional knowledge
Mental Health Services	Organisations whose primary function is the provision of care, treatment, support and education for recovery to people with mental illness or mental health problems.
Mood disorder	Includes illnesses where there is a major disturbance in feeling states. Such feeling states can include, despair, depression, elation or anxiety. Often these feeling states are accompanied by an over or under-abundance of energy. Major depressive disorder and bipolar affective disorder are examples of mood disorders. Anxiety states can also be present alongside the conditions detailed above or be disabling conditions in their own right.
NGO	Non-government organisation.
Pakeha	New Zealand people of European ethnicity.
PTSD	Post traumatic stress disorder
Rangitiratanga	Authority of, control (of)
Tangata Whenua	The indigenous people of Aotearoa
Tapu/Noa	Sacred, prohibited
Te Reo	The Maori language
Te Tiriti (O Waitangi)	The founding document of Aotearoa/New Zealand that defines the terms of relationships between Iwi Maori and the Crown
The Treaty of Waitangi	
Tikanga	Correct procedure, method, practice
Tinana	Body
Tino Rangitiratanga	Self determination

Treatment	Specific physical or psychological assistance provided by a health professional to reduce (mental) illness and assist recovery.
Waiata	Song, traditional chant
Wai	Water
Whaikorero	Speech
Whakatuia	Integration
Whanau	(extended) family
Whanaungatanga	the process of establishing and maintaining connection between people
Whare	house, specifically at times, the wharenuī (meeting house on the marae)
Wairua	spirit
WINZ	Work & Income New Zealand

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CHAPTER 1 INTRODUCTION

I think the key factor in surviving mental illness for me has been the fact that I am a mother.

When you are classed as having mental health (issues) and you are a mother, it makes it all the more daunting to be a mum.

Raising children under the most favourable of circumstances can be a stressful occupation; however, parents living with mental illness face unique challenges arising from a combination of managing their illness, stigma and discrimination which can affect their capacity to effectively respond to their children's needs. It is speculated that large numbers of children now live in homes where there is a parent who experiences mental illness but the exact numbers are unknown.

Women with an existing mental illness are now as likely to become a mother as any other women and for all women, pregnancy and childbirth can be a risk factor in the development of a mental illness. Not only are mental health organizations unaware of the extent of the issue but, apart from the development of Maternal Mental Health services, they have been slow to consider the needs of mothers living with mental illness within the context of their family circumstances.

Women's mental health issues have the capacity to affect each and every family member, especially children, because of women's roles as mothers, often at the centre of the family grouping. Women experience a greater burden of mental health issues with significantly higher rates of most common mental health issues such as depression and anxiety. They are more likely to present to and receive care from mental health services. Therefore, responding to women's mental health needs is one way to potentially reduce mental illness in the population as a whole, particularly in terms of the future incidence of mental health issues.

Research into the circumstances of mothers living with mental illness has been increasing across the world but there are few in-depth accounts based on the experiences of New Zealand women. A desire to contribute the New Zealand perspective to the evidence base was the stimulus to undertake the research. In addition, the research is the logical extension to years spent in the Maternal Mental

Health field as a social worker and working alongside consumers to develop peer support and advocacy services.

This led to a realisation that the lived experience of mothers was missing from current service delivery. Influenced by a foundation in recovery approaches and consumer-run initiatives, the intention was to ground the study in the real experiences of women, articulated in their own words and to gather their suggestions for improvements in services, building on what has worked for them and what could change.

This study is occurring in the context of increased interest and research into parenting and family resilience – the factors which characterise healthy or resilient families. The concept of family resilience has its roots in the strengths perspective, an approach which has also become an important influence in the mental health arena. Parents living with mental illness have often been cast as inadequate parents and their children as 'at risk' of developing a mental illness or psychosocial problems. In addition, the care giving role of children (also referred to as 'parentification') has been highlighted as a risk factor. Being identified as 'at risk' is a label which can have long-term consequences for children living in families with mental illness. Devlin & O'Brien describe this as a "perpetual cycle of dysfunction and disadvantage" (1999, p. 26), which, they believe, builds an intergenerational need for mental health and welfare services.

The research question will seek to discover how well the experiences of eight mothers living with mental illness concur with the perceived picture of parenting in the context of mental illness. In keeping with recovery models which are "grounded in the belief that people who have reflected critically on their own experience of mental illness are able to promote the recovery of their peers" (Mental Health Commission, 2007, p. 127), the participants will be asked to reflect on their own experiences to suggest how services might work effectively for parents living with mental illness. Recovery, strengths-based and Kaupapa Maori research philosophies will also influence the structure of the research as the process is as important as the data outcomes. The research will be based on the development of whakawhanaungatanga – respectful research relationships – and the concept of reciprocity.

Stigma and discrimination are further environmental factors informing this study. New Zealand is now considered a world leader with the *Like Minds, Like Mine* anti-discrimination campaign. However, the effect of stigma and discrimination on the lives of parents living with mental illness and their children has been well documented. Recently, a subset of stigma called "self stigma", has achieved recognition. This is a form of stigma in which people with experience of mental illness incorporate society's negative views of those experiencing mental illness into their own worldview, thus negatively influencing their self-esteem and confidence. Mental illness and motherhood is not a combination which has been viewed positively and this has led to a reluctance to seek help until a crisis point is reached.

This research is underpinned by an ecological perspective meaning that experiences of mothers living with mental illness are best considered within the current mental health context. The literature review consists of three chapters which together set the scene for the consideration of the views and experiences of mothers living with mental illness interviewed for this study.

The structure of the thesis is as follows:

Chapter Two addresses the question of why the experiences of mothers living with mental illness are being explored at this point in time by taking a brief historical journey from institutionalisation through to community care for mental illness. Current directions within the Aotearoa/New Zealand mental health environment such as recovery and strengths-based models, alongside Maori concepts of health will be examined as they have been central influences on both the lives of the participants but also on the process of the research.

Chapter Three takes a closer look at women's mental health, in particular the relationship between women's health and their social worlds. The importance of gender and the effects of violence and abuse have been identified as major determinants of women's mental health. A connection has been made between maternal mental illness, attachment difficulties and children's mental health so this theory will be critically investigated. Finally, varying views of modern day childhood will be described and the rationale for the development of specific services to meet the support needs of children in families where there is mental illness will be considered.

Chapter Four examines what is known about the views and experiences of mothers living with mental illness through a review of both international and New Zealand literature. Studies were targeted which focus on the firsthand experiences of mothers living with mental illness. Research which included women's views as part of considering other issues such as service design is also considered. The themes identified from this literature review provided the basis for the comparative analysis of the data collected.

Chapter Five outlines the methodology utilised in this study. A qualitative study was undertaken which sought to explore the views and experiences of a small group of New Zealand mothers living with mental illness. Participatory action research influenced by feminist and Kaupapa Maori research models led the researcher to emphasize the building of respectful research partnership relationships with the participants and make use of a consumer advisor in recruitment, the provision of information and support.

Chapter Six presents the findings of the interviews undertaken with eight mothers based around four questions asking about the effect of mental illness on motherhood, things that have worked and suggestions for service improvement. The voices of the mothers who participated are at the heart of this chapter.

Chapter Seven discusses and analyses the findings in the light of the literature review undertaken in Chapter Four, developing principles out of the discussion points.

Chapter Eight concludes the study with five recommendations arising from the principles developed in Chapter Seven.

CHAPTER 2 "THE BIGGER PICTURE" FROM ASYLUMS TO RECOVERY

Recovery is not a gift from doctors but the responsibility of us all. We must become confident in our own abilities to change our lives; we must give up being reliant on others doing everything for us.

Coleman, 1999, cited in Roberts & Wolfson, 2004. p. 41.

2.1 Introduction

A major paradigm shift in mental health policy and practice is occurring across the developed world (Lapsley, Nikora, & Black, 2002). It is changing the orientation of services from illness and chronicity towards recovery, informed by the direct experience of mental health consumers. The implications of this major paradigm shift are reflected throughout this research. An essential feature of recovery is its focus on the subjective experience of each consumer (Curtis, 1997) and it is the desire to hear the stories of mothers who experience mental illness, which forms the basis of this research.

The interaction between people and their environment, which provides the foundation of an ecological perspective, is a central feature because it allows for a consideration of the complexities of any situation (Bronfenbrenner, 1979). Applying an ecological focus to the current research question suggests that the experiences of mothers living with mental illness are best comprehended within the context of an historical understanding of the current mental health environment, especially the development of the most relevant models.

As this is a study based in Aotearoa/New Zealand, it is necessary and indeed, imperative, to further contextualise the research through a brief exploration of Maori health perspectives. The application of these models is underpinned by Te Tiriti O Waitangi, the founding document of Aotearoa/New Zealand whose principles must be incorporated into all aspects of health services provision, particularly for Tangata Whenua (Mental Health Commission, 1998). Furthermore, the emergence of Maori health perspectives in the early 1980's struck a chord with a wide cross-section of New Zealanders who had been worried by the increasing medicalisation of every-day life (Dyall, 1997).

Accordingly, this chapter will briefly describe the reason for the present focus on this particular group of mental health consumers, a condensed history of psychiatric provision in New Zealand and the consequent dominance of the medical model in psychiatry. Deinstitutionalisation and simultaneously, the growth of alternative models such as recovery, the strengths-based approach, the bio-psychosocial framework and the stress-vulnerability model will then be outlined. All of these models have a common recognition of the complexity and individuality of each experience of mental illness and the importance of the context in which it occurs.

2.2 Motherhood and Mental Illness

By becoming a parent, one can travel from outcast to a valued and honoured status.

Apfel & Handel, 1993, p. 10

Various studies in the United States of America, Britain and Australia suggest that at least 20% and perhaps up to 50% of adults known to mental health services have children (Falkov, 1998). It is estimated, internationally, that over half of women with experience of mental illness have children and that, at any time, around 10-20% of them will be parenting dependent children in their homes and that they are the primary parent in approximately one third of families (Blanch, Nicholson, & Purcell, 1994; Brunette & Dean, 2002; Hearle, Plant, Jenner, Barkla, & McGrath, 1999; Joseph, Joshi, Lewin, & Abrams, 1999; Mental Health Commission/KITES, 2005; White, Nicholson, Fisher, & Geller, 1995).

This was not always the case as the experience of parenting alongside mental illness has occurred in tandem with the historical developments of the last three decades. Deinstitutionalisation has led directly to the development of interest in mothers with experiences of mental illness, because it shifted the focus of mental health treatment from institutions to the community (Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001). In the psychiatric institutions of the past, any evidence of sexuality in those resident was denied, ignored or quietly managed, with any resulting children fostered or adopted (Apfel & Handel, 1993; Sands, 1995); Mental illness following childbirth usually resulted in the mother being hospitalised, often permanently.

Now that the majority of people who experience mental illness live in the community, they also have the opportunity to undertake all of the normal roles of adulthood, chief amongst these roles are close relationships and bearing children (Mowbray et al, 2001).

2.3 Asylums, The Medical Model And Chronicity

Linking mental illness (or madness or lunacy) with unreason, excess, incapacity and unreliability are historically entrenched attitudes in Western societies.

Lapsley *et al*, 2002, p. 4.

The asylum/psychiatric hospital is a relatively recent invention, evolving in Europe and Great Britain in the seventeenth century from institutions created to accommodate and contain the poor, the homeless, the unemployed and included among them, the insane (Rosehan & Seligman, 1992). The insane generally received more physically brutal care than other inmates, even though there was no legal sanction for this behaviour. By the end of the eighteenth century, reforms occurred which would have an influence on treatment approaches two centuries later. First amongst these was the establishment of the Retreat at York, set up in 1796 by the Yorkshire Society of Friends. The founding treatment principles of the Retreat were the need for esteem (through the acquisition of social skills and socialisation) and the value of physical work (*ibid*, p. 14).

In contrast to the more negative way in which they were later viewed, asylums in the nineteenth century were initially conceived to replace the chaos of urban life with its unhealthy conditions with new therapeutic environments sited in less stressful rural settings (Rothman, 1971). During the 1880's in New Zealand, rural asylums were also constructed in response to the poor conditions and cruel treatment in the 'pauper lunatic asylums' which had developed in the early days of the colony (Brunton, 1996). These establishments were run by attendants with an emphasis on "moral treatment", defined as good food, cleanliness, light employment, exercise and recreation (Bridgman, 1990).

Throughout the nineteenth century, institutional treatment of those suffering insanity became increasingly dominated by medical thinking and control moved from the custodians to medical personnel. Study into insanity increased and this culminated in the development by Emil Kraepelin (1856-1926) of the first systematic classification of mental diseases by causes and symptoms. An assumption of the chronicity of psychiatric disorders was integral to Kraepelin's definition of schizophrenia (Carpenter, 2002) and became a mainstay of the medical model within mental health. Schizophrenia was described in the first *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (American Psychiatric Association (APA), 1952) as being a disease of ongoing deterioration (Kruger, 2000) with the fourth edition (American Psychiatric Association (APA), 1994) still counselling that remission was rare.

The medical model was governed by the view that psychiatric disabilities were organic, biological diseases (Chamberlin, 1998) with an almost near-exclusive reliance on treatment through medical interventions. This model has been described as focused on assessing, diagnosing and treating what is wrong with the individual (Rapp & Goscha, 2006) with a strong focus on the illness rather than the person to the extent that Deegan, (1996) believes that through this process, people can be defined, limited and may be ultimately dehumanised by their experience of mental illness.

Rehabilitation psychiatrists, Roberts & Wolfson (2004, p. 5) counter that it is the largely non-medical literature which describes the medical model as solely focused on disease, treatment and biological reductionism, supported by evidence-based medicine, with psychiatrists depicted as "risk averse and hooked on a prescribing, relapse-prevention and maintenance model of care, which fosters dependence." However, the experience of consumers reported in "*Kia Mauri Tau!*" *Narratives of Recovery from Disabling Mental Health problems* (Lapsley *et al*, 2002) confirm the enduring hold of the medical model into the 21st century. Consumers interviewed spoke of "not being treated as an individual, not being listened to. ...and being given medically oriented treatments, which seemed to make ward management easier but did not address the mental health problems" (ibid, p. 36).

Critiques of the medical model by service users and carers/family members have ended up by focusing less on the rights and wrongs of the model and its philosophical underpinnings and more on its practical irrelevance to consumers' lives. A consumer articulates this view "I am against the medical model not so much because it is true or false, but because it is so pessimistic and not very practical. It doesn't help people" (O'Hagan, 1991).

2.4 Deinstitutionalization and the Rise of Recovery

Being ecological, recovery is also organic – fleshed out by each person who experiences it and gives it his or her own interpretation.

Onken, Craig, Ridgway, Ralph, & Cook, 2007, p. 18.

Deinstitutionalisation began in Europe after World War II, spread to the United States in the 1950's and continued for three decades across the developed world. The Report of the Commission of Inquiry, *Psychiatric Services at Oakley Hospital* (1971) into conditions at Oakley Hospital, Auckland was seen as the founding document of deinstitutionalisation in New Zealand. It instigated the closure of Oakley hospital and contributed to the Mason report (1988). Deinstitutionalisation was driven as much by economics as by psychiatric philosophy because the new treatment modality that was created – community mental health – was largely considered a more cost-efficient way to deliver services than institutional care (Gibbs, Fraser & Scott, 1988).

Deinstitutionalisation and community mental health care were further assisted by firstly, the development of antipsychotic and antidepressant medications, which encouraged a sense of optimism about patient functioning (Mowbray & Holter, 2002). Secondly, the practice of psychiatric rehabilitation was developing, influenced by concepts borrowed from physical rehabilitation, such as the recognition of the value of community resources and the role of work (Curtis, 1997). In addition, psychiatric rehabilitation demonstrated that functional ability does not depend just on the illness and its symptoms but is a product of the individual and their interaction with their environment.

Deinstitutionalisation, combined with the civil rights movement, the independent living movement of physically disabled people and the self-help approach in health, to create a climate in the 1960's/70's out of which developed a new model which emphasized greater participation in and control of the helping process (Tower, 1994). Of particular relevance to every aspect of this study is the influence of feminist perspectives also developing during this period. Definitions of normal and abnormal began to be viewed within a context of a society whose structures of gender, culture, class, race and sexuality served to simultaneously oppress but also provide sources of resilience (Ballou & Brown, 2002). Feminists privileged the experiences of women, as reported by women themselves.

Underpinning this new model was a philosophy that individuals with direct experience of a particular life condition would be more knowledgeable about their own needs and interests than the professionals treating them (Tower, 1994). The redefining of the role of patient to one of a consumer was seen as increasing the individual's sense of control over his or her own life and for the first time, to challenge the professional dominance of the medical model within health.

Emerging consumer narratives in the 1980's (Anonymous, 1989; Chamberlin, 1978; 1988; Leete, 1989) began to speak of personal journeys, of meaning ascribed to the experience of mental illness and of ways to live well with or without the symptoms of mental illness. Lastly, the work undertaken by Harding *et al* (1986a; 1986b; Harding, 1994) began to challenge the official belief that a deteriorating course for severe mental illness was the norm. Anthony (2000) believes that it was their ongoing analysis of long-term outcome studies which supplied the empirical basis for the recovery vision.

The term 'recovery' was borrowed from addiction self-help language (i.e. being 'in recovery' from alcoholism) meaning an acknowledgment of the presence of illness even when not directly suffering the effects of the illness (Davidson, Lawless, & Leary, 2005). The term 'recovery' has various meanings within this context and is often called an approach, model, philosophy, paradigm and movement (Roberts & Wolfson, 2004) indicating the far-reaching infiltration of recovery at all levels within mental health from the macro of a social movement to the micro of a practice model.

Whilst hailed by many as a new approach, Roberts & Wolfson (ibid, p. 2) view recovery as directly descending from the philosophy and practice of the early nineteenth century Tukes of York, in England, which was based on kindness, compassion and hope of recovery.

The most fundamental message of the recovery paradigm, in stark contrast to the articulated chronicity of the medical model of mental health, is that people with mental illness can, and do recover (Carpenter, 2002). The essential elements of recovery are defined as hope, personal responsibility, self-advocacy, education, support and personal meaning (Wells, 1999). Recovery as a concept has been articulated in all of the strategic documents that have guided the development of the New Zealand mental health sector since this definition in the Blueprint for Mental Health Services in New Zealand (1998, p. 1): "Recovery is happening when people can live well *in the presence or absence of mental illness*, and the many losses that come in its wake, such as isolation, poverty, unemployment and discrimination". In 2001, the New Zealand Mental Health Commission published 'Recovery Competencies for New Zealand Mental Health Workers' which signalled a fundamental change to all aspects of the education of mental health workers by broadly defining recovery-based competencies for mental health workers and service users.

Over the last five to ten years, concepts of recovery have increased in status to become the overarching goal of mental health services around the world (Davidson *et al*, 2005). Initially, recovery was defined more narrowly as the remission of symptoms and the restoration of functioning but more recently, and more significantly in terms of this research methodology, it has come to signify a more personal, subjective perspective on living a life worth living in the presence of ongoing mental illness (ibid, p. 65). Such personal accounts have become the founding stories of the movement and have been utilised by governments in the United Kingdom and New Zealand to fight against stigma (Roberts & Wolfson, 2004) and to emphasize the worth of the personal perspective (Lapsley *et al*, 2002; Leibrich, 1999; Ramsay, Page, Goodman, & et al, 2002).

One of the central processes through which recovery is realised, is via the sharing of stories and the development of nurturing, supportive relationships especially those between consumers (Peer Respite brochure, undated). Out of this has arisen the development of "by consumer/for consumer" services which encourage the development of reciprocity and mutuality between peer support workers (themselves, consumers) and consumers. Such mutual relationships eliminate the traditional sense of 'being a patient who requires fixing'. The growth of these services, which form a major characteristic of the consumer movement, is seen as one of the ultimate manifestations of the recovery approach. Similarly, "by Maori, for Maori" services were the first manifestation of services which today are referred to as Kaupapa Maori. This cultural parallel takes control of the process of determining the content and delivery of health and mental health services.

The second means through which recovery approaches are being utilised on a regular basis across the western world is via the rich body of knowledge, developed through the daily experiences of consumers, on strategies to cope with the symptoms of mental illness (Curtis, 1997). Deegan (1995) developed *"Coping with Voices: Self Help Strategies for People who hear Voices that are Distressing"*. Similarly, networks for Dutch voice-hearers were initially established by social psychiatrist, Marius Romme and Sandra Escher. These groups encourage people to accept their voices as part of the normal range of human experience and to avoid mental health services wherever possible (Bentall, 2003). Similar groups now exist in the United Kingdom, New Zealand and Australia.

American consumer, Mary-Ellen Copeland has been particularly prolific in developing self-help workbooks and trains consumers around the world in the use of her Wellness Recovery Action Plan (WRAP), an individualised plan of both wellness/lifestyle planning and crisis prevention/planning/advance directives (Copeland, 1992, 1994, 1997). The Mental Health Commission in New Zealand formally endorsed the use of advance directives in 2003. An advance directive is a statement to others, usually in writing, setting out treatment preferences to be used if a person experiences a further episode of mental illness that leaves them unable to communicate preferences at the time (Mental Health Commission, 2003).

There are many parallels between recovery models and strengths-based approaches and these will be considered next.

2.5 Strengths Model in Mental Health

Implementing the strengths model elevates the consumer from a passive recipient of services to the director of the process.

Sullivan cited in Rapp & Goscha, 2006, p. xxv

Both the recovery movement and the strengths model are an integral part of the larger paradigm shift in mental health because both have moved the locus of control from professionals to clients. Case management for the chronically mentally ill became the focus of attention for community support services in response to deinstitutionalisation in the United States, with various states exploring case management systems. Charles Rapp and Ronna Chamberlain of the University of Kansas Social Work School took on the challenge of constructing an approach, which centralised a focus on individual, family and community strengths (Rapp & Goscha, 2006). Carpenter (2002) believes that social work's most significant contribution to mental health services has been the use of the strengths perspective in the development of case management models for people living with mental illness.

The strengths model was developed in response to other case management approaches which seemed to emphasize the deficits, pathology and impairments associated with psychiatric disorder rather than considering the personal resources and abilities that a person could use to achieve personal goals (Curtis, 1997). The six basic principles on which the strengths model is based are a focus on individual strengths; the community as the site of resources; consumer self-determination guiding the helping process; the relationship between the consumer and the case manager being essential and based on collaboration; community integration being fostered by intensive outreach and people with severe mental illness possessing the inherent capacity to learn and grow (Rapp, 1998). A point of difference with other case management approaches is that the strengths model puts emphasis on the gradual disengagement of the client and the replacement of professional help with resources sourced from the client's community (Curtis, 1997).

Research carried out to test the effectiveness of the strengths model has found that hospitalisation and the use of crisis services have decreased. In addition, those receiving strengths model case management services reported fewer problems with mood, thinking and experienced greater psychological well-being (Ryan, Sherman & Judd, 1994; Macias et al, 1994, cited in Rapp & Goscha, 2006). South Canterbury Mental Health Services in New Zealand have been utilising a Strengths Model in their practice since 2001. They have combined the Strengths Model with Knowing the People Planning (K.P.P.), a means of planning to meet specific needs of people in mental health services and believe this combined approach has brought benefit to their service users (Mental Health Commission, 2007).

A component of the strengths model, with special relevance to New Zealand and this study, is the acknowledgement of the importance of culture and society as contributing factors to mental health and wellbeing (Ministry of Health, 2001). A strengths-based approach to mental health promotion emphasizes the presence or absence of components such as housing, socio-economic status and employment as being highly influential to both positive and poor mental health. A community can have enabling or entrapping niches and support for enabling environmental conditions is a key component in terms of building community strengths (Rapp & Goscha, 2006).

The idea that an entire community might be viewed as an oasis of potential resources for consumers (Kisthardt & Rapp, 1992) has resonance with Engel's biopsychosocial model of health applied to mental health, and this will now be explored.

2.6 The Bio-Psychosocial Approach To Mental Health

George Engel believed that to understand and respond adequately to patients' suffering – and to give them a sense of being understood – clinicians must attend simultaneously to the biological, psychological and social dimensions of illness.

Borrell-Carrio, Suchman, & Epstein, 2004, p. 576.

The modern view that several factors combine to produce an illness (whether physical or psychiatric) had its basis in the 1977 seminal work of George Engel (along with colleagues, Adolf Meyer in the USA with Aubrey Lewis and Anthony Clare at the Institute of Psychiatry in London) in which he articulated a bio-psychosocial framework (BPS) for understanding health and disease. The BPS model became established in the 1970's as part of the psychiatric orthodoxy (Pilgrim, 2002), was supported by psychiatric social workers and clinical psychologists (Falloon & Fadden, 1993) but has recently become somewhat overshadowed by the increased prominence of recovery approaches combined with the growing legitimisation of the experiences of the mental health service users.

Engel's purpose was to take the broadest possible view and to assert that the prevailing 'reductionist' view of merely considering biological factors was not sufficient to explain health and illness. Engel argued that a framework which was fully scientific and also inclusive needed to be based on systems theory in which mental illness is seen as emerging within individuals who are part of a whole system (Engel, 1980). The system consists of physical elements, which on a sub-personal level are made up of the nervous system and organs/cells. The supra-personal level sees the individual existing in a psychosocial context of increasing complexity from the couple through family, community, and culture to society (ibid, p.2).

Biopsychosocial factors are involved in the causes, manifestation, course and outcome of mental illness. Social factors can modify the expression and outcomes of any disorder. For example, post-traumatic stress disorder (PTSD) is clearly caused by exposure to an extremely stressful event, e.g. rape or war, but the likelihood of the development of PTSD is influenced by pre-trauma vulnerability, the magnitude of the stressful event and the quality of the care received after the event (Yehuda, 1998). The relative importance of biological, psychological and social factors varies across individuals and across different ages in the lifespan (Surgeon General, 2006).

A consideration of the Biopsychosocial model is relevant to the present research as it not only provides us with an explanation for the complexity of the situations of mothers living with mental illness but also points us in the direction of potential areas of remedy. An understanding that the interaction of both biological and environmental factors is important in the development of mental health conditions lies at the heart of the next model to be described – known as either the stress-diathesis model or latterly, the stress-vulnerability/protective factors model.

2.7 The Stress-Diathesis Model

Individually, vulnerability and stress are important concepts but their real power lies in their interaction.

Ingram & Luxton, 2005, p. 43.

Zubin & Spring (1977) first introduced the stress diathesis (also known as the stress vulnerability) model as a means to explain some of the causes of schizophrenia. Their model grew out of the work of George Brown in exploring the stressors within the families of those living with mental illness in the 1970's. The model was later utilised to inform the design of comprehensive, integrated, community-based mental health care which emphasized early intervention and work with families by Falloon & Fadden (1993).

The model suggests that people become ill when stress is too much to cope with and that a person's ability to deal with stress (their vulnerability) varies. Extreme stress can lead to psychotic experiences in almost anyone. However, in relation to the development of mental disorders, and schizophrenia in particular, Zubin & Spring postulate that a person may have a predisposition to develop schizophrenia, which, when triggered by a stressful life event, will cause an acute episode.

Vulnerability refers to the factors that predispose an individual to develop a particular syndrome at any given time (Falloon & Fadden, 1993). Genetic predisposition is one vulnerability which is linked with biochemical abnormalities. A biological vulnerability relevant to this study is the female menstrual cycle as it is associated with the re-emergence of symptoms of mental illness (ibid, p.188). A pre-existing brain dysfunction (such as epilepsy or a birth injury) is another factor that enhances vulnerability to major mental illness. Recent work integrating the biological and psychosocial aspects of depression postulates that vulnerability to depression has both a biological and psychological basis (Schotte, Van den Bossche, de Doncker, Claes & Cosyns, 2006).

Stress in this context is defined as being an individual's response to threat with the following components, psychological (emotional response), physiological (autonomic arousal, hormonal and biochemical responses) and behavioural (escape and/or avoidance responses) (Falloon, Laporta, Fadden, & Graham-Hole, 1993).

There are two types of relevant stressors. Firstly, ambient stress – stress that is experienced when dealing with daily issues of life in the community. Important sources of ambient stress are the stresses surrounding homemaking, childcare, interpersonal relationships (these first three sources of stress are extremely pertinent when considering the situation of mothers who live with mental illness) and unemployment. Persistent high levels of ambient stress in an environment have predicted the development of depressive disorders (Falloon *et al*, 1993).

The second type of stress is that associated with life events. Whilst this is a more discrete stressor such as the loss of a job, birth, death or a relationship break-up, life events that develop into long-term ambient stress are associated with (again) major depressive disorders (Brown & Harris, 1978; Schotte *et al*, 2006), schizophrenia and mania (Ambelas, 1987; Brown & Birley, 1968 cited in Falloon & Fadden, 1993). Women also experience the well being of their family members as a major source of concern with stressful life events experienced by significant others being a source of more distress in women than in men (Rosenfield, 2000).

A person's response to stress is determined by many factors – biogenetic factors influence the physiological responses with psychological factors (personality, conditioning from past experiences, coping skills and being prepared for an expected occurrence) combining to make the individual's particular actions in response to a specific stress (Falloon & Fadden, 1993).

The reformulation of the model into the Stress Vulnerability Protective Factors model has encouraged research into strategies to lessen stress. These include rigorous, individualised psychopharmacology, skill building and of relevance to this present study, the development of support services for both individuals and their families (Lieberman et al., 1993; Lieberman et al., 1998).

Caregivers can also become stressed and be vulnerable to an episode of mental illness especially in the case of a couple where both partners suffer mental illness. Therefore, the model needs to encompass both the nominated client and his/her caregivers. Studies have shown that the risk of recurrence is most likely when a person spends time with people who cause them interpersonal stress. If time is spent with supportive persons or the person experiences increased interpersonal support then the risk of recurrence is lessened (Beck, Rush, Shaw, & Emery, 1979; Leff & Vaughan, 1980). Falloon & Fadden (1993) postulated that repeated episodes of mental illness could be minimised by integrating biological and psychosocial strategies within the vulnerability-stress model.

Having detailed three approaches which all recognise the inter-related and complex nature of influences on mental wellbeing and the development of illness, it is fitting to complete this chapter with a consideration of how Maori view health, much of it based on a re-working of traditional practice.

2.8 Tirohanga Maori: Maori Health Perspectives

For Maori to be healthy, people need a sense of identity, self-esteem, control over their own destiny, a voice that is heard, knowledge of te reo Maori and tikanga, and economic and whanau security.

Dyall, 1997, p. 91.

An understanding of the traditional underpinnings of Maori health is relevant to this study as such explanations for illness continue to have meaning for Maori and have implications for the management of Maori patients (Durie, 1994). In addition, the research involved Maori participants.

Traditional healing practices, used by Maori prior to the arrival of European pioneers and settlers, were based on matoranga Maori (traditional knowledge) encompassing the twin concepts of tapu and noa and generally, on re-establishing a balance between the two (Durie, 1994). These concepts are still fundamental to being Maori and underpin tikanga (practices) and the activities of everyday life. Tapu is connected to sacredness and is concerned with conferring mana (respect) to certain people, objects, events, places or parts of the body and recognising that all objects have their mauri (life force). Noa is concerned with removing restrictions or associated protective mechanisms (Dyall, 1997).

Protocols used to respect tapu and noa change according to the situation. Usually, karakia (prayer), whaikorero (speech), waiata (song), karanga (call), wai (water), and kai (food) will be utilised. If Maori feel unwell, this could be interpreted as being the breach of certain cultural protocols (mate Maori). A traditional diagnostic process was often concerned with establishing the possible presence of such a breach (Durie, 1994).

The effects of colonisation produced a steady decline in Maori standards of health throughout the nineteenth century. However, progress was made during the twentieth century, especially through the efforts of inspirational Maori kaumatua and kuia (elders), until in the 1970's, a view of health re-emerged that made sense to Maori in Maori terms. A number of Maori health perspectives were developed, through a series of hui (meetings) in the mid to late 1980's, all of which emphasized the value of traditional beliefs systems to understanding Maori health and the importance to Maori health of the wider context of Maori development (Durie, 1994).

The Te Whare Tapa Wha model, which depicts health as a house with four walls, each representing a different dimension and all four necessary to maintain strength (Durie, 1994), is now seen by many as the defining Maori health perspective (Ellis & Collings, 1997; van Meijl, 1993). It is often described as a traditional Maori approach but is more correctly considered by its creator to be: "A view of health, which accorded with contemporary Maori thinking" (Durie, 1994, p. 70). It also reflects an holistic view of health, influenced by social and cultural factors, which is articulated in this World Health Organisation (WHO) definition: "Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity" (World Health Organisation, 1947, p. 12).

However, unlike most non-Maori models of health, Te Whare Tapa Wha is firmly anchored to a spiritual rather than a physical base. A recent study (Marie, Forsyth, & Miles, 2004) which explored the evidence that Maori usually attribute ill-health to deficits in spirituality concluded that Te Whare Tapa Wha presents a strong metaphor for how Maori *ought* to think about health phenomena rather than current reality.

Nevertheless, Te Whare Tapa Wha was endorsed as being a broad view of health for Maori at the Hui Whakaoranga in 1984. The idea that there are different Maori and non-Maori health perspectives is now enshrined in many policy documents (Ministry of Health, 2000, 2001a, 2002a) and Te Whare Tapa Wha has congruence with the other models (e.g. biopsychosocial and recovery perspectives) which provide the context for this study and as such, is worthy of exploration.

Te Whare Tapa Wha consists of firstly, *taha wairua*, considered to be the most crucial requirement for health. An individual cannot be healthy unless he/she has a spiritual awareness and *mauri*. Belief in God is a reflection of *wairua* but *wairua* is also present in the relationship with the environment as lakes, rivers, mountains and rivers all have spiritual significance and are celebrated in *waiata* (song) and *whaikorero* (speeches). Furthermore, the natural environment is seen to be pivotal to strong identity and basic to a sense of well being (Durie, 1979).

Secondly, taha hinengaro is seen as the expression of thoughts and feelings, which compares with the area now traversed by western psychology and psychotherapy. However, healthy thinking is thinking which looks outside of the individual for answers as ill-health is usually seen as a manifestation of a breakdown in harmony between the individual and his/her wider environment. Communication of this breakdown can be through emotions and non-verbal communication rather than solely through the use of words (Durie, 1994).

The third wall is taha tinana which equates to physical health. The concepts of tapu and noa are relevant here with particular parts of the body seen as tapu and activities such as the preparation of food and cleaning/toileting being kept very separate for the same reason. Lastly, taha whanau speaks to the relevance of the extended family to health, in supplying the physical, emotional and cultural nurturing and care. It is often thought that ill health in an individual is a reflection on the family. Taha whanau strengthens identity, itself a component of health. The underlying theme of Te Whare Tapa Wha is whakatuia (integration) with individual health being affected by systemic influences such as culture, economics, social standing as well as the ongoing effects of colonisation.

The Hui Whakaoranga (1984) saw the presentation of Te Wheke, in which the eight tentacles of the octopus signify the components needed for wellbeing (Pere, 1984). To the four walls of Te Whare Tapa Wha (wairuatanga, hinengaro, taha tinana and whanaungatanga) is added whatumanawa (emotions), mauri (life-sustaining principles which are present in te reo), mana ake (the uniqueness of individuals and a positive identity based on those unique qualities) and ha a koro a kui ma (good health linked to a positive awareness of ancestors and their role in shaping the family) (Dyall, 1997).

Two further models, Nga Pou Mana and one developed at the Te Ara Ahu Whakamua hui (Te Puni Kokiri, 1994b) further extended Maori perspectives of health to include the right to be healthy through relevant social and economic policies. Such policies need to recognise the importance of whanaungatanga, taonga tuku iho (cultural heritage), te ao turoa (the physical environment) and turangawaewae (the source of identity) (Dyall, 1997).

2.9 Conclusion

A historical perspective has been utilised to explain the climate in which many of the models influential to this research have developed. Maori health perspectives contain similar themes to the previously articulated models, in that they seek to broaden our understandings of health and to explain health in ways that are culturally significant and which balance physical and biological approaches with cultural and sociological beliefs (Dyall, 1997). Tirohanga Maori mirror and parallel the ecological nature of Engel's biopsychosocial model; the interrelated nature of stress, vulnerability and mental illness in the stress-diathesis model; the strengths perspective which speaks of the enabling nature of the family and community and the new cultural perspective that reflects the recovery culture of the tangata whai ora.

The following chapter now looks at the context of women's mental health, reflecting first on the changes in the construction of women's mental health throughout the ages, introduces the concept of gender and then specifically considers an area of increasing relevance to women's mental health, that of the influence of trauma.

CHAPTER 3 WOMEN'S MENTAL HEALTH: GENDER TO MOTHERHOOD

Once the individuality of persons with mental illness is acknowledged, gender identity can no longer be ignored.

Apfel & Handel, 1993, p. xxv.

3.1 Introduction

The development of feminist perspectives from the 1960's onwards arose from a concern about the marginalisation of women and a neglect of their experiences within mainstream society. Feminist theories also highlighted the issue of gender. Gender plays a major part in influencing mental health and these influences will be explored, firstly within their historical context and then by looking at the specifics of its influence on women's mental health. The influence of trauma on the development of mental health problems in women in particular will be considered. This is a topic which has been controversial but is now entering the psychiatric mainstream as both biological and psychological research confirms trauma as a contributing factor to the development of mental illness and mental health problems.

The second section of this chapter will focus on motherhood – its present-day construction predominately influenced by Attachment Theory – and childhood with an emphasis on the child whose parent/s experience mental illness.

3.2 The Historical Lens

Psychiatric history reflects the thoughts and views of philosophers, clerics, and clinicians, predominantly male. The dominant paradigm is male.

Kulkarni, 2006, p. 191.

Each historical epoch has produced a model of women's mental health that is strongly gender influenced and connected to the prevailing beliefs and cultural norms around the role of women in that particular society. Since Greek times, the character, form and aetiology of women's emotional distress have been of concern to, mostly, male scientists and religious figures.

The first and most enduring explanation for female distress was linked to female reproductive functions (Astbury, 2006).

In the latter half of the nineteenth century, Europe's male psychiatric establishment described what became known as the archetypal female malady. Hysteria was named after the Greek word for uterus and most female psychological problems were believed to be caused by a wandering womb and treated accordingly by male physicians. Astbury (2006, p. 378) further contends that: "the prejudicial linking of women's mental health to reproductive functioning meant that sources of distress emanating from outside women's bodies, including social origins, aroused little scientific curiosity". Interestingly, an early female commentator on gender differences, sexuality and medicine, the 12th century religious visionary, Hildegard of Bingen espoused what we would now describe as a biopsychosocial approach to the causes and treatment of psychosis but hers was a lone voice, disguised as dreams, and reported through a male pope (Kulkarni, 2006).

The connection between women's mental distress and societal norms was further illustrated in Victorian times when psychiatrists linked deviancy and madness with any example of female sexuality that did not conform to the accepted convention of females as sexually innocent and passive. Women who were considered promiscuous, bore illegitimate children or were traumatised as a result of sexual/physical assault were confined to asylums or isolated at home. In the later Victorian era, the diagnosis of hysteria again took centre stage when women who were campaigning for access to educational/ professional opportunities and for the right to vote were labelled mentally disturbed and diagnosed as displaying symptoms of "over education and rebelliousness" (Kulkarni, 2006, p. 193).

Freud and colleagues noticed a strong connection between the somatic symptoms of women diagnosed with hysteria and psychological trauma (particularly from sexual abuse) but the social implications of such observations led Freud to substitute intrapsychic conflict and sexual fantasy for the real events that had contributed to the hysteria (Bloom, 1997; Van der Kolk, Weisaeth, & van der Hart, 1996). In the words of Herman (2001, p. 14) "Sexuality remained the central focus of inquiry. But the exploitative social context in which sexual relations actually occurred became utterly invisible".

The diagnosis of schizophrenia developed from Kraepelin's work on dementia praecox (Kraepelin, 1919) which he described as only occurring in men. However, by the

1920/30s, the woman with schizophrenia had become a central cultural figure, symbolising sexual and religious breakdown. The experiences of women such as the actress Frances Farmer who battled against the stereotypical female norms of the 1940's and was repeatedly detained in psychiatric institutions, were later viewed as symbols of the way society repressed women. Women were being incarcerated in asylums and subjected to psychosurgery, insulin and shock treatments in greater numbers than male patients (Kulkarni, 2006).

Moving into the last four decades of the twentieth century, the rise of second wave feminism has not only reformed the practices of psychology and psychotherapy to reduce sexism (Bem, 1974; Constantinople, 1973) but in its emphasis on the social context of women's lives, has finally pointed out the link between mental health and the wider political, social and economic structures which influence women's lives in the twenty first century (Marecek, 2002).

Awareness of the need to focus on the gendered experience of consumers dates back more than 20 years when Test & Berlin (1981, p. 136) declared that the "chronically mentally ill are regarded as almost genderless". The importance of gender, in the context of the increasing rates of mental illness that constitute a serious public health problem, will now be considered.

3.3 The Gendered Experience Of Women In Mental Health

Gender determines the differential power and control men and women have over the socio-economic determinants of their mental health and lives, their social position, status and treatment in society and their susceptibility and exposure to specific mental health risks.

World Health Organization, 2007. p. 1.

Throughout history and into the present day, there has been a marked predominance of women in the estimates of the number of people with significant psychiatric/psychological symptoms within New Zealand and across other western countries (Johnson & Buszewicz, 1996). Women and men experience a similar range of mental disorders at similar rates but striking gender differences occur in the patterns of mental illness. As this is a study looking closely at the experiences of women living with mental illness, this area will be emphasized.

There are no marked gender differences in the rates of severe mental disorders such as schizophrenia and bipolar disorder (World Health Organization, 2007). However, gender is implicated in the following ways. There are differences in age of onset of symptoms with women developing schizophrenia between five to ten years later than men (Kulkarni, 1997); the frequency and type of psychotic symptoms in schizophrenia shows women experiencing more affective and less negative symptoms (Seeman, 1982) and the course of the disorder shows women generally experiencing a more benign form of the illness (Angermeyer, Kuhn, & Goldstein, 1990). Whilst the picture is generally better for women, major social stressors such as poverty, abuse and violence contribute to a poorer quality of life (Milburn & D'Ercole, 1991).

Studies in the United Kingdom (Johnson & Buszewicz, 1996; Metzger, Gill, Petticrew *et al*, 1995) and in the USA (Robins, Helzer, Weissman *et al*, 1984) have all concluded that women are more likely than men to suffer from depression and anxiety. One in five women experiences a clinically significant depression at some time in their lives (Kessler, 2002). Many experience more than one episode (Belsher & Costello, 1998); many experience subclinical (mild to moderate) levels of depression for extended periods (Boland & Keller, 2002) and between 8 - 15% of women experience a depressive episode during the postnatal period (O'Hara, 1997). Depression is the world's most prevalent psychiatric condition and is predicted to be the leading cause of disability burden by 2020 (Murray & Lopez, 1996). The most marked difference between men and women is found in the diagnosis of eating disorders where over 90% of the patients diagnosed with anorexia nervosa are female.

Te Rau Hinengaro: The New Zealand Mental Health Survey (2006) confirmed a high prevalence of anxiety, major depression and eating disorders in women, as has the longitudinal study, the Christchurch Health and Development Study (CHDS) and the Mental Health and General Practice Investigation (MaGPIe, 2001, 2003). The overall prevalence of any 12-month disorder was higher for women than men (24.0% compared with 17.1%) and women again had higher lifetime prevalence for anxiety, mood and eating disorders (Oakley Browne, Wells & Scott, 2006. p. 57).

Gender also explains women's exposure to specific risks in relation to their mental health. Women are over represented in the numbers of those with three or more co morbid disorders (Astbury, 2006). Co-morbidity is related to increased use of services, more severe mental illness and higher levels of disability associated with mental illness (World Health Organization, 2007). Depression rates are higher for those living in poverty. Women are over-represented in both the rates of depression and in lower socio-economic groups (Astbury & Cabral, 2000; Patel, Araya, de Lima *et al*, 1999).

Along with poverty, disability and social position, gender-based violence of all kinds is associated with multiple negative health outcomes. The World Health Organization (2007) estimates the lifetime prevalence rate of violence against women ranges from 16 - 50% and that at least one woman in five suffers rape or attempted rape in their lifetime. Gender-based violence in childhood and adult life (physical, sexual, emotional violence, abuse and victimization) contributes to an increased risk of depression and co morbid complaints such as anxiety disorders, post-traumatic stress disorder, suicidality, substance abuse, eating disorders and borderline personality disorders (Astbury, 2006; Campbell, 2002; Resnick, Acierno, & Kilpatrick, 1997).

Thus, it can be seen that violence and abuse play a substantial role in the life of many women and children around the world. Again, the World Health Organization (2007) estimates that 80% of the 50 million people affected by violent conflicts, civil wars and disasters are women and children so it is now pertinent to briefly explore the role that trauma plays in the development of mental illness.

3.4 Trauma's Implications For Mental Health

The mental health system is filled with survivors of prolonged repeated childhood trauma.

Herman, 2001, p. 122.

Trauma is not abuse but is clearly the result of, or consequence of abuse for many people (Wells, 2004). Many parents with mental illness have experienced a range of harmful and traumatic circumstances in their childhood, which then not only increases their chances of experiencing mental illness in adulthood but also makes the passage to parenthood difficult (Royal College of Psychiatrists, 2002).

Both New Zealand and international studies consistently confirm a 50 - 80% prevalence rate of physical and/or sexual abuse amongst people who later receive a mental illness diagnosis (Beitchman et al., 1992; Briere, Woo, McRae, Foltz, & Sitman, 1997; Goodman, Rosenburg, Mueser, & Drake, 1997; Palmer, Bramble, Metcalfe, Oppenheimer, & Smith, 1994; Read, Agar, Barker-Collo, Davies, & Moskowitz, 2001). People with trauma histories are often misdiagnosed and mistreated within the mental health system. The number and complexity of their symptoms means that their treatment is often fragmented and piecemeal (Herman, 2001).

People with trauma histories generally receive many diagnoses over the period of time in which they have contact with the mental health system. It is rare that mental health service users are actually asked about their abuse history, leading them to be given diagnoses and treatment based on their primary presenting symptomology. Child abuse has been shown to contribute to the development of depression, anxiety disorders, post-traumatic stress disorder, eating disorders, substance abuse, personality disorders and dissociative disorders (Boney-McCoy & Finkelhor, 1996; Kendler et al., 2000). Read, Goodman, Morrison, Ross, & Aderhold (2004) also demonstrate that the relationship between childhood trauma and schizophrenia is strong.

Herman (2001) describes how repeated trauma in childhood forms and deforms the personality and that the personality shaped in such an environment is not one which is well able to cope with adult life, having fundamental problems in trust and the capacity to form stable relationships. This constellation of symptoms – impairment in affect regulation, alterations in attention and consciousness, characterologic changes and somatization - was recognised as distinct from PTSD in the DSM-IV (APA, 1994) and is known as Complex PTSD or DESNOS (disorders of extreme stress not otherwise specified) (ibid, p. 119).

Women with trauma histories, and therefore likely to qualify for such a diagnosis, have characteristic difficulties with relationships and frequently experience re-victimization. Herman (2001) quotes Diana Russell's 1986 study when stating that the risk of rape, sexual harassment or domestic violence is approximately doubled for female survivors of childhood sexual abuse.

Hence it can be seen that women are at high risk of experiencing violence and abuse and subsequently suffering the long-term effects of trauma which can potentially contribute to the development of a mental illness. Being a woman can also involve being a mother. For women experiencing mental illness, motherhood may be the primary way to share a normalizing life experience; a way to create a role with value and meanings removed from the negative experiences of being a patient (Nicholson, Sweeney, & Geller, 1998a). The role of motherhood is now examined with particular consideration to the social construction of both motherhood and childhood. Following this, the specific circumstances of children living with parents who experience mental illness will be explored with reference to the evolution of support services known as COPMIA - Children of Parents with Mental Illness and Addiction.

3.5 Being a Mother

My children are my biggest responsibility and also my biggest vulnerability.

A consumer interviewed: Like Minds, 2003, p. 2.

Being a mother is central to the understanding most women have of themselves and to how others define them (Phoenix & Woollett, 1991). Being a parent is a role which many adults assume they will undertake. In the past, parenting was learned through observation and modelling the experience of being raised in large, extended families. In the last five decades, smaller families, (the so-called nuclear family) and the movement of people around the world in search of economic security has meant that both men and women now have less exposure to hands-on parenting and there is less support available to them (Pound & Abel, 1996). Parenting is, essentially, being learned anew in each generation. The prevalence of parenting courses, a late twentieth century phenomenon, (Bassett, Lampe, & Lloyd, 1999) can be seen as evidence of the importance (and perceived need) of the transmission of this set of skills to parents. It is significant in terms of this study that little emphasis is paid to mental health issues within mainstream parenting courses.

Simultaneously, the expectations placed on parents and mothers in particular, have never been greater. Feminist postmodernist approaches, which have congruence with the approach of this thesis, view motherhood as a socially constructed role that depends on the prevailing political ideologies of the society in which it exists (Ballou, Matsumoto, & Wagner, 2002) and increasingly on psychological ideas of "good mothering". Modern western societies, including New Zealand, subscribe to a romantic, somewhat idealised view of motherhood that does not include mothers with mental illness (Montgomery, Tompkins, Forchuk, & French, 2006).

Furthermore, the picture of the so-called 'normal' mother (in which normal is defined as good or ideal) is often in opposition to the reality of motherhood for most mothers (Phoenix & Woollett, 1991). This concept of normality has arisen out of psychological theories that have helped define the circumstances in which motherhood should occur and how mothers should interact with their children.

Societies in the developed world view motherhood as being the vehicle to ensure that children are brought up in the "right way"; therefore, concerns are often raised when the "wrong women give birth in the wrong circumstances" (ibid, p. 16). Mothers from 'other' groups (for example, young, unmarried, mentally ill and disabled) are viewed in a negative light and often painted as pathological mothers (New & David, 1985).

The most powerful and enduring theory in terms of defining the normal emotional experience of motherhood and the development of attachment relationships is Bowlby's Theory of Attachment (Bowlby, 1969). Negative attachment experiences have been implicated in the development of future mental illness (Lancaster, 1999; Mercer, 2006). This is an area which now requires elaboration and critical review.

3.6 Attachment

A mother's current parenting capabilities can be strongly influenced by past experiences with her own attachment figures during the years of infancy, childhood and adolescence.

Jacobsen, 2004, p. 113.

John Bowlby (1907-1990) was a child psychiatrist with a background in ethnology and psychoanalysis who developed the fundamentals of a theory that postulated that relationships with early caregivers, usually the mother, are the basis for good or poor social and emotional development (Bowlby, 1969; Mercer, 2006). His beliefs were substantiated by the work of Melanie Klein in the children's department at the Tavistock Clinic in London and Harlow's work with rhesus monkeys around the idea of the imprinting of experiences (Mercer, 2006).

In a later development, Mary Ainsworth devised the Strange Situation Test (a laboratory observation of mother, child and stranger), which was used to measure attachment (Ainsworth, Blehar, Waters, & Wall, 1978). Four attachment types were described. When the relationship between adult and child is sensitive and adapted to the infant's needs, then the child develops a secure attachment from which he/she is then able to explore the outside world without feeling despair due to fear of abandonment. An anxious-resistant attachment can occur when a parent is anxious or depressed and is unable to reassure the child who then clings to the parent on reunion.

An anxious-avoidant attachment is said to occur when the parent consciously supports notions of independence at a developmentally inappropriate age and the infant subsequently learns to not look for comfort so does not approach the parent on return. Lastly, children with disorganised attachment may not have a consistent pattern of seeking comfort because the parent can be both the source of comfort and pain so may display both running to and away from the parent at the same time (Sved Williams, 2004).

These attachment categories are believed to endure into adulthood and to influence how one parents one's own children. Bowlby postulated that relationships with early caregivers could be the foundation of childhood and later, possible adult psychopathology (Contratto, 2002). A further link appeared with Rutter's landmark study which corroborated an association between parental mental illness (and/or chronic physical illness) and disturbances in their children (Rutter, 1966).

The specific symptoms of major mental illnesses which the parent experiences, are said to affect the parenting style of the individual. The negative symptoms of schizophrenia (lack of energy, drive, motivation to interact and withdrawal) may impede the ability of a mother to carefully attune to her infant, reducing the likelihood of a secure attachment (Riordan, Appleby, & Faragher, 1999; Sved Williams, 2004). The first presentation of bipolar disorder, which affects 1-2 women per 1000, often occurs in the context of giving birth but the manic phase of the illness in the postnatal period was not found by Hipwell, Goossens, Melhuish, & Kumar (2000) to be associated with insecure attachment.

The depressed part of the cycle, as with other types of depression, is associated with more negative effects on infants (Weinburg & Tronick, 1998). Maternal depression in the infancy period is said to disrupt secure attachment formation (Downey & Coyne, 1990; Lyons-Ruth, Connell, & Grunebaum, 1990; Murray, 1992; Righetti-Veltema, Bousquet, & Manzano, 2003) and because maternal depression may affect the regulation of emotions in both the mother and the child, it may be constructing an early vulnerability to life events and ease of coping with new situations for the child (Manning & Gregoire, 2006).

Postnatal depression in particular has been found to have a greater impact on boys than on girls (Sharp et al., 1995). Eamon's study (2001) found that depressed mothers tended to resort to physical punishment more often than those not experiencing depression.

Later research (Rutter, 1979, 1985; Rutter & Quinton, 1984; Sameroff, 1998; Seifer & Dickstein, 1993) established that whilst insecure attachment is more common in children of ill parents, maternal mental illness is but one of many risk factors (poverty, psychosocial stressors, relationship problems and domestic violence) which in combination can determine both psychopathology and resilience.

A key factor in the development of resilience in children is the presence of both a healthy mother-child relationship in the first year of life and warm, intimate relationships with an adult which can convey a protective influence on a child into adulthood (Musick, Stott, Spencer, Goldman, & Cohler, 1987).

Although Attachment Theory is viewed by many as the pre-eminent theory when considering relationships between parents and children, recent streams of research have emerged which provide an alternative view to the rather vulnerable picture of children painted by attachment theorists. (Hill, 2004) states that there has been somewhat inconsistent support for Bowlby's contention that early attachment relationships become a template for later relationships. Contratto, a feminist psychology researcher, has expressed concerns about the wholesale adoption of attachment theory, especially the assumption of the importance of early development; the privileging of mother-child interactions that ignores work on temperament and resilience; a neglect of environmental stressors and documented ethnic biases (Contratto, 2002, p. 31).

In an overview of the effects of parenting, (O'Connor, 2002) notes the pervasive focus on the uni-directional (i.e., parent to child) assumption when considering parental effects. He states "Temperament is a natural candidate as a child characteristic that moderates the effect of parenting" (p. 563). He advocates a continued research focus on the ever-changing, bi-directionality of the relationship between parent and child. (Bell & Harper, 1978) determined that numerous child characteristics such as gender,

physical condition, intellectual ability and general attractiveness induce differential behaviour from parents and teachers/caregivers.

Kagan (1994) refers to the fundamental assumption of attachment theory, that the first two years builds a foundation for the rest of life, as "infant determinism". He asserts that it is the consistent and repetitive stressors that a child faces in childhood that are critical to the development of problems and bases this conclusion on a longitudinal study of over 600 children in Hawaii who were followed up from birth to 30 years (Werner, 1992; Werner & Smith, 1977). This study showed that it was poverty and prematurity or other biological stressors surrounding the birth that might predict later psychological problems, but even then the resilience of children was commented upon.

Both Contratto and Kagan, from differing perspectives, view Attachment Theory as a somewhat limited approach which allows people to ignore the reality of women's lives. Contratto from her feminist standpoint concludes that the delicate, helpless picture of children dependent on their mother's presence, has contributed to the guilt and stress of mothers and working mothers in particular. Kagan claims that Attachment Theory is full of western, middle-class assumptions which brush aside the impact of poverty on children's development and of trauma on emotional health (Herman, 2001) and thus allows society to abdicate its responsibility for social change, placing the blame for society's problems squarely on the shoulders of imperfect mothers.

3.7 Risk And Resilience: The Social Construction Of Childhood

Resiliency denotes positive adaptation and competence despite the presence of substantial risk.

Smokowski, 1998, p.338.

Interest in the concept of resiliency, and the identification of factors which protect children and may increase the likelihood of positive outcomes, arose out of earlier work which focused on risk. The risk/resilience discourse is a central theme in the work of Gladstone, Boydell, & McKeever (2006) who challenge the dominant viewpoint that children of parents with a mental illness are 'at risk' and those that succeed under such circumstances are especially resilient. They locate the risk/resilience discourse within a larger discourse around the nature of childhood which is regarded as a pivotal

developmental period, a preparatory rather than a participatory phase of life (Mayall, 2002; Qvortrup, 1985).

They concur with Masten (2001) and Luthar & Cicchetti (2000) in viewing resilience as a more common trait than is usually expected but which is substantially moulded by the children's life circumstances. Whilst acknowledging that children are physically and emotionally vulnerable in relation to the adults in their lives, they feel that children need to be considered as active participants in the life of the family rather than as vulnerable victims.

Like motherhood, the modern, western, picture of childhood is of an idealised state of non-work in which children are perceived as free from responsibility but this conceals the reality of children's existence. In this context, children of parents with a mental illness are often described as having been "robbed of their childhood" (Gladstone *et al*, 2006. p. 2546) by the reversal of roles known as parentification. However, Mayall in her 2002 research into children's experiences of childhood found that the children's stories emphasized notions of interdependence and reciprocity which confirmed earlier research (Gordon, Benner, & Noddings, 1996; Rose, 1998) which highlighted the less concrete aspects of caring, that is the 'being with' rather than 'doing for' somebody. An exclusive focus on aspects of young carers may detract from the need to provide services for parents to support them in their parenting roles (Olsen, 2000).

Most theories about the nature of the parent-child relationship seem to agree that it is a combination of factors which leads to not only the worst but also the best outcomes for all children not only those whose parents experience mental illness. Downey & Walker (1992) and Patterson & Dishion (1988) suggest that the association between poor parental mental health and childhood psychopathology is not necessarily direct. It can be accounted for by the disruptive effect of poor mental health on adequate parenting which then leads to children's disturbance (cited in O'Connor, 2002).

If this is indeed the case, then it lends support to both family-centred mental health models and the approach which focuses on ways to support children (and by extension, their parents) who live in families where a parent experiences mental illness. It is this relatively recent area of service provision that will now be highlighted as it has made visible, the "up-to-now" invisible lives of these children.

3.8 Children of Parents with Mental Illness and Addiction: (COPMIA)

Talking with children is (therefore) an essential part of best practice in the treatment of their mentally ill parents.

Falkov, 2004, p. 55.

Whilst Mental Health Services have nominally worked with families for many years, it was only in the last decade of the twentieth century that clinicians and researchers began to investigate the daily, psychosocial impact of mental illness on the children of parents with mental illness and to give thought to the types of support they might need (Cowling, 1996; Thomas & Kalucy, 2002). The first Invisible Children's Project was commenced in 1993 in New York State, USA with the mission to ensure that all children with a parent/guardian with a mental health problem were able to obtain all supports and services necessary to function in healthy ways. The implementation of the national Children of Parents with Mental Illness (COPMI) project in Australia was begun in 2001 with initiatives occurring in five states. In 2002, the Royal College of Psychiatrists in the United Kingdom issued a report exploring the needs of patients as parents.

Although many people experiencing mental illness are able to parent successfully, there are many ways in which parental mental illness can impact upon children. Physical separation through hospitalisation can affect attachment; mental illness frequently means a reduction in living circumstances and loss of the support of family and friends can occur through periods of mental unwellness (Clausen & Huffine, 1979; Fudge, Falkov, Kowalenko, & Robinson, 2004).

There are many factors associated with a higher likelihood that parents will have difficulty in ensuring that their children's safety needs are met. One example quoted by Fudge *et al* (2004) is that children seem most at risk when parental mental illness or substance abuse co-exists with domestic violence. The effect of such risk factors are dependent on the age of the child in the family with older children seeming to be more able to cope with parental mental illness (Falkov, 1998).

The discrimination faced by people who experience mental illness also has an effect upon their family members and the level of discrimination is influenced by the cultural milieu in which the family is living. This affects the amount of assistance and support available to both parents and children.

The first task of any COPMIA approach is to identify those parents who experience mental illness, recognise their support needs and acknowledge the needs of their children (Falkov, 2004). The support needs of parents can be best met through a holistic approach which involves collaborative approaches between adult and child & youth mental health services, child protection services and relevant NGO family support organizations. One of the most important aims of a COPMIA service is to listen to and talk with children because, as Falkov (2004) hypothesizes, the nature and extent of a child's understanding of parental mental illness is closely linked to the child's adaptation to it. Talking and listening to children is perceived as an excellent way to mitigate some of the adverse effects of parental mental illness and boost children's adaptive skills. Group work, especially peer support groups, after-school and holiday initiatives complement individual and family approaches (Cowling, 2004).

3.9 Conclusion

Parenting is subject to intense public scrutiny in the twenty first century. Attachment theory is one of the main lenses through which parenting (and parenting alongside mental illness) is viewed but one that is being challenged by a discourse of resilience and 'risk as opportunity'. Mental illness can affect the relationship between parent and child, both positively and negatively, so it is timely to concentrate on what international studies can tell us about what it means to be a mother with experience of mental illness.

CHAPTER 4 WHAT DO WE KNOW ALREADY?

What is known about a phenomenon is influenced by the sources of information about the phenomenon.

Nicholson et al, 2001, p. 7.

4.1 Introduction

The aim of this part of the study is to examine both international and New Zealand research referring to the views and experiences of mothers living with mental illness. The primary interest of this review is in literature which depicts firsthand the experience of being a mother with mental illness. Such studies are sparse but increasingly, research has appeared which places the narratives of mothers living with mental illness at its centre. Savvidou et al (2003), employing a social constructivist approach, call this "giving space to weak voices", as an alternative to the very powerful, scientifically-based, dominant discourse of mental illness which is mainly connected with deficits. These stories can then become part of building a new narrative which includes more liberating, strengths-based interpretations of mothering with mental illness. They also reflect the growing prominence of recovery approaches which views the sharing of stories about the experience of mental illness as potentially transformative (Lapsley et al, 2002).

4.2 The Process

Both international and New Zealand literature were examined for articles and references around the experience of living with mental illness from the perspective of mothers, either in qualitative studies or in studies which explore service delivery from the perspective of consumers. Although firsthand accounts are increasingly seen in mainstream journals and books (Cowling, 1999; Cowling, 2004; Fox, 1999; Perkins, 2003), consumer research is often small scale and has not always been viewed as robust enough to feature in academic journals (Peterson, 1999). However, the development of a research model supporting recovery approaches, which utilises the actual experience of consumers, gives support to the growing use of the firsthand account (Mental Health Commission, 2007). Mental health conferences and mental health websites were also helpful for up-to-date references.

A history of research in the area highlighting the major researchers will now be described which will then be followed by a consideration of the major common themes.

4.3 Overview of the Literature

Most research, and possibly clinical concern, has been directed toward understanding the effects on the children of having a deviant mother; whereas the needs of chronically mentally ill persons as mothers appear to be almost totally neglected.

Test & Berlin, 1981, p. 139.

Test & Berlin's 1981 study based in the United States of America was one of the first to describe the social and psychological aspects of the lives of women experiencing chronic mental illness. They recommended that a range of services be made available to assist with daily parenting tasks and in coping with the stresses of caring for children – such services are still the exception rather than the norm twenty-six years later.

Several American studies in the early 1990s pointed out that parenting had been a seriously neglected issue within psychiatric rehabilitation literature (Mowbray, Oyserman, Zemencuk, & Ross, 1995; Nicholson & Blanch, 1994; Oyserman, Mowbray, & Zemencuk, 1994; Zemencuk, Rogosch, & Mowbray, 1995). Apfel & Handel (1993) were among the first to acknowledge that women with mental illness could parent successfully if effective support systems were in place. They established principles for long-term treatment plans such as the importance of consistent but flexible care utilising a case management approach based on a thorough, multi-factorial assessment, stressing the importance of good communication and a team approach (p.149).

In their reviews of state policies and programmes for both 'at risk' children and mothers with mental illness, Blanch, Nicholson & Purcell (1994) and (Nicholson, Geller, Fisher, & Dion, 1993) concluded that mental health service clients were not being identified as parents because parenting was not generally considered a mental health issue. Both sets of authors identified that the fragmentation of services was an impediment to effective service delivery and recommended integrated services for parents with mental illness.

Ritsher, Coursey & Farrell (1997) and Cogan (1998) focused on the importance of relationships in the lives of women with serious mental illness. Ritsher *et al*/concluded that, contrary to the views of the services provided for them, women with serious mental illness did not perceive their mental illness to be the main feature of their identities, rather that they viewed relationships with others as their central source of empowering energy and psychological growth. Cogan was one of the first researchers to use what she described as "a consumer as expert" approach to hear the voices of women in relation to the stressors associated with being a mother. She suggested that special attention be paid to the matter of mothers who lose custody of their children and what they need in order to be able to cope with this experience.

Several United States and Australian researchers began to describe the daily lives of mothers with mental illness. Sands (1995) contrasted the experiences of mothers with mental illness in a residential programme with mothers of similar status (single parents, usually on welfare benefits) without mental illness. She found that mothers with mental illness had a strong desire to lead normal lives for themselves and their children but they were often unwilling to ask for help with parenting through fear of custody loss.

Nicholson, Geller & Sweeney (1998a) and (1998b) asked mothers, within a focus group setting, to describe their experiences as parents and then recommended solutions to the problems identified. In the first study on the competing demands of parenting and living with a mental illness, significant themes which emerged were the satisfying nature of motherhood and its role as a motivator to remain well, alongside the stigma of mental illness and fear of custody loss. The authors concluded that whilst some issues are specific to the context of living with mental illness, many of the issues of mothers with mental illness are generic to all mothers. They recommended that service providers include mothers themselves in the planning of appropriate services.

In the second study, investigating the family relationships and social supports of mothers with mental illness, they concluded that having supportive husbands/partners/family members is usually an asset and that lack of family support alongside other factors like poverty, put mothers and children in a more risky situation. A study into contact with children and assistance with childcare amongst parents with psychotic disorders living in Queensland, Australia concluded that providing childcare and supporting the parents can enable support networks to remain intact (Hearle et al., 1999). Another Australian study by Bassett, Lampe & Lloyd (1999) on the experiences of parents living with mental illness, identified again the importance of the relationship with their children, but also their fear of losing custody of children, the social isolation and stigma which surrounds mental illness and the lack of support in the community.

A further contribution to understanding both the stressors and resources experienced by mothers with serious mental illness from their own perspective arose from the study by Mowbray, Schwartz & Bybee in 2000.

Stressors identified were poverty with two-thirds interviewed with incomes below the poverty line; general financial concerns with only 14% not revealing any financial worries in the past three months; physical health and disability with 74% reporting fair or poor health and finally, life events and hassles with over half the participants' reporting a psychiatric crisis, major financial crisis or the death of a close friend or relative.

While being a mother with a mental illness was undoubtedly stressful, in terms of available resources, nearly all of the women were able to access some form of social support from relatives, friends or parents. Many found comfort in God or religion. Although most of the women were clients of mental health services, there was a low level of assistance available from mental health services for parenting issues.

Montgomery (2005) remarked upon the limited published research on the subjective experiences of mothers with mental illness in her critical review of the literature. Furthermore, she saw many of the studies as reinforcing the view of mothers with mental illness as a pathological problem requiring professional interventions. Montgomery commented that only a very few studies (Mowbray et al., 2000; Nicholson & Biebel, 2002; Nicholson et al., 1998a; Nicholson, Sweeney, & Geller, 1998b) had, at the very least, painted a more holistic picture of the lives of the mothers, recognizing the circumstances that made mothering difficult. Montgomery concludes that when the mothers with mental illness are able to bear witness to their own realities, "by taking up a position as speaking subjects" then appropriate service delivery planning can begin.

In their study of Canadian mothers who experience mental illness, Montgomery, Tompkins, Forchuk & French (2006) identified that watchfulness (the interpretation of the responses of others) was a core component of keeping close to their children. Watchfulness in the context of illness was exhausting, inherently stressful and likely to exacerbate already fragile mental health. Watchfulness also involved conforming to an ideal image of a mother, which was necessary because of the stigma attached to being a mother with mental illness. They ended by linking their study to others (Diaz-Caneja & Johnson, 2004; Nicholson, Biebel, Hinden, Henry, & Stier, 2001) that illustrate the complexity of mothering within the context of mental illness but also the absolute desire of mothers to create meaningful relationships with their children.

Oyserman, Bybee, Mowbray & Kyoung Kahng, (2004) explored how mothers with mental illness make sense of themselves as parents and what implications these meanings have for them in their parenting role. They discovered that mothers did sometimes feel burdened by parenting as they were usually single and poor, but, simultaneously also viewed themselves as competent and many saw parenting as a personal growth experience. If the mothers viewed their own parenting as efficacious, this attitude helped them to be a more effective parent.

In summary, interventions that aim to support mothers with experience of mental illness with parenting can help these mothers develop a sense of competency as parents and provide them with a buffer against future parenting stress. If mothers with mental illness are able to parent more effectively even under adverse circumstances, they will protect their own children from these stresses.

Research in New Zealand is very much at an emerging stage and is represented by three pieces of work, one a collection of stories, *Mums and Dads, Parents with experience of mental illness share their stories*. (2005), *Ko Au Wahine Maori* (Semmens, 2006) a Masters of Social Work thesis which looked at the experiences of pregnancy and childbirth of Maori women diagnosed with a mental illness and another Masters thesis exploring ways of working with families where a parent has a psychiatric disability (Nightingale, 2001).

The stories of several of the parents in "*Mums and Dads*" focused on the loss of custody of children, the lack of support from the Child, Youth & Family Service to keep mothers and children together and the need to conceal mental illness as this was seen to increase the risk of losing a child. On the positive side, several of the mothers had become involved in the Consumer movement and had used their experience of mental illness to develop new understandings about helpful ways to deal with mental illness and strategies for health and wellbeing. Associated with the report was a hui held in Wellington in 2005 to explore the needs of families where there was parental mental illness. Key issues expressed by participants were that services were only funded to work with individuals, not families; funding constraints led to a lack of flexibility in service delivery and a lack of collaboration and cohesiveness between services and providers meaning that often families have multiple agencies involved in their care and support (Jackson, 2005).

The Maori mothers interviewed in "*Ko Au Wahine Maori*" spoke of the isolation that a diagnosis of mental illness brings especially when it exists against a backdrop of social stress that itself can be a precipitant to mental unwellness. Secondly, the diagnosis of mental illness led to a perception of difference by the general public which also affected their sense of identity and belonging.

The four clients interviewed by Nightingale again spoke of the feeling of difference and isolation that a diagnosis of mental illness brings but in addition, they expressed their desire that their expertise in their own health be recognised by clinicians. Nightingale concluded with the suggestion that parents with psychiatric illness and their children might be neglected by Mental Health care providers in terms of clinical attention and support (Nightingale, 2001, p. 2).

The major themes of the literature will now be elaborated.

4.4 Theme 1: Invisibility

There is a tendency for Mental Health Services to fail to systematically collect data about numbers of mentally ill mothers and to determine whether, indeed, they are the primary carers for their children.

Nicholson et al, 1993 cited in Devlin & O'Brien, 1999, p. 26.

The first major theme, which does not arise from the narratives of women with experience of mental illness but is evident from the literature review, is the invisibility of mothers with experience of mental illness when seeking specific mental health data.

Fourteen years after Nicholson et al commented on the lack of robust data, the situation is no better across most mental health services in the developed world. There appears to be few mental health services within the Western world that systematically record the percentage of parents living with mental illness who have dependent children (Falkov, 1997). Nicholson et al (1993) found that less than one-third of U.S. states collected data on whether clients had children; however, by 2005, the USA Substance Abuse and Mental Health Services Administration (SAMHSA) was still documenting the lack of comprehensive data as a critical issue.

Dipple, Smith, Andrews & Evans (2002) highlighted the scarcity of information in English case notes around the patient's role as a mother. In the same year, the Royal College of Psychiatrists in their report "Patients as Parents" (2002) found a lack of clarity around the proportion of adults who experienced mental illness who were parents. It stressed the need for the systematic identification of the 'hidden' children of patients who are parents so that earlier referrals for support might lead to a decrease in parental burden and promote parenting capacity. Anyaegbunam, (2001) had already recommended that a core requirement be to record which adults who were clients of mental health services had children.

A recent Australian survey observed that many adult mental health services do not (or have only recently started to) document whether their clients have children (Fudge, Falkov, Kowalenko & Robinson, 2004). Although there is a national mental health data collection system in New Zealand, it does not routinely collect information on whether consumers who use mental health services in New Zealand are parents, care for their children or have contact with them although apparently some DHBs do collect this information (B. Arnold, personal communication, October, 23, 2005).

The existence of this group has been highlighted in *Te Tahuhu – the Second New Zealand Mental Health & Addiction Plan* which identified parents with a mental illness and/or addictions who have dependent children as a group in need of specific support and assistance (Ministry of Health, 2005, p. 3). Finally, because it is the perspective of mothers which is paramount in this study, not only are mothers missing from data which could inform specific service provision but the feeling that Mental Health Services focus solely on illness, led participants interviewed in a Canadian study to feel invisible as women. Over time, this negative identity, defined by illness, contributed to them feeling powerless to control many aspects of their lives, thus exacerbating any existing poor self esteem (Chernomas, Clarke, & Chisholm, 2000).

4.5 Theme 2: Losses – Custody/Access to Children

After that we heard my husband's account of our life together and my parenting skills, then the child psychologist's opinion (which weren't very high) about my mental health and parenting ability and finally an independent psychiatrist who had seen me for an hour session some months earlier. Three days later, the judge awarded my husband full custody of our children.

Mental Health Commission, 2005, p. 8/9.

A central theme throughout women's accounts is a pervasive fear of losing custody or losing current access to children. The rate of custody loss for mothers with experience of mental illness is high (Mowbray et al., 1995) with reported percentages varying from 28% to 60% (Bazar, 1990; Miller & Finnerty, 1996; Test, Burke, & Wallisch, 1990). Many are separated from their children (Dipple, Smith, Andrews, & Evans, 2002; Hearle et al., 1999; Poinso, Gay, Glangeaud-Freudenthal, & Rufo, 2002; Savvidou, Bozikas, Hatzigeleki, & Karaavatos, 2003; Wang & Goldschmidt, 1996) but another study by Ritsher et al (1997) found that although custody loss can be high, 80% of mothers with experience of mental illness were raising, or helping to raise at least one of their children. In these circumstances, even the intermittent or co-parenting of children can contribute to a deep emotional influence between mother and child (Holley & Holley, 1997).

Hearle et al (1999) found that a third of mothers were reluctant to seek help for fear of removal of their children. Diaz-Caneja & Johnson (2004) and Seeman & Cohen (1998) concur that fear of losing custody or access to children dominated interactions with mental health and child protection services. There has been little recognition of the effect on parental mental health of any sense of inadequacy in parental duties or from the fear of having children removed (Devlin & O'Brien, 1999). Chris Hansen, New Zealand advocate for the human rights of people with mental illness describes the situation: "A significant percentage of us have ended up being denied the opportunity to fully parent as a result of our mental illness and other people's perceptions and fear of what that may mean for the children involved (Like Minds, 2003, p. 2).

Mothers with mental illness are often doubly victimized. Firstly, by the experience of the illness and then by finding themselves at risk of losing their children because they are seen as permanently damaged and not able to fulfil one of society's most valued roles (Ackerson, 2003). The ongoing grief caused by lost custody or contact with children exerts a powerful lifetime influence with many struggling to work through their experience of being judged as an unfit mother (Chernomas et al, 2000; Cogan, 1998). Lindy Fox (1999) describes her devastation at the loss of her children and advocates strongly that parenting and mental illness should not be viewed as mutually exclusive.

Whilst there have been a plethora of studies which have considered the effect of maternal mental illness upon children, there are few studies which have aimed to study the impact of separation on the well-being of a mother with experience of mental illness and insufficient attention to the effects of this separation and subsequent loss on their children (Cogan, 1998). Several studies have agreed on the negative impact of separation and loss (Apfel & Handel, 1993; Nicholson et al, 1998, Savvidou et al, 2003; Schen, 2005).

Mothers who experience mental illness suffer multiple, overlapping losses. Firstly the illness itself can bring a loss of control over one's life and the loss of a consistent relationship with children. Schwab, Clark & Drake (1991) found that when parents lost custody this resulted in a feeling of loss that permeated their everyday existence and their interactions with mental health providers. Secondly, the treatment of illness can lead to subsequent losses such as the side effects of medication causing loss of physical well being and loss of self-esteem through sometimes traumatic and humiliating treatment (Chernomas et al, 1999). The final series of losses are caused from within the family and the community and include the loss of partner/spouse, loss of meaningful, ongoing relationships with children, loss of friends, loss of rights/freedom and for some, loss of hope (Dipple et al., 2002; Kelly, 1999).

4.6 Theme 3: Stigma and Discrimination

My own experience and those of mothers I have come in contact with is that we quickly learn that there is a danger in seeking treatment for our illness.

Julie Anderson, Victorian Mental Illness Awareness Council Inc. 2005, p. 1

Stigma and negative societal attitudes affect women with mental illness even before they become pregnant. The accepted desire to bear and raise children is undermined by the negative stereotypes of risk surrounding mental illness which leads to the assumption that women with experience of mental illness will be inherently poor parents (Nicholson et al, 1998).

This stigma is insidiously stressful as mothers not only felt that they had to prove themselves but the sense of surveillance communicates messages of their own tenuous positions as mothers (Montgomery) 2005; Nicholson et al. 1998a). Stigma and ignorance about mental illness, treatment and recovery often influence family and friends' responses towards mothers and children and may affect their willingness to give support (Chernomas et al, 2000; Nicholson et al, 1998b). Diaz-Caneja & Johnson (2004) found that stigma prevented mothers from talking openly about the problems they were experiencing. This reluctance to reveal publicly their histories for fear of discrimination towards themselves or their children meant that women often cut themselves off from sources of peer support (Blanch et al, 1998).

Mothers were also concerned that stigma would impact upon their children and cause them to be rejected. One mother commented: "If other mothers knew I had a mental illness they might not allow their children to play with mine" (Diaz-Caneja & Johnson, 2004. p. 477). Sarah Gordon, a consumer researcher, describes a type of stigma which she calls self-stigma, wherein the consumer experiences the internalising of those negative attitudes and beliefs about mental illness that they have grown up with and hold alongside everyone else (Gordon, 2007).

Two pieces of research give support to this notion. Nicholson et al (1998a) report that mothers often blame themselves for the problems they are experiencing with their children, or misinterpret normal behaviour of childhood or adolescence as being signs of a developing mental illness. Furthermore the authors found that mothers often translated the difficulties of managing everyday stresses into "illness-related personal deficits" rather than seeing them as the normal stress of having too much to do. Mothers were often assessing themselves against unrealistic standards, failing and experiencing even more stress. This is also a common failing of professionals. The mothers surveyed by Diaz-Caneja & Johnston (2004) also worried about the effects of their mental illness on their children, especially at time of relapse. In addition, they felt guilty at the idea that their children might also develop an illness, either through a genetic cause or from the environment in which they were being raised.

A survey into discrimination faced by people with experience of mental illness in Aotearoa New Zealand (*Respect Costs Nothing*, 2004) devoted a section to parenting in which 38% of parents surveyed said they had been discriminated against in their experience as parents. They felt that stereotypical views of mental illness influenced the outcome of custody disputes and their dealings with the Child Youth & Family Service, rather than a realistic view of the impact of their mental illness on their parenting abilities. They described discrimination from fellow parents following disclosure of mental illness, from family members and even from health professionals, as did the respondents in the study by Nicholson & Biebel (2002).

4.7 Theme 4: Poverty

Mothers with experience of mental illness frequently live in an environment which is characterised by poverty (Mowbray et al, 2000) and this is reflected in the fact that the prevalence of psychiatric disorders increases as socio-economic status decreases (Rogler, 1996). There are other risks associated with mental illness and poverty such as a higher risk of substance abuse, health problems and being the victims of physical and sexual abuse (Mowbray et al, 2000). Falkov (1997) reports that domestic violence is a significant feature in the context of maternal mental health problems.

In their study investigating the stressors and resources in the lives of mothers with mental illness, Mowbray et al (2000) noted that the very high level of poverty experienced by most of these women was significant. The women's stories spoke of major money crises, financial worries and insufficient money for rent, social activities and medical needs. Many of the challenges that women with experience of mental illness face are not brought about by their illness but rather are caused by stresses brought on by poverty and isolation (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006). This finding gives support to the stress-vulnerability model as a relevant influence on treatment approaches.

4.8 Theme 5: The value of Parenthood

Motherhood is a wonderful, fulfilling experience, one that women with mental illness have every right to experience and enjoy.

Fox, 1999. p.3.

In spite of a prevailing emphasis on psychopathology, deficits and dysfunction, in studies which listened to the voices of the mothers themselves, they emphasized the value in being a mother. Several studies used similar language, speaking of the focus and purpose that children brought to the lives of the mothers and how they provided an anchor in their lives (Sands, 1995; Schwab et al, 1991). The mothers interviewed by Diaz-Caneja & Johnson (2004) viewed being a mother as a way to increase their self-esteem and as an incentive to recover and remain well. Canadian parents with mental illness writing of their lives in *Visions*, British Columbia's Mental Health & Addictions Journal (Lees, 2004) agreed that the parental role can be a vital factor in a person's recovery through being a source of motivation, providing a structure to assist with daily duties, and in providing a sense of identity and status.

The first study by Mowbray et al (1995) presented what was then, an alternative view of motherhood that it is as an opportunity for positive self-endorsement and as a chance to reintegrate the fragmented parts of the self. Nearly half of the mothers in a second study by Mowbray et al (2001), when questioned as to the changes which motherhood had brought, described one of the positive emotional consequences of being a mother as being a sense of personal worth and accomplishment.

4.9 Conclusion

In a world in which they are subject to stigma and discrimination, where parenting and mental illness are sometimes viewed as mutually incompatible, most mothers saw childbearing and parenthood as a means to affirm their normality and connect them with their communities (Cogan, 1998; Sands, 1995). In many studies, the aspirations of mothers living with mental illness were similar to mothers in general (Apfel & Handel, 1993; Miller, 1992; Nicholson et al, 1998; Ritscher, Coursey, & Farrell, 1997; Sands, 1995). They wanted to lead a normal life, with marriage, children and jobs, not a life where their every move was viewed through the negative lens of mental illness. However, poverty and the experience of loss of contact and/or custody with children were widespread. The lack of understanding of the experience of parenting alongside mental illness was reinforced by a paucity of robust information held by mental health services across the developed world.

CHAPTER 5 RESEARCH DESIGN AND METHODS

A research methodology should liberate individuals from the effects of hegemonic processes of suppression of alternative views of the world.

Bishop & Glynn, 1992. p. 217.

5.1 Introduction

This chapter outlines the influences which led to the choice of a qualitative approach utilising in-depth interviews for data collection and a thematic analysis for identifying results. The views and experiences of New Zealand mothers living with mental illness have seldom been recorded and there have been few specific studies carried out in New Zealand. To understand their worlds, the researcher needs to be allowed to enter and interpret these worlds. The appropriate methodology is one that allows the nature of their complex experiences to be revealed within the enquiry (Ungar, 2003).

Following an elaboration of methodological influences, the second section will contain a detailed description of the research process.

The Personal Lens

Major goals for this research process were the development of a partnership which involved respectful, research relationships with the participants and the desire for change through knowledge gained from their lived experiences. An important start to defining the influences on this methodology is to recognise and articulate the contribution brought to the research by the researcher. The researcher is central to the process even when the intentions are participatory (Birch & Miller, 2002). Griffin fittingly describes the contribution of the researcher and its impact: "Researchers are always speaking for others. This is not something to be denied or avoided; it is a (potential) power and responsibility" (Griffin, 1996. p. 100).

Researchers, particularly those working in the qualitative arena, often draw upon their own experience as a resource in their enquiry (Denzin & Lincoln, 1994) so it is appropriate now that the background of the researcher is described. Kamira (13 July 2007) in *A Code of Practice for the Tangata Whenua, Community and Voluntary Sector Research Centre*, speaks of the usefulness of researchers coming from within the community in which they research. I have been physically located in one of the communities from which participants were recruited for much of my life and rapport with these participants was fostered by this connectedness.

I can also draw on personal experience of a family member whose mental illness was a factor in the loss of custody of her child. As a family member experiencing the negative effects of acute mental illness, as a carer for her child and as a mother myself, I can relate to the mixtures of emotions that occur in the situation where a woman with experience of mental illness has a child/ren.

As a social worker, I have an awareness of the structural and social barriers that stand in the way of mothers with experience of mental illness successfully caring for their children. Social workers utilise therapeutic relationships as one of their main tools of practice within the mental health arena. A pivotal imperative for the researcher's methodology was the opportunity to develop respectful, honest relationships characterised by reciprocity that formed the basis for the research and its consequences.

My professional background as a social worker within a community mental health setting, working alongside consumers and families/whanau opened my eyes to the development of new influences on research and changing definitions of what constitutes ethical and non-discriminatory research with consumers of mental health services (Peterson, 1999). Recognition of the need for consumer participation at all levels of mental health services, including research has been articulated since 1995 in New Zealand (Mental Health Commission, 2002; Ministry of Health, 1995).

Participation is not just viewed as the means to providing better and more effective mental health services but also, and just as significantly, as a means to provide opportunities for the empowerment of consumers of mental health services (Lammers & Happell, 2004; Ochocka, Janzen, & Nelson, 2002; Rapp, Shera, & Kisthardt, 1993).

Increased participation, it is suggested, may decrease the power imbalances that exist within the mental health world (Trainor, Pomeroy, & Pape, 1999). Lord & Dufort (1996) believe that power and control of both knowledge and resources are vital dimensions within the relationship between professionals and consumers (cited by Ochocka et al, 2002. p. 380).

It becomes clear that to increase consumer power and control of the generation of 'new knowledge' within mental health, the involvement of consumers should be integral to any research project in mental health (Lammers & Happell, 2004). Participation, empowerment and an awareness of power and control issues are all influences brought to the choice of methodology by the researcher's interests and experiences.

Adamson describes her research process as being a path of discovery wherein the research can be considered as an accumulation of knowledge from different perspectives and paradigms, and from different theory and practice settings (Adamson, 2005). Just as mental health is a field constructed from many perspectives, so the methodology for this research is woven from a number of different influences, all of which reflect both the worldview of the participants and the interests and experiences of the researcher.

The Qualitative Choice

An appropriate methodology is one that is congruent with the worldview of the participants (Gibbs, 2001). The participants, whilst from differing backgrounds, all belong to one of the most marginalised groups in current society. The main influences on the development of this methodology have in common an interest in groups which have experienced marginalisation and/or oppression and a desire that, through research that embodies an emancipatory perspective, empowerment and change may occur.

In an appropriate parallel to the considerations needed for research within a whanau, hapu and iwi context (Walsh-Tapiata, 1997), the process in undertaking my research is as important an outcome as any data which may be produced by the interviews. A process in which full participation is encouraged and which involves the sharing of skills, contributions and information can empower any group or community (Kemmis & McTaggart, 1988, cited in Bishop & Glynn, 1992). In yet another parallel with Maori Health research, Durie (1996) describes an essential characteristic of such research as being "whakapiki tangata" - the empowerment of people so that either their health improves or they can take control of their health.

The use of a qualitative methodology to research in the mental health area allows the potential for the research process to be empowering and meets my goal that the research be a social and interactive process through which both researcher and participants benefit (Bishop & Glynn, 1992). A qualitative methodology works best in researching issues that involve complex social relationships. Any study of motherhood lends itself to the use of an interpretive methodology, which views social reality as something that is both socially constructed and negotiated, and the concern of which is to understand the world from the point of view of the participants in the research (Briar, 2003). Social reality is generally constructed through language, so a study which seeks to hear and record the stories of mothers living with mental illness is best investigated by using a qualitative approach.

Critical Theory

The issue of power is a pervading theme which underlies the development of my methodology. All of the contributing influences derive from an understanding that research has the potential to both extend knowledge and sustain one group, or to perpetuate ignorance and disempower another (Bishop, 1996; Stokes, 1985; Teariki, Spoonley & Tomoana, 1992; Tuhiwai Smith, 1986). Choosing a methodology that sees research as a partnership and utilising, within constraints, methods which involve power sharing is a political act of communication and intent on my part.

Critical theory, which recognises that facts are socially constructed according to the interests of the various power groups in society, is pivotal in understanding both the silence of mothers with experience of mental illness, and the structural impositions that they face in society that contribute to their powerless state. Critical theory requires that the researcher work with those who have suffered oppression to confront their situation and work towards some form of social change (Fook, 2002).

Critical theory is strongly linked to both feminism frameworks and the emancipatory politics of (Freire, 1972), who developed the concept of conscientization, a process by which people deepen their awareness of their sociocultural identity and their capacity to transform their lives (Taylor, 1994, cited in Birch & Miller, 2002). The central aim of Critical Theory is to first understand and then change power relations. Research is first and foremost about the creation, reproduction and gathering of knowledge. Research viewed through a Critical Theory lens aims to rethink the very purposes of knowledge creation, and redesign the relationships within the research process (Maguire, 2001). Critical Theory has been an influential underpinning in the development of Maori models of research (Durie, 1996).

Maori Models of Research

Whilst not Maori myself, there are a number of principles central to Kaupapa Maori research which fit comfortably with my personal values. Secondly, many of the themes of Maori research (participation, partnership and emancipation) have much in common with models considered appropriate for research by mental health consumers and also have a relationship with the values of social work. Lastly, my research is based in an area and with some participants who strongly identify as Maori. I see a parallel with the approach of Tiakiwai, (2001) who (after Tuhiwai Smith, 1999), defined her Kaupapa Maori approach to research as being a weaving together of Maori cultural beliefs and values, Western ways of knowing and education and Maori histories and experiences under colonialism (2001. p. 120).

Researchers (Bishop, 1996; Durie, 1996; Smith, 1997; Stokes, 1985; Te Awakotuku, 1991; Teariki, Spoonley, & Tomoana, 1992; Tuhiwai Smith, 1986, 1999) have positioned Maori research within a growing body of international work which questions traditional approaches to researching on/for/with indigenous peoples or minority groups and calls for a stronger emphasis on both power relations and the role of culture in research. In the past research has been used both to perpetuate negative stereotypes about Maori and to minimise the flow of resources to Maori.

The development of appropriate methodologies for Kaupapa Maori research is about Maori taking back control of the generation of knowledge about Maori. The basis of such a methodology has been formed from Maori values such as an emphasis on people and the important concepts of generosity, co-operation, reciprocity, mutual assistance, kinship and tribal identity (Stokes, 1985). Many researchers (Durie, A. 1985; Durie, M. 1996; Teariki, Spoonley & Tomoana, 1992) have used the principles of Te Tiriti O Waitangi as a starting point in the development process.

Mana Maori, tino rangitiratanga (self-determination) is an overarching principle of Kaupapa Maori research. Indeed, Bishop (1996) describes the main focus of Kaupapa Maori research as being the operationalization of self-determination (p.114). Although my research is not initiated or controlled by its Maori participants, my hope is that enhancement of mana (A. Durie, 1985) will occur through a positive contribution to the needs of all mothers living with mental illness, including Maori.

The principle of partnership is one that is of extreme importance to my research. It is seen as a pathway toward not only the enhancement of the mana of both Maori individuals and the collective but to mutual mana enhancement through power sharing between researcher and participants which is at the heart of partnership (Selby, 1996). Partnership can also be an empowering activity through the exchange of knowledge and skills (Tomoana, 1992). Finally, an approach which incorporates partnership is considered essential to achieving cross-cultural competence in research (Bishop & Glynn, 1992) which I believe needs to be the aim of all non-Maori researchers working with Maori participants.

Finally, participation is closely allied to partnership and fits comfortably with an emphasis on teamwork and co-operation – mahitahi, one of Durie's criteria for the basis of good research (Durie, 1996). Furthermore, Durie defines participation as the active engagement in research by the researched. This definition of participation finds a parallel with Action Research and Participatory Action Research approaches in which research is done *with* and not *to* others. Kemmis & McTaggart (1988) could be speaking of Kaupapa Maori approaches to research when they describe Action Research as: "(it) does not treat people as objects for research but encourages people to work together as knowing subjects and *agents of change and improvement*." (p. 22).

Smith (cited in Mead, 1996, pp. 190-192) described a framework for Pakeha researchers undertaking culturally appropriate research in the Maori domain and many of the models have some relevance to the way in which I conducted my research. Firstly, the tiaki or mentoring model, in which authoritative Maori guide and sponsor the research. Secondly, the whangai or adoption model, in which lifelong relationships assists the researcher. The third model is called the power-sharing model, wherein the researcher seeks the assistance of the community to support the research enterprise. Fourthly, the empowering outcomes model which addresses the questions to which Maori want answers and lastly, the bicultural partnership model in which Maori and Pakeha work together (Walsh-Tapiata, 1997).

Long-term relationships with local Maori health organizations have assisted me in negotiation around planning my research. I view my research as being conducted, as far as possible, within a power-sharing, partnership framework that will convey mutual benefits to all involved. As a non-Maori New Zealand researcher who began by working in partnership with Maori health (hauroa) organizations holding Kaupapa Maori contracts, my hope is that my research, utilising a methodology derived from western research philosophies which hold compatible values, can provide a beginning to the exploration of the experiences of all mothers, both Maori and non-Maori, who live with mental illness.

Researchers investigating the development of appropriate methodologies for conducting research with Maori also found a convergence between feminist approaches to qualitative research and those compatible with Maori concerns (Durie, 1996). Both approaches have contributed greatly to this 'woven' methodology therefore feminist influences will be considered in the next section.

Feminist Models

Feminist research is research that recognizes the essential importance of examining women's experiences.

Hesse-Biber & Yaiser, 2004

Being a mother is a unique experience to women. Motherhood in the context of mental illness is an experience that needs investigating and to undertake this effectively, for me, implies the use of research informed also by feminist methodology. Feminist approaches to research arose out of a sense that the voices of women were not being heard within mainstream, mainly positivistic research. The voices of women who experience mental illness were similarly not being heard at the time.

These approaches have had a significant influence not only on my methodology but also on my research method and choice of data collection process. Feminist research is often qualitative and phenomenologically based in that it seeks to understand the everyday experiences of women in order to change and therefore improve their circumstances. Feminist researchers also have a preference for qualitative methods as being methods which value subjectivity and allow women to express their experience fully through the use of their own narratives (Jayaratne & Stewart, 1991; Reinharz, 1992; Scott, 2002).

Feminism is not purely a way of looking at the world or a knowledge base but is, "also an ontology, or a way of being in the world" (Stanley, 1990. p. 14). There is no universal feminist perspective, no single method, methodology or theoretical base for feminist scholarship; indeed there are various methodologies (Reinharz, 1992). However, underlying all feminist perspectives is a commitment to work for social justice, structural and personal transformation (Maguire, 2001).

One theme within feminist research which has particular relevance to my research methodology is that of the metaphor of 'voice' (Maguire, 2001). Freire's work (1972) began the process of breaking through the code of silence amongst marginalised groups and this has become a common theme in feminist research. Reinharz (1998) describes it thus – "by dealing in voices, we are affecting power relations. To listen to people is to empower them" (cited in Way, 1997, p. 706). This approach has special relevance for the role of the researcher as it is not our task to 'give voice' to those who are marginalised but, from our privileged position, to facilitate the breaking down of barriers to the communication of previously unheard stories.

Parallels exist with recovery approaches, consumer and tangata whenua perspectives in mental health because these perspectives privilege the sharing of experiences as a means to raise public consciousness, e.g. the *Like Minds, Like Mine* media campaign in New Zealand using real people talking about their illness in the context of their life. Secondly, the environment in which personal stories and experiences are shared is seen as a setting which allows the development of supportive (and potentially challenging) relationships.

An underlying connection has been made between empowerment and the processes inherent in relationship making, as feminists believe that people grow and change in context of human relationships (Maguire, 2001; Miller, 1986).

Conclusion

As this study has an exploratory focus, the appropriate methodology was a qualitative one underpinned by Critical Theory, feminist and Kaupapa Maori approaches, which has been constructed to give voice to the experiences of mothers who live with mental illness. This particular 'weaving' has also had a strong influence on my research design and process and this will now be described in detail.

5.2 Research Methods

Data Collection

The purpose of interviewing, then, is to allow us to enter into the other person's perspective.

Patton, 2002. p. 341.

Initially, the focus group method was chosen as the preferred means of data collection as it was considered a valuable qualitative feminist method which brings people who experience similar problems together and utilises the natural processes of communication (Wilkinson, 2004). Furthermore, the focus group method has been described as an appropriate method when working with powerless and disadvantaged groups within society. It lessens the power of the researcher within the group and allows the interaction between the group members to stimulate and encourage the sharing of information around the topic questions. When the involvement of a hauora organization as a partner in the research was unable to proceed due to the sudden death of the kaiwhakahaere (manager) and soon after, the destruction of their wharenuī (meeting house) by fire, time limitations meant that the second choice, individual interviews, were the timeliest method of data collection. This was a valuable lesson for the researcher in the need to maintain a flexible and responsive approach when undertaking research.

A combination of a general interview guide approach and a conversational interview style was utilised. The general interview style allows for subject areas within which the interviewer is able to explore and ask questions that will illuminate the specific subject. Its advantage is that it contributes to a more systematic process, especially valuable during the analysis process. In contrast, the conversational interview style allows for flexibility and a more spontaneous, "go with the flow" response (Patton, 2002).

The questions used to guide the discussion were:

- How does mental illness affect you being a mother?
- How does being a mother affect your mental illness/mental health?
- What has helped you as a mother with experience of mental illness?
- What suggestions for services/service improvements do you have?

Participants were offered a choice of the interview occurring in their home if convenient or in another location. Tea/coffee and a muffin were available before the interview proper began and the choice of having a support person present was offered. One mother chose to have her mother present for some part of her interview.

The interviews were recorded using a digital recorder and transcribed by the researcher. The advantage of the researcher transcribing the interviews personally was another layer of confidentiality and the opportunity to listen closely to the voices of the participants as a beginning of the data analysis process.

Participants and Recruitment

Purposeful sampling to select information-rich cases whose study will illustrate the research questions (Patton, 1990) was undertaken. Homogeneous sampling is the strategy employed as it allowed the description of a particular subgroup (mothers with mental illness) in depth.

The criteria for inclusion in the study was to be a mother, to be able to speak in English, to have experienced mental illness and/or to have used mental health services and to be mentally stable at the time of the interview. Initially, it was the intention of the study to allow mothers to define mental illness for themselves, as this has been the case with recent research undertaken by consumer researchers. However, the Health & Disability Ethics Committee specifically requested that a definition of mental illness was provided to clarify eligibility. The manager of a local Maori Mental Health team, who had herself carried out research in the field, suggested that a definition containing some names of mental illnesses would be helpful for potential Maori participants (C. Mokokoko, personal communication. Sept, 2006).

Hence the following definition was chosen from an internet search to find a definition in plain English, containing some well-known diagnoses:

Mental Illness is defined as a psychiatric or psychological condition, regardless of cause, such as schizophrenia, depression, bipolar illness, anxiety, personality disorders and/or adjustment disorder or other conditions.

Downloaded from: www.vpaweb.com/About/glossary/default.asp

Recruitment was undertaken via consumer networks across the Bay of Plenty and through advertising in the waiting rooms of the local Community Mental Health Centres and consumer-run service centres. A deliberate decision was taken not to recruit through mental health professionals, as it has been the experience of the researcher that selection can then be subject to their personal preferences. Self-selection is one aspect of the research process, which gives participants the power to be involved from the very beginning.

Wadsworth (1991) and Wadsworth & Epstein (1996) consider the inclusion of a critical reference group to be essential to ensure the relevance of the research and its methodological credibility (Lammers & Happell, 2004). This study utilised a consumer in this advisory role and she was pivotal in the recruitment process, and in discussion around the dissemination of the findings. A working relationship with the consumer advisor had already developed through her involvement with the local Consumer Advocacy Network Trust. Potential participants spoke first to the consumer advisor who gave them information and then passed on contact details to the researcher. Thus, the researcher was separated from direct recruitment and risk of potential coercion.

An arrangement was made for a tangata whai ora with whom the researcher had a long relationship through support of consumer initiatives, to act as support person/referee if any potential participants needed additional information about the researcher's background and experiences in working alongside consumers. This is consistent with Kamira's (2007) principle of participation in which she states that the community being researched has the right to seek references from the researcher and/or the learning institution.

Ten women indicated an interest in participating and following initial discussions, interviews were organised with eight women. The interviews took place over a five-month period from December 2006 to May 2007.

Ethical Issues

As the research intended to involve consumers of mental health services, it was decided by the Massey University Human Ethics Committee that the proposal should be submitted to a Health and Disability Ethics Committee and it was their process that guided the ethics application. The intent of the researcher was optimal power sharing with the participants, especially around the dissemination of the findings however, because the Health and Disability Ethics Committee specifically asked that details on information sharing from the project be included in Information Sheets, this became a decision to be taken by the researcher.

In the first instance, my ethics approval process was based on my desire to utilise focus groups in partnership with a local Maori Trust and the local Consumer Advocacy Network Trust. When this proved impossible due to circumstances beyond the control of the research, permission was sought from the Health & Disability Ethics Committee to use an interview format. The potential participants were approached with information about the change to an individual interview and all agreed to continue to participate.

Several ethical issues of relevance to this study will now be elaborated.

Minimisation of Harm

The basis on which the research was undertaken was of minimal risk and maximum benefit to the participants. The concept of whanaungatanga (connectedness and beneficial, inter-dependent relationships) was utilised to "do no harm". Bishop (1996) describes whanaungatanga as: "One of the most fundamental concepts within Maori culture, both as a value and as a social process" (Bishop, 1996. p. 215).

When a woman indicated a willingness to participate in the research, an initial visit was undertaken to talk through the research using the information sheet and to get to know the woman's mental health history. After a week, the woman was contacted to ask if she wanted to participate and the signed consent form was then collected. As part of the ethics approval process, a resource list was prepared containing information on relevant mental health services for each participant if help was needed after the interview. A winding-down time at the end of the interview was allowed so both the researcher and participant could check together on the after effects of the interview. This was followed up with a phone call a week later.

One mother was probably still mildly depressed during her interview and it was not as forthcoming an interview as most of the others. She revealed a suicide attempt between my first visit and the interview (which was delayed until the very end of the data collection process) but was still keen to be involved. The decision to be involved was hers to take given the desire to share power within the research process; however care was taken on the day of the interview to determine if she felt able to participate. She stated that the interview was a positive experience and, once the interview had concluded, the researcher was able to help her with advice to prepare for an interview with a psychiatrist. This seemed to the researcher to be representative of the spirit of reciprocity within which the research had been conducted.

People will often reveal more in an interview or focus group than they intend to and an ethical framework is needed to deal with this issue. The transcripts of the interviews were returned to the participants for editing and the opportunity to remove sections was made available. In the main, the editing that occurred involved spelling and grammar corrections. Once the copy was edited, the participants then signed the form to give consent for their interview to be used.

Privacy and Confidentiality

People who have experienced mental illness still face discrimination in their daily lives so the issue of confidentiality within research is of paramount importance (Peterson, 1999). Half of the mothers were involved in consumer organizations and as such, had varying public profiles and some had been involved in public campaigns against the stigma and discrimination experienced by people living with mental illness. Nevertheless, the mothers were assured that no identifying information would be used and they were given the opportunity to edit the interviews to make sure that any information with which they were uncomfortable could be removed.

Informed Consent

The use of a consumer advisor during the recruitment process was instituted to make participation as fully informed and subsequently as voluntary a process as possible. As the researcher had previously worked in the mental health sector in the Eastern Bay of Plenty, the consumer advisor was made available to any potential participants from that area to ensure that their involvement was voluntary. In most cases, the participants did not take up the opportunity presented. The initial visit provided the opportunity for questions to be asked and a full exploration of the parameters of the research to be undertaken before consent was sought.

Another aspect of informed consent is that the participant should be mentally well during the interview. An additional purpose of the initial visit was for the researcher (who has a background in mental health crisis work) to be aware of the mental health history of the potential participant so that during the actual interview, signs of distress could be identified.

Cultural and Social Responsibility

The Health & Disability ethics approval process required the use of locality assessments for the ethics approval process. These were carried out with the local Maori trust and the Consumer Trust and required a series of meetings to explain the proposed research, talk with relevant staff and then formally ask permission to carry out the research in the form of a partnership.

Most of the methodological influences on this research privilege consultation and relationship building even though this is at odds with normal academic practice which can value separation, objectivity and distance. Bishop (1996) speaks of the need to build research relationships characterised by connectedness, engagement and participatory consciousness. In a similar vein, Narayan encourages researchers to focus their attention on the quality of the relationships with the people who are being represented in the research, and on the bonds of reciprocity within which the research should be carried out (Narayan, 1993).

The basic principle underlining an incentive to participate in a research project is that of reciprocity. The researcher offers something in exchange for “the thing of great value” (Patton, 2002). In a situation where the potential participants are from a low-income section of the population, then it is sensible to reimburse them for expenses that might occur as a result of taking part in the research, for example, transport or childcare costs. Whilst researchers need to be aware of the possibility of inducement through any payments connected to research projects, in this case, the researcher wished to acknowledge the value of the participation by the mothers who lived with mental illness. The koha (gift) took the form of a \$20 voucher from a nationwide cut-price retailer, which the researcher encouraged the women to spend on themselves rather than their family.

Data Analysis

Experience is at once already an interpretation and in need of interpretation.

J. Scott, 1991. p. 779.

Patton (1990) describes qualitative findings as having a more variable content than quantitative data leading to responses which are not systematic or standardized, and analysis that is more complicated. However, for the purposes of this study, analysis was based on a simple version of content analysis coupled with aspects of grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1990), a type of thematic content analysis outlined by Burnard (1991). Theory arises from data by using a constant comparative method involving comparing emerging themes from the data with those which have already been identified from the accounts of mothers in the literature review (Ryan, Merighi, Healy, & Renouf, 2004).

The analysis took place in three stages. Firstly, notes were made after each interview with initial thoughts around emerging themes. In the second stage, the transcripts were read through and notes made on a phrase-by-phrase basis looking for both similar and unique themes, guided by the question format (van Heugten, 2004). This part of the process used a series of Word documents and written notes. These themes were then outlined in the third stage, grouped in relation to the questions asked and supported by direct quotes from the participants. The audiotapes were also listened to and were often a more vivid indicator of women's experiences than the transcribed, edited word.

One of the problems highlighted around the use of interviews as a research method is the interpretation of results and the potential for bias therein. (Bishop & Glynn, 1999) warn that the data has the potential to be interpreted according to the focus of the research subject and the researcher's agenda. A process of checking on the validity of the thematic categories was considered either via the participants themselves or by the use of colleagues but both time and confidentiality issues made this difficult. The strength of the commitment of the researcher to hearing and recording the voice of personal experience, and the use of themes from a series of international studies as a comparative tool provided a counterpoint to this concern.

5.3 Conclusion

In summary, the main approach used in this exploratory study was a qualitative one guided by four questions. This chapter has highlighted the various influences contributing to the development of the research methodology in order to research appropriately and effectively in the mental health arena. The personal philosophy and professional background of the researcher is made explicit. The end result is a methodology that reflects the value of hearing the voice of personal experience and through these stories, has the potential to bring about positive changes in both individuals and services.

The next chapter will present the results related to the questions described above and the following chapter will analyse and interpret the results and discuss them in relation to the themes described.

CHAPTER 6 FINDINGS

The adjustment took quite a long time before I saw myself as someone who was worthwhile. I'm finding myself an identity as a mum.

A participant, 2007.

6.1 Introduction

This chapter explores the findings of the interviews undertaken. A brief description of the participants will be followed by an account of the findings arranged into themes, some of which reflect the firsthand accounts in the literature review (chapter four) and others which are unique to this study. Finally, this chapter will explore what mothers with experience of mental illness consider to have been helpful in their lives, and their suggestions for services. As this is a study which seeks to place the narratives of the mothers who experience of mental illness at its very heart and thus as a central influence, the themes will mainly be articulated using the words of the mothers themselves.

The questions used to guide the research and which will structure the exploration of the themes were:

- How does mental illness affect you being a mother?
- How does being a mother affect your mental illness or mental health?
- What has helped you as a mother with experience of mental illness?
- What suggestions for services/service improvement do you have?

6.2 Description Of The Participants

Eight women were interviewed using the questions above as a guide to allow for an exploration of their views, experiences and needs. The criteria for inclusion in the study was to be a mother with experience of mental illness and/or a consumer of mental health services who could speak English and assessed by the researcher to be mentally stable at the time of the interview. Four women lived in the Eastern Bay of Plenty and four in the Western Bay of Plenty. Four identified as Pakeha or European New Zealanders and four as Maori with three of those women also acknowledging non-Maori ancestry.

Their ages ranged from 31 to 61 years at the time of the interviews. Five of the eight women were diagnosed with bipolar disorder, one with borderline personality disorder and two with depression and anxiety conditions. Five of the eight women also suffered postnatal depression and one a severe phobia following the birth of her child. Five mothers had two children, two had one child and one mother had four children. Lastly, three of the mothers were married at the time of the interviews with the remaining five parenting alone. All of the mothers were raising their children but four had adult children now living away from home.

6.3 How Does Mental Illness Affect Being A Mother?

Most women in international studies (Ritsher et al, 1997; Sands, 1995) and this present study expressed the opinion that mental illness was not the defining aspect of their lives, rather, as with most women, it was relationships that were central to their wellbeing (Cogan, 1998). Unfortunately, in terms of the effect of mental illness on being a mother, it is not only the periods of unwellness that affect both mother and child/ren but also the ongoing influence of society's stereotypes of mental illness as manifested, for example, through the attitudes of health and social work professionals.

Four main themes were identified in answer to this question and these will now be described.

6.4 The Impact Of Illness On Motherhood

When you are unwell, you are in a different world. You are on another planet and the children are left, more or less, in a kind of state where they don't know (what's going on).

The effects of the symptoms of different mental illnesses can have a dramatic effect on parenting abilities. The manic episode of bipolar disorder can bring loss of control and disinhibited behaviour. Examples of such behaviour recounted by the participants were fast driving and roaming around the countryside in a disorganised and erratic fashion, or a spontaneous garage sale in which the entire contents of the house were put up for sale. Many of these situations were ones in which children were often present alongside their mentally ill parent.

In one such episode, a mother interviewed described being pulled over by the police after driving at nearly 100 kilometres per hour in a fifty kilometre zone, being pepper-sprayed and then handcuffed by police, all in the presence of her child.

The depressive phase of bipolar disorder and a major depressive episode brings with them such a lack of energy, motivation and decreased levels of patience that even the smallest tasks of motherhood seem insurmountable.

One mother described a two-year period of depression:

Then I went down completely, for basically two years I wasn't normal it felt like I was drugged out too much and I was functioning at a really slow pace and didn't have, felt like I had no memory, no brain. I just thought I was worthless and didn't want to get out of bed every morning.

A severe phobia around water, arising from childhood trauma, experienced by another of the mothers, made caring for her newborn baby impossible without the assistance of a support worker. Confusion, both for mother and child/ren, is a theme, which re-occurs in the illustrations of illness given by mothers in the study. Additional doses of medication, following an acute episode, can lead to forgetfulness, poor memory and lack of concentration. An unwell mother with a small baby being bottle-fed by several family members and herself used a sheet of paper on the pantry door to remind her when and who had fed the baby. Another mother described her medication as like being in "an emotional straitjacket".

The last resort is often an admission to an inpatient facility, which could have led, in the past, to prolonged periods of separation of mother and child/ren. One mother, being detained in Tokanui Hospital for a year, was told she couldn't have leave unless she agreed to her eight year old son coming to the hospital for a week so the interaction of mother and child could be observed. She agreed reluctantly. He was attacked by another patient in the men's toilets, the only place in which his mother was unable to protect him. She describes the consequences of that situation:

It's made me feel guilty all these years. I held this huge guilt about me becoming unwell and that happening to (my son).

Finally, one mother commented on the lack of follow-up on discharge from the inpatient psychiatric unit around her parenting role. The emphasis of adult community mental health services was seen to be on the individual client's mental health care with little acknowledgement on how this might affect their experience of parenting.

6.5 The Effect Of Mental Illness On Relationships With Children

I think you are like a child because I think the mental burnout...It puts you back so that you have to learn a lot of things again. And that puts you in a situation where your children are probably more grown-up than yourself.

Children, unlike adult family members, have no choice but to be involved with their parent who is experiencing mental illness. The effect of parental mental illness on children has been much explored in the last decade; most of this exploration has been from the perspective of children, what is observed about their behaviour and their firsthand experiences (Cowling, 1999 & 2004). Some consumers (Anderson, 2005) have questioned the validity of Australian data which says that many children of parents living with mental illness experience mental illness themselves. It is her contention that in order for these children to receive counselling about any aspect of their parents' behaviour, they need to become clients of a Child and Adolescent Mental Health Service (CAMHS), thus inflating the numbers of those deemed to be actually affected by mental illness. There is no doubt that parents' ongoing mental illness does have an effect upon their relationships with their children and the mothers interviewed for this study articulated experiences which were both poignant but often full of humour.

A common impact on the children of parents with experience of mental illness is the reversal of roles known as parentification. Two mothers gave detailed accounts of this phenomenon with their older children becoming the protectors of their mentally unwell mothers and subsequently experiencing increased anxiety levels (especially around the taking of medication) and sometimes, high levels of embarrassment.

One mother depicted the dichotomy thus:

It was clear that XXXX had a problem with me. Not only in connecting but being the caretaker when I became ill and we had arguments and I remember when she said, "Mum, you are like a child, I have to look after you" and in the next moment, she said, "Do you have \$10?"

And the second mother illustrated the assumption of the parental role in this anecdote:

She would have been about 12 or 13, and she accepted my rambling so she tucked me into bed and said "now is there anything you think you might need? Could I bring you a bell?" Because this is what I used to do when she was unwell, I'd give her a bell and she'd say I could bring a bell and I'd say something like maybe we need to say prayers. She'd say all right then, would you like to pray? So we had this whole process where she'd make light of quite a serious situation really and at times, she would make connection with the mental health services.

For these children growing into adulthood, there can be the added confusion of needing to deal with changed roles when mothers, after many years of variable mental health, stabilise and no longer need their child's protection. Furthermore, difficulties in relationships with parents have been hypothesized as a psychosocial risk factor in the development of postnatal depression (O'Hara, Reim, & Campbell, 1983).

A third mother with a history of severe anxiety and panic attacks dating from her first pregnancy, articulates the range of emotions felt about her children:

I loved them dearly and wanted to over-nurture them in one respect but on the other hand, I couldn't cope with them. I wanted them to go away. And when they would go away, I just got so anxious about where they were or what was going to happen to them. And they suffered because of that, it wasn't neglect, in terms of their food and clothing and (being) left home alone. But they were home alone with a mother who was not there in her head, a mother who had withdrawn into herself and her deep, dark hole and couldn't communicate with them or play with them.

Severe insomnia led to difficulty in enjoying days with her children because of high levels of anxiety around her likelihood of sleeping at night. She alternated between over-involvement in their lives and a desire to be free of their care with resulting cycles of increasing anxiety into their teenage years. Both children subsequently became alcohol and drug dependent themselves.

Half of the mothers in the study felt an anxiety that they might have passed on mental illness to their children, either through the environment in which they were brought up or via genetic transmission. This meant that they were often over-vigilant and risked misinterpreting normal teenage behaviours as the early signs of mental illness.

In spite of the difficulties of growing up with a mother who has experience of mental illness, the mothers with adult children expressed pride in how their children had developed, speaking of them learning good values, being understanding and intolerant of abuse. The mother of a younger child with an acute episode in her recent past saw her child as confident, outgoing and with a remarkable ability to bounce back. Both school and Child, Youth & Family (CYFs) personnel supported her assessment of her son.

6.6 The Effects Of Stigma And Discrimination

Mental illness is one of the most stigmatised human problems in our modern times. Stigma is defined as being what people think and feel inside either as individuals or collectively, and discrimination as a description of what we say or how we behave as individuals or as a society (O'Hagan, 2007). At the heart of stigma and discrimination about mental illness are stereotypes containing a perception of dangerousness and unpredictability in spite of evidence to the contrary (Mullen, 1997). The stigma and discrimination associated with mental illness can be seen to increase the pressure on parents whose mental health is already fragile. All of the mothers interviewed could give examples of stigma and discrimination experiences in their lives. For example:

I remember when XXXX was about six months old, I joined Plunket and started going to a morning tea. One day we were driving over to the woman's house and I said, Oh, I have bipolar. That was the last time she picked me up. She just cut me off like that. She had been phoning once or twice a week. This particular woman did not want a bar of XXXX and I, once she knew I had a mental illness. I think in the car, she was literally terrified that I was going to pull out a knife and cut off her head.

Most of the mothers interviewed in this study were not able to be as open about their history of mental illness unlike the mother in the example above. The belief that mothers who experience mental illness are likely to be inadequate mothers, makes it difficult for mothers to discuss openly the problems they might be experiencing and seek help at the earliest possible opportunity.

Recently self-stigma or internalised stigma has been recognised as a type of stigma. Debbie Peterson, Senior Policy Analyst and Researcher at the Mental Health Foundation defines it first, as negative thoughts or feelings towards yourself because you experience mental illness and secondly, self-belief in negative stereotypes that have become associated with the experience of mental illness (McDonald & Peterson, April/May 2007). The next two examples detail the negative self-belief that characterises internalised stigma. Firstly, a mother talking about being with her baby whilst becoming unwell and the second mother's statement illustrates the profound damage caused by internalised stigma:

It just crossed my mind that maybe I could do something to her. To xxx just because she was crying. Not that I probably ever would but because that's what everybody says could happen.

I had deep-founded fears about my ability to be a mum, and it didn't really matter how many people said I was doing a good job, I never really believed them.

Sometimes I wonder, even now, if I'm good enough to be his Mum.

Stigma, whether internalised or not, not only affects the self-esteem and self-confidence of the mother with experience of mental illness, but can impact upon her children and family members. This is known as secondary stigma, a type of stigma by association and it can lead to a cycle of blame, shame and further secrecy.

Both mental health and health service professionals can also hold stigmatising attitudes and behave in discriminatory ways. The power of such beliefs is expressed by this mother:

I think that the big picture is you can't have a child if you've got a mental illness and it's still out there and even within the mental health system, there's that discrimination.

Four of the mothers had experienced treatment in the older psychiatric hospitals, which in this present day would be called abusive. One of those mothers, being pregnant only three years ago, felt that most of her pregnancy and labour was viewed through the filter of her psychiatric diagnosis. She described her labour experience in this way:

I had had enough epidural to knock out an elephant, that's what the anaesthesiologist said. And I had a reaction, I remember I was kicking my feet because one side of me was numb and it caused restless legs so my midwife decided that I was having a psychotic episode and tried to get, rang the crisis team to get me, during labour to have an anti-psychotic.

6.7 The Fear Of Loss Of Contact Or Custody Of A Child

Around the world, most mothers who experience mental illness endure not only the constant fear of losing their child/ren but also the reality of loss of custody and contact with their children. Figures between 28 – 60% custody loss have been quoted by international studies (Miller & Finnerty, 1996). Statistics of New Zealand women with experience of mental illness who lose custody of their children are difficult to obtain.

However, in an analysis of 500 lower urgency cases notified to the Child, Youth & Family Service in 1999, 30% of caregivers had mental health problems including alcohol or drug conditions (Service design brochure: Supporting Parents project, 2005).

One mother in this study described her fear in this regard thus:

If he (his father) was to bring that up, I worry about the discrimination thing, judging and saying you can't have your child even though he has been in your care.

Two mothers expressed general concerns such as:

*That's one of my fears, is that, you know, they will take XXXX.
I was at the beginning, really always scared that my mental illness, if anything happens, they take the children away. So this was my biggest fear in the first year.*

For the two mothers interviewed for the study who did have involvement with CYFs, their fears of involvement of Child Protection agencies were not born out by reality. One was assessed by CYFs workers following a referral post-delivery by her midwife and felt reassured by their positive report of her mothering capabilities and the close support of her parents. However, the whole experience was intensely stressful and she believes that true bonding with her child was delayed by around four months because she constantly feared that her child would be removed because of her psychiatric history. The second mother had nothing but praise for the work of the CYFs workers to re-unite her with her child, following a psychiatric episode requiring an inpatient admission. She received support from a family therapist, CYFs social worker and Alcohol & Drug counsellor and was re-united with her child within six weeks. Involvement with CYFs and A & D staff was ongoing for six months when she was passed onto a Community organisation for support.

6.8 How Does Being A Mother Affect Your Mental Illness Or Mental Health?

The Negative Effects

The birth of a child can trigger the onset of a mental illness and the essential tasks of motherhood can be a source of stress for a mother who has a vulnerability to mental illness, which hastens the development of conditions such as postnatal depression and anxiety disorders. It is estimated that one in ten mothers develops depression before or after childbirth and around one third of these will need treatment from mental health services (Ward, 2006). Furthermore, 1.5 – 2% of women experience postpartum posttraumatic stress disorder (PTSD), which is often misdiagnosed, leading to long-term mental health consequences (Wijma, Soderquist, & Wijma, 1997). Lack of rest, broken sleep and breast-feeding difficulties were commented on by several mothers as being instrumental triggers to a deterioration in their mental health. Three mothers specifically described the pressure they felt was put on women to breastfeed and their subsequent guilt and stress when, for many reasons, including often the need to take psychiatric drugs, which would cross over into their breast milk, they had to resort to bottle-feeding.

Society says that breast-feeding is good, that breast-feeding is the only way, the perfect food, so you go through all of that as well. I mean, I'm a less(er) than good mother (because of it).

Two mothers identified lack of sleep and rest as being devastating to their mental health. One described the development of long-term insomnia following childbirth, which led to erratic behaviour, self-absorbed thoughts and an extremely short concentration span. In this mother, pregnancy brought the first manifestation of a lifetime's experience of panic attacks and anxiety disorder. A second mother suffered a pregnancy psychosis, which led to an admission to a secure psychiatric inpatient unit and the re-appearance of self-harming behaviour from her youth.

The story of one Maori mother interviewed epitomises the detrimental effect that pregnancy and birth can have on mental health. It is the story of how cultural dislocation and a birth experience in a foreign country became a turning point in her mental health. Due to her isolation from her whanau and the nurturing experience which she believed she would have expected had she given birth in New Zealand, her youth, her lack of communication skills and a relationship which was characterised by domestic violence, she developed a postnatal depression which led to a more severe psychiatric illness. Her husband arranged for a doctor to assess her and the cultural divide between herself and her English husband and the English doctor is illustrated here:

With XXXX, I had her in England so that was traumatic in itself because not many Maori women have babies isolated from their whanau. It did affect Aroha and my wairua.

She (the English doctor) asked me the question, "What do you think is the difficulty here?" and I explained, "It's so cold here, it's so cold" and I was really referring to the wairua of our relationship and I've got a clear image of (my husband) getting up and turning the gas fire on. I knew he's not understanding me.

The Positive Effects

There are positive aspects to being a mother with experience of mental illness. All of the mothers interviewed commented on the value of motherhood. In line with the experiences of mothers interviewed in studies in the USA and Britain, the New Zealand mothers felt that motherhood did have a beneficial effect on their mental illness and mental health. Three mothers had experienced physical and sexual abuse in childhood, which they felt, had impacted on their ability to form functional relationships in adult life. However, they viewed their relationships with their children as turning their lives around, providing them with a more valued role in life than that of psychiatric patient. One mother expressed it this way:

I had already suffered mental illness previous to being a mother after my childhood sexual abuse experience so that tendency was already there but the fact that I am a mother and the fact that my (children) bring to me unconditional love because when you have been tainted

by abuse, it's something that makes you feel unworthy even if it's not your fault. Even if you are loaded with a burden of unworthiness and you have people in your life that make you feel like you are such a worthy person, it's wonderful.

A second mother described a ten to twelve year period of repeated inpatient admissions, suicide attempts and abusive relationships before the birth of her child. Since that time she has had eight years of stability, living at the same address and being largely mentally well. Another mother supported this account by viewing the value of caring for her son as being more beneficial to her care than other forms of treatment in a large psychiatric hospital. Finally when asked what had assisted most in her recovery from mental illness, one mother emphatically stated that her baby gave her strength to maintain wellness.

6.9 The Context Of Parenting With A Mental Illness

The relationship between parenting and mental illness is a dynamic one in that experiencing a mental illness can affect the ability to parent and the parenting role may have an influence on the way that a mother experiences her illness. Many of the types of issues faced by mothers who experience mental illness are connected not to their illnesses but to the fact that many mothers are dealing with challenges related to poverty and isolation. Many mothers who experience mental illness are parenting alone, existing on benefits which make it difficult to obtain adequate housing, appropriate childcare and reduces their ability to fund recreational activities usually seen to enhance the development of children in the modern day. Of the eight mothers interviewed, five were parenting alone and one further mother, whilst currently married, had also brought up her first child on her own. Three mothers specifically mentioned the difficulties they encountered living on benefits. They described it as challenging and as an additional stress, which affected people with experience of mental illness more than the general public:

You can't survive. I can't survive now. I can't survive on the benefit I get, I'm on the invalid's and I run out of money every week. I can't afford stuff. I can't afford clothes for myself, that's got to feel like crap. There's ways you can do it cheaply but most of the time you gonna find yourself stuck.

One mother speaking of specific assistance, the Working for Families allowance, describes:

Well, we could survive (without it), but we really wouldn't have much of a life really. It just makes it so we can basically have a bit of a life instead of stay home all the time and never buy anything. It's really good.

The cost of care from the primary health sector was highlighted by a mother who chose to obtain both her physical and mental healthcare from her GP which ended up costing hundreds of dollars a year, causing financial pressures which meant she often could not afford to go to the doctor when she needed to.

An additional environmental context in which mothers with experience of mental illness parent, is one in which they live with the ongoing effects of trauma related to abuse. Over half of the mothers in the study had experienced either childhood physical and sexual abuse and/or relationships characterised by domestic violence. An important risk factor for women's mental health and substance abuse is gender-based violence (at any age). Its influence is felt in diverse and mutually reinforcing ways; for example, the use of alcohol and/or drugs to cope with an abusive relationship can bring increased levels of depression and anxiety which then increases women's vulnerabilities to further abuse. Two of the mothers in this research have had ongoing treatment for drug problems, both prescription and non-prescription and experienced depression and anxiety in this context.

6.10 What Has Helped You As A Mother With Experience Of Mental Illness?

The idea behind the question of what was helpful to mothers with experience of mental illness was to identify what worked for them so that these strengths could be fostered and built upon when this research considers its findings. Two themes came through strongly and these will now be elaborated.

Support

Support was mentioned by all of the interview participants. The source of support ranged from spouses/partners, family, mental health professionals and peer support and advocacy services. The three married mothers in the research all cited their husbands as being an important source of support for them both with their mental illnesses but also in sharing parenting duties. One of the mothers, whose husband also uses mental health services, becomes his whanau support person when he is unwell. She has not always felt listened to by mental health professionals and attributes that to being both a tangata whaiora herself and Maori.

In spite of some studies, which have found that family help is often less available than presumed (Kelly, 1999), overwhelmingly, families were the prime supporters for all of the women interviewed. The level of support ranged from moving in with a mother to help her care for her baby, through to taking care of a child whilst a mother was admitted into an inpatient unit for up to three to four weeks.

Six of the mothers referred to various mental health professionals whom they felt had been instrumental to their short or long-term recovery. Words like humour, encouragement, empathy and understanding were used to describe the most effective approaches. Maternal Mental Health Services were found to be very helpful in initial assessment of mental health problems and in their ability to refer to practical services like home-based support workers, whilst one mother praised her psychiatrist as being a positive male role model in her life. Another mother commented favourably on the care received from her GP, who had an interest in both mental health and paediatrics.

Lastly, peer support and advocacy were mentioned by half of the mothers as being essential. Two other mothers with much younger children mentioned that they would like to attend a support group but geographical distance and financial pressures prevented this. The benefits of peer support were fittingly described by one thus:

Peers with similar stories or peers, that not only do we share stories but share the support of each other as a mutual relationship.

The second theme is intricately connected to the first, being both a precursor to support and the result of support.

Education/Information/Reflection/Empowerment

Four of the mothers were involved to varying degrees in consumer-run services, a fifth was studying at postgraduate level and two others with pre-school children were already considering voluntary work in the mental health sector with a view to ongoing education at a later point. All of the mothers interviewed had spent many years learning about themselves and their illnesses. Education about their illnesses, their triggers to becoming unwell, lifestyle changes to achieve a more balanced existence and awareness of the influence of thinking styles were all mentioned as being helpful. One mother specifically mentioned an empowerment course, recommended by her mental health professional, which she believed assisted her to leave an abusive relationship. Others talked of practical measures, which they felt had assisted their recovery such as listening to music, yoga, the use of flax omega oil and camomile tea.

The stories of two of the mothers interviewed, both of whom have had second children many years later than their first, illustrate the changes that personal growth and reflection can bring. For one mother, who experienced a period of illness with her second child, the difference was that she had taken the trouble to communicate clearly with her family around her support needs should she become unwell. They were then able to become swiftly involved with the care of her child, thereby lessening the impact of her admission. She commented, speaking of her older child:

There's a new sister on the scene who is reaping the benefits of a much healthier mother than she ever had. So I feel like I have a debt to her just to give her the benefits of the healthier mother that I am now, as opposed to what her experiences were then.

Recovery-oriented services, which Mental Health Commissioner, Mary O'Hagan believes can assist in overcoming self or internalised stigma, consist of services which aid the development of peer support and give opportunities for service users to lead and work in services thus providing positive role models to other service users.

The personal journey to self-awareness has now become the opportunity for employment with all of its benefits, attested to by one participant:

Working is really important, not just for the money but for that sense of being needed, value, having confidence, success.

6.11 What Suggestions Do You Have For Services/Service Improvements?

At the end of the interview, the mothers were invited to consider ways in which their experiences could be put to good use in suggestions for either new services or improvements to current services. Their suggestions will now be summarised under four headings.

Practical Assistance

The mothers interviewed had a range of suggestions for practical ways in which they could be assisted to parent in the context of mental illness. Top of the list, and mentioned by all eight mothers interviewed, was the idea of being able to access respite services which allow mothers with mental illness to either have a break somewhere with their baby (that is, in a situation where there was someone to help with the baby whilst they were able to sleep) or someone who came into their home to give support and possibly remain overnight to help with the baby. One mother suggested a type of Mobile Intensive Nursing Service (MINS) for mothers with experience of mental illness would be useful. Whilst some mothers had been able to access a Mothercraft Unit and found it to be helpful, its focus was perceived to be on the babies, rather than the mothers and the distance from their home to the hospital could be an obstacle. Participants felt that all families where there was an experience of mental illness needed ongoing access to local time-out or respite services.

All mothers who received home-based support services commented on how helpful they were. Five mothers felt that home-based support services (especially access to cleaning and help with organisational skills) should be available for a longer period of time and that workers should be replaced when they were away for training/holidays. One mother commented that the loss of even one day of help was devastating when it was the only opportunity to have some assistance. Finally, one mother summed up an additional benefit of home-based support in this way: "Talking is as valuable as a clean house".

Family-Focused Services

All of the mothers interviewed spoke generally of the need for a holistic approach to their needs. Over half the mothers (five) talked of the need for more family-focused mental health services where adult mental health services would have a focus on the needs of the mother in her role as a parent. A similar English study (Diaz-Caneja & Johnson, 2004) commented that generally women interviewed were satisfied with the mental health care they received, however they did not feel that their needs as mothers were of interest to mental health professionals and were rarely discussed. Apart from Maternal Mental Health Services, whose involvement was limited to the first year post-partum, the needs of these women as mothers seemed only to come up in times of crisis. Three mothers specifically mentioned the need for counselling and therapy services for their children, utilising a family approach. One mother explained her reasoning in this way:

(Mental illness) puts you in a situation where your children are probably more grownup than yourself. And at that time, I think it's really crucial for the mother to be supported because otherwise, the children have to take over the role and that's very traumatic.

Children suffer stigma and discrimination through the effects of their parents' illnesses so they need help to understand their emotions and to talk about it and be listened to.

Another mother wanted more access to counselling and talk therapies for mental health consumers much earlier on in their treatment for mental illness. She felt that if these have been available for her, rather than only the more traditional focus on medication then she would have understood herself and her mental health better and been able to achieve stability earlier.

Education and integration

Improved education of the health service professionals, CYFs social workers and Work and Income (WINZ) staff who work alongside mothers with experience of mental illness was suggested by over half of the mothers. Two mothers stated that midwives needed to have an increased understanding of mental health issues in their training, especially related to post-natal depression and the stress that some mothers feel around strong encouragement to breast-feed. A third mother felt that anti-discrimination workshops would be helpful for people using Plunket services. Finally a mother whose child was in temporary care of CYFs, felt that all of the CYFs workers needed a better understanding of the signs, symptoms and treatments for the various mental illnesses so that staff might realise that how a person presents when unwell is not necessarily how they are in an ongoing way as a parent. Lastly, two mothers stressed the need for an integrated approach to the needs of mothers with experience of mental illness by obstetric and mental health services.

In terms of education for women consumers, two mothers emphasized the large numbers of women consumers in mental health who had either experienced abuse as a child or domestic violence and suggested access to education around the effects of trauma and abuse especially during pregnancy.

Support

Receiving support, one of the areas that mothers thought had assisted them, was also one in which mothers felt more could be done. Three mothers suggested support groups or a peer support system. One mother portrayed a basic tenant of the recovery approach, which is Hope, when she described it this way:

When I am sick, it is nice to see someone who is well, who has got through.

Two women stressed the need to counter the isolation that mental illness can bring through the use of peer support systems, that is, consumers who could support fellow consumers whether in crisis or through an assessment of parenting abilities by a CYFs worker. Finally increased support for whanau who care for their tangata whai ora was proposed so that they could better understand the mental health system, the illnesses and treatments.

Primary Mental Health Focus

Two mothers who had experienced their mental health care being provided in a primary mental health setting were keen that more women could access similar care. A GP who could both check on mental health and the health of a baby was seen to be a reassuring combination. In order for mothers to readily access this type of care, work needs to be done on funding schemes which would allow mental health consumers to access such care at no cost, as they currently do, when care comes from Community Mental Health professionals.

6.12 Conclusion

Findings from this research mirror those of previous studies undertaken in North America, the United Kingdom and Australia. The mothers who participated gave insightful and eloquent accounts of their lives as mothers with experience of mental illness and of the practical and emotional problems which confront them daily. Although most women were engaged with mental health services and largely found them to be satisfactory, like women in other countries, their needs as mothers were seldom at the forefront of their mental health treatment, even though for most of them, being a mother was the role that gave the most meaning to their lives. The implications of these findings will now be explored.

CHAPTER 7 DISCUSSION

Organized collaboration between existing agencies is critical, especially since it is unlikely that all components of the service can be offered by one agency.

Seeman & Cohen, 1998 cited by Jacobsen, 2004. p. 120.

7.1 Introduction

The aim of this research has been to hear the stories of New Zealand mothers who live with mental illness, in their own words, and to contribute this perspective to an evidence base, which might inform and influence service development. The recovery and strengths approaches within mental health privilege the lived experience of mental illness as a means to educate and inform. Mothers living with mental illness are a group whose parenting experiences have not been considered as a vital component of their mental health care. The literature suggests that this leads to a lack of consideration of the support needs of both parents and children.

This small study has identified some issues which merit further exploration and from which principles will be drawn. These principles will then form the basis of recommendations to be made in the concluding chapter. The lack of adequate data (both quantitative and qualitative) about parents who live with mental illness underpins the consideration of all the issues examined in this chapter. The structure and content of mental health services will be discussed in the light of the experiences of the mothers interviewed followed by an analysis of the effects of stigma and discrimination on their lives and those of family/whanau. Finally, the chapter will conclude with a consideration of the influence of recovery and strengths-based approaches on the research and the researcher. Following the exploration of these issues, the strengths and limitations of the study will be considered.

7.2 Adequate Data Capture

In many systems of mental health service provision, the identity of the patient as a parent does not receive sufficient recognition.

Seeman & Gopfert, 2004, p. 8.

The literature review revealed a lack of concrete data internationally around the role of parenting alongside mental illness. This lack of data was substantiated by the researcher when attempting unsuccessfully to find out how many mothers live with experience of mental illness in New Zealand. In order to consider the needs of both parents and children, we need first to know how many families live with the experience of mental illness. It is the opinion of this study, backed up by the literature, that this requires an information system which asks mental health consumers about their status as parents and has the capacity to store information about their involvement with their children in whatever form, including access arrangements.

Dean & Macmillan (2005) recorded the effectiveness of such a system when detailing the approach to meet the needs of families where there is a mental illness by the South Eastern Sydney Area Health Services. Dependent children were routinely identified through compulsory questions on their Intake/triage forms and their subsequent care needs were met through increased referral rates to local Child, Youth & Family Services and other community agencies (Dean & Macmillan, 2005).

The first question to be asked is, "are you a parent?" And then, "are you the child/ren's primary caregiver?" When information exists about how many parents (both mothers and fathers) are the primary caregivers of their children, then we will have accurate figures which may be able to tell us if the common perception that mental illness leads to a loss of custody/access (well-documented in both international research and mentioned as an anxiety in this study) is accurate. The experiences of two study participants who were involved with their local CYFs were both positive in terms of support to keep mother and child together. This may reflect practice changes in that particular CYFs office but the survey sample is too small to be able to make a definite statement.

Accurate data can provide us with the means to ask the question: If parents are not the primary caregivers, then why not? And furthermore, what could help them to take a more active role in their lives of their children? Women in the study have talked about the negative effect on bonding brought about by fear and anxiety about losing their child. This fear/anxiety may contribute to the development of postnatal depression and/or anxiety conditions which are also implicated in the disruption of secure attachment between mother and child. Further research is needed in this area but first, a firm foundation of accurate data is required.

Women participating in the study talked about their feelings of isolation and of "suffering in silence". Two of the women interviewed hoped that their participation might lead to the development of a support group for other mothers dealing with the stress of mental illness and motherhood. One way to lessen isolation might be through the adequate collection of data with its potential for the identification of those with similar needs. Wang & Goldschmidt (1996) found that 40% of families surveyed had never received professional help related to their children and that 33% had a need for support that wasn't received because they were uncomfortable asking for help. Women in the study have echoed that reluctance to ask for help. A method of collecting data on parenting status simultaneously with other required information might assist in the recognition of their needs.

Data capture of the number of people with mental illness who are parents is, apparently, a logged requirement in the development of PRIMHED (the combining of the current two national mental health information systems – MHINC and MHSMART). However, according to a Ministry of Health official, it may only be practical to collect minimal data such as whether or not the adult client has dependent children for which they have care giving responsibilities but the capacity to distinguish between full or part-time or access may not be possible (C. Hamlin, personal communication, June 1, 2007).

Principle

That all services working with mental health consumers collect accurate and comprehensive information about the parental status of their adult clients.

7.3 The Structure And Delivery Of Mental Health Services

Development of effective, evidence-based interventions for families in which a parent has a mental illness is critical.

Hinden *et al*, 2006, p. 34.

For many years, the dominant model within mental health has concentrated primarily upon treatment offered to the individual; but a developing paradigm shift towards viewing the unwell parent within their immediate and wider family context is believed to be pivotal (Thornicroft cited in Gopfert, Webster & Seeman, 2004). The literature suggests that the compartmentalisation of services into Adult and Child & Youth Mental Health & Addiction Services and separate Child Protection Services makes such an integrated approach to the needs of families more difficult. This view is supported by the mothers interviewed in this study who spoke of a desire to receive family-focused services. By that, they meant services which are able to cater for both their mental health needs and give assistance with parenting issues and, at the same time, offer support and education to their children to assist them to understand and adjust to their parents' illness.

Key issues around the delivery of services expressed by New Zealand families and the mothers interviewed in this study are that services are funded to work with individuals not families; there are multiple agencies and workers involved in their care and a lack of flexibility in the care that is received. Two New Zealand initiatives are underway which are attempting to address these concerns. Current practices within Mental Health Services have been highlighted in the earliest findings of one of these projects as contributing to difficulties in receiving adequate referrals to the service.

The Auckland-based Home and Family Society pilot project provides counselling and support to families where a parent is using mental health services but the required number of referrals from their local adult Community Mental Health Services have been slow in coming.

Preliminary results seem to indicate that for the best utilisation of the support and counselling offered, any future service would need to be integrated within adult mental health teams (B. Staniforth, personal communication, October 8, 2007). Earlier on in the project, the lack of a co-ordinated response from all the agencies involved with families was commented on (Scoop, 20/2/07).

A similar structural difficulty has hampered the development of two COPMIA initiatives, both of which are located alongside Child & Adolescent Mental Health teams. A perceived lack of collaboration and cohesiveness with adult mental health services, which it is considered lacks a focus on the needs of families, has made it difficult to support children of parents with mental illness (S. Worthington, personal communication, February 2, 2007).

A second example of service development, informed by the results of a 2001 hui which consulted parents with experience of mental illness, has arisen because a CYF review identified that access to mental health services for their clients was a key problem. CYF is now funding a project to work with families notified to them who experience mental health and addictions issues, so that parents can retain or resume care of their children, thus keeping them out of CYF custody. It is planned that two pilots lasting two years in the first instance and likely to be based in Palmerston North and Porirua, will provide services to around 20 families at any time. The successful organizations will need to provide multi-cultural workers, use case management/needs assessment models, have good links with their communities and available services and finally be able to link into intensive home-based support services, including peer support services (K. Harrison, personal communication, June 29, 2007).

In spite of early intervention models being an effective, evidence-based approach in other areas of mental health treatment, it seems from the stories of the mothers interviewed, that there is little emphasis on an early intervention approach to parenting within the context of mental illness; rather the findings suggest that women almost need to reach a crisis threshold before help is made available. Even in a crisis situation, the assessment received by one mother was via telephone only in a situation where she was alone with two pre-school children whilst experiencing deterioration in her mental health.

Both the international literature on best practice services for families living with mental illness, and mainstream parenting literature within New Zealand stress that early identification of parenting issues and speedy assistance are vital to prevent dysfunctional environments developing. Mothers living with mental illness around the developed world and in this study have spoken about the stress of living with the social consequences of mental illness such as poor housing, poverty and isolation. Stress is generally associated with exacerbation of mental illness.

Integrated, family-focused services of the kind delivered by Family Support Services/PACE (Parents, Advocacy, Co-ordination and Education) in Iowa City, Iowa, and the Invisible Children's Project in Orange County, New York, both in the USA, are examples of community mental health programmes which, whilst having parents with experience of mental illness as their focus, can cater for all their family needs in a "one-stop shop" setting (The Invisible Children's Project, 2006). Such a service design has the additional bonus of normalising the experience of mothers with mental illness by being community-based and could potentially be sited alongside primary mental health and Well Child initiatives.

Hallwright (cited in Mental Health Commission, 2007. p. 8) has spelled out a vision of mental health and addictions services which are an integral part of health services, available wherever people go with health concerns, for example, in maternity services, school health services and health centres. This concurs with the views of two of the mothers interviewed who have been receiving their mental health care from their G.P. The positive impact for one mother was to get care for both her child and her mental health in the same place. The only disadvantage for the other respondent was in paying for the cost of receiving what would be free care from Mental Health Services. It might be useful to consider the shifting of individual costs from Mental Health Services to Primary Mental Health settings or the transfer of staff from secondary services to primary services so that mental health consumers have the choice about where they receive their mental health care.

Care Plus, which is a primary healthcare initiative which targets people with high health needs due to chronic conditions, could be instrumental in this area but it is speculated that it may be difficult for mental health clients to be accommodated as they may need more appointment time than is made available under this scheme (D. McArley, personal communication, June 11, 2007).

Principle

Mental health care for mothers living with mental illness is funded and delivered in the context of family-focused services which meet the needs of both parents and children.

7.4 The Content of Mental Health Services

Someone To Talk To: Parents And Children

Ideally all mental health service users should be offered some form of psychological therapy, or simply the opportunity to talk to someone, as a main part of their treatment. People with complex and long-term mental health problems and those whose troubles may appear less severe have an equal need to talk.

(Information Booklet for Service Users.
South London & Maudsley NHS Trust, London 2004, cited in Ward, 2006).

The literature review revealed several examples of best practice services for families living with mental illness which involved a mixture of practical assistance with parenting and individual and/or family therapy. Most of the women interviewed in this study support the idea of both mothers and their children having someone to talk to.

The lack of access to talk therapies for both those with severe mental illnesses and those with a more moderate form was commented on by half of the mothers interviewed and has been mentioned in several policy documents (Mental Health Commission, 2005). *Te Kokiri: The Mental Health & Addiction Action Plan 2006-2015* includes an action around expanding the range of effective and integrated services to include psychological therapies and a second action to revise and update the Child & Youth Mental Health & Addiction Services framework to consider the children of parents and whanau with mental illness and the maternal and infant mental health arena (p. 18).

Talking therapies are known to be effective for treating a wide range of mental health issues (Peters, 2007) including depression and anxiety, conditions in which women feature strongly (Oakley Browne, Wells, & Scott, 2006). The mothers interviewed for this study had mental health profiles characterised by co-morbidity and over half had suffered depression in the post-partum period in addition to their primary mental health conditions. One mother, whose history had encompassed several admissions to one of the former psychiatric institutions, believes very strongly that early access to counselling is vital, even for those with diagnoses such as schizophrenia and bipolar disorder.

The potential risks for children living with parents experiencing mental illness are well documented in both the literature review and in the findings of the interviews undertaken. Two mothers with adult children spoke specifically about their children being their main caregivers during times of illness, and of experiencing acute embarrassment in their teenage years about the behaviour of their mothers. One mother, with foresight, took her children along to her psychiatrist's appointment so that they could also have someone to talk to. It was her suggestion that services to support the children of parents with mental illness and addictions become an integral part of mental health and addiction services.

The risks for children living with parents experiencing mental illness are well understood but increasingly, studies are documenting the benefits of services which support children whose parents experience mental illness and addictions (Cowling, 1996, 1999, 2004; Hinden et al., 2006). Although COPMIA services are becoming more common in the New Zealand mental health context, they are still the exception rather than the rule. Currently children need to have a serious mental health problem in their own right (as well as support needs relating to their parents experiencing mental illness), to receive services from CAMHS which contributes to the picture of higher rates of mental illness in COPMIA children. The most well established services in the U.S.A and Australia generally work in an holistic, collaborative fashion promoting both the support of children and parents in a family-focused environment (Cowling, 1999; Hinden *et al*, 2006). Mothers interviewed for this study, in asking for support, have talked about that support being delivered in a way that does not contribute to further stigmatisation.

Principle

The content of mental health services is modified to take into account the needs of both mothers with experience of mental illness and their children and allows for appropriate counselling and support approaches.

Trauma-informed Services

The person with unrecognised post-traumatic stress disorder is condemned to a diminished life, tormented by memory and bounded by helplessness and fear.

Herman, 2001, p. 49.

The prevalence of abuse and domestic violence in the backgrounds of a majority of the research participants supports research, which has pointed out the link between trauma and mental illness (Read, van Os, Morrison, & Ross, 2005). This link was also emphasized in another recent New Zealand study (Boden & Boden, 2005) into the support needs of women who experience mental illness which also found that the vast majority of the consumer participants reported a history of either physical or sexual abuse. The literature reports that abuse of all kinds and domestic violence are issues which predominantly affect women and are considered a factor in the correspondingly high rates of depression and anxiety experienced by women.

The commonly held view that "people with mental illness are violent" is, to some degree, negated by the high rate of partner abuse experienced by women living with mental illness, although many may live with a partner who also experiences mental illness. This is supported by the finding that over half of the women interviewed (five) reported at least one abusive relationship and that these relationships had had a negative effect on their self-esteem and subsequent mental health. However, District Health Board (DHB) Mental Health & Addiction Services have routinely passed on referrals for counselling or therapy solely for abuse, in spite of the prevalence of abuse histories in those who fall within the 3% serious and ongoing mental illness category.

Te Haererenga mo te Whakaoranga 1996-2006, a report on *The Journey of Recovery for the New Zealand Mental Health Sector*, published by the Mental Health Commission (2007), acknowledges that there have been difficulties in women with mental health histories accessing counselling via the Accident Compensation Corporation (A.C.C.) because there are not enough therapists with experience in working with trauma within the context of mental health conditions. The current programme to screen for domestic violence in all health settings has not yet been fully translated into the mental health arena. Women with mental health histories are often excluded from Women's Refuge services but access to mental health respite services which cater for women and children is limited.

Women in the current study spoke of the need for the training of health and social services professionals to be informed by the direct experience of mothers living with mental illness. Specifically two mothers commented on the large numbers of women consumers in the mental health field who had either experienced childhood abuse and/or domestic violence in adult relationships and suggested access to education around the effects of trauma and abuse during pregnancy for midwives and other obstetric personnel. As with some aspects of mental health treatment such as seclusion and restraint, care during pregnancy and labour has the potential to re-traumatise a vulnerable woman (Simkin & Klaus, 2004). Post Traumatic Stress Disorder (P.T.S.D.) as a result of labour is increasingly recognised (Wijma et al., 1997).

Nicholson, Sweeney & Geller, 1998a/b state that less well studied is the impact of childhood traumatic experiences (perpetuated by women's parents/caregivers) on the parenting style of women living with mental illness. Three of the mothers interviewed experienced childhood physical and sexual abuse which they believed had impacted negatively on their ability to form functional relationships in adulthood. Nevertheless, they found being a mother brought meaning into their lives with positive consequences for both them and their children. This experience lends weight to the assertion that the rehabilitative aspects of parenting have been often unrecognised or ignored (Zemencuk, Rogosch & Mowbray, 1995). This could represent a potential opportunity to "increase women's self-esteem, feelings of competence and usefulness to others" (p. 89).

Recent mental health strategy documents (Ministry of Health, 2005, 2006) have recognized the need for a broader range of services for people with specific mental health needs, including people who have suffered trauma. The problem of the exclusion of people with trauma/abuse histories may be tackled by the revision of the National Services framework to ensure that all service users have their needs well met, e.g. people with experience of trauma (p.18).

Principle

All services which work with people who experience mental illness and/or addictions identify trauma/abuse histories in their clients and make available appropriate services to treat trauma and its long-term mental health consequences.

Practical Services

A lack of social support can exacerbate symptoms while the presence of adequate social support can alleviate symptoms, or can mitigate the negative effects of stress and trauma.

Boden & Boden, 2005, p. 10

Trauma and stress are widely acknowledged as triggers for mental illness and the participants in this study have attested that being a mother with experience of mental illness can be a stressful role. The Stress Vulnerability model would view support for mothers experiencing mental illness as a Protective Factor, a buffer against the effects of stress. Mothers interviewed spoke of the importance of support in their lives, even when that support was short-lived.

One of the features of the data collected was the wide range of very practical suggestions for services and improvements to services suggested by the mothers interviewed. Many seem feasible to implement and may require extra resources, rather than a modification of existing funding. For example, most of the mothers, unprompted, talked of the need for some form of respite, either out of the home with their babies or to have someone come into the home to help in the nature of a mobile service.

This approach is supported by a study looking into women's respite needs (Boden & Boden, 2005), which found that respite options needed to be improved. One mother interviewed had experienced a supportive, calm respite environment where both she and her child were cared for but this was only available to her for less than a week. Generally, respite is currently available for individuals but not for families.

Presently most MH&AS have access to home-based support services but the current philosophy is to 'work alongside' rather than 'do for' and this has sometimes restricted access to practical assistance even when this might be the most beneficial action. Childcare is not usually part of the remit of home-based support services. Most mothers found the home-based support offered valuable but too short-term. They suggest that the assistance offered needs to be flexible, supportive and consistent with cover for sick and annual leave of home-based support workers.

Principle

A wide range of supportive care options for mothers who experience mental illness are explored including appropriate respite options and flexible approaches to home-based support.

7.5 Stigma and Discrimination

The project (*Like Minds, Like Mine*) has the potential to improve mental health by enhancing the self-esteem of people with mental health conditions and by reducing stigma around seeking help.

Mental Health Commission, 2007, p. 199

Excellent work is being done through the national *Like Minds, Like Mine* campaign to educate the New Zealand public about mental illness by the use of positive role models (Phoenix Research, 2005). The mothers interviewed in the study still attested to the power of an image of ideal motherhood that does not involve mental illness. Half of the mothers interviewed were not at a point of being able to speak openly about their mental illness but half were working within consumer-run services in which the experience of mental illness was a pre-requisite for employment.

The experiences of these mothers who have become involved in peer support and advocacy services support the belief expressed in the literature that one way to overcome stigma is by the development of peer support and recovery education services. These offer belonging, hope, choice and self-determination through positive role models (O'Hagan, April/May 2007). The value of consumer experience in mental health is being acknowledged, as evidenced by one of the mothers who did not have any involvement with the consumer movement but was already planning for training in a mental health field once her younger child began to attend childcare.

Employment of consumers (and in this instance, mothers with experience of mental illness) can be seen, by the experience of the working participants in this study, to intervene positively on two levels of stigma. Firstly, employment positively affects self-stigma wherein the consumer has internalised negative beliefs about people living with mental illness and secondly, employment changes the way in which the community views people living with mental illness. Employment allows the opportunity to refute stereotypes about people experiencing mental illness (Like Minds, August 2007) as it is these stereotypes which contribute to stigma. The participants of this study attested to the value of employment and its beneficial effects on their mental health.

Recovery approaches within mental health incorporate social inclusion as a core component. The link between social connection and wellbeing is well known – “In the end, what promotes recovery from mental illness is the same as what promotes healthy communities and good mental wellbeing” (Like Minds, August 2007, p. 4). This means that people with experience of mental illness play an active part in their communities and receive services in their community. For mothers living with mental illness, services which have a family focus, and are located within community settings could potentially lessen the stigma of mental illness by dealing with the illness as but one issue within the lives of those who experience mental illness, rather than the primary focus. Family-focused services may lead to the lessening of secondary stigma on family/whanau and make it easier to seek help. Women interviewed strongly endorsed the concept of support for those who support them.

The spread of information and education about mental illness in the context of motherhood is seen as yet another means of lessening stigma and discrimination. Two of the participants made suggestions around specific input into the training of two of the professions involved with mothers who experience mental illness – that is midwives and CYFs staff. Currently there may be a component of education about mental illness/mental health issues to both the midwifery and social work curricula. The inclusion of such experiential learning programmes as the Hearing Voices workshops and hearing firsthand from mothers living with mental illness might augment formal training and maximise its relevance.

Principle

Information about the experience of mothers living with mental illness is incorporated into the training of relevant professional groups.

Support is given to training and employment opportunities for mothers living with mental illness.

Like Minds Like Mine destigmatisation campaign utilises the stories of mothers living with mental illness to educate the public.

7.6 Support – family/whanau

The support from my family has been marvellous. I was pleased that other people had more of an understanding. It allowed me to reach out to them and they can reach out to you.

Fahy & Lysaght, 1999, p. 20.

Both the literature review and the findings of this research have identified family/whanau as the primary support for mothers with experience of mental illness. Simultaneously, the literature talks of family/whanau as being “the forgotten resource” (Jack-Kino, 2007). This view is supported by a recent SANE: Australia survey which found that 72% of those surveyed had received no support and 70% also stated that they had not received any training or education for their role as carers of those experiencing mental illness. A New Zealand stock take of Family Advisors and their work identified a wide range of unmet needs including gaps in information and education and marginalisation by services (Mental Health Commission, 2005).

One in four of the Australian carers surveyed in the above study also had a mental health diagnosis, as did one of the mothers interviewed whose partner also experiences mental illness. She specifically stressed the need for effective discharge planning which involves family/whanau and which puts services in place before the consumer leaves the hospital. Other mothers interviewed endorsed the availability of enhanced home-based support during times of deteriorating and/or recovering health and appropriate respite options as components of such a support package.

Australian caregivers asked for proven family interventions to be offered as part of standard clinical care (SANE, 2007). Best practice examples from the United States offered both individual and family therapy to the parents in their service and, as reported earlier, half of the mothers interviewed wanted family-focused treatments. Engagement of family may improve the overall effectiveness of community mental health treatment for clients. Women's families (partners, parents and others) need to be the first network to consider enhancing by providing supportive engagement and education about mental illness (Brunette & Dean, 2002). Comprehensive information/education needs to encompass much more than the symptoms of illness and the types of treatment. It needs to be set within experiences of mental illness as particular context – hence the experiences of mothers with mental illness are essential to understanding how best to support them.

Principle

Practical support options for family/whanau who care for a person experiencing mental illness exist.

A family-focused approach to mothers living with mental illness is fostered by shared training between family/whanau and mental health staff.

7.7 Recovery And Strengths-Based Influences On Research

The use of a strengths-based and recovery focused perspective to guide the study is congruent with the overall philosophy shift underlying the delivery of mental health and addiction services in New Zealand over the past twenty years. Literature which considers research from a recovery and/or strengths perspective is sparse but within social work in particular, approaches have been developed which utilise an empowerment paradigm. Rapp *et al*, (1993) state – “One way of empowering is to explore consumers’ strengths” (p. 730).

The experiences of mothers living with mental illness with mental health services in the past have been characterised by failure – failure to be well and failure to be an adequate parent (Gopfert *et al*, 1996). When services, staff or researchers look for what is working in order to support women’s efforts to remain well, this can become the basis for meaningful research. Acknowledging that the causes of mental illness are many, allows us to focus on strengthening the environment in order to promote internal resilience. When asked, women had many suggestions for what had worked and how services might change to better support them.

Out of such an approach has emerged the discovery of motherhood’s rehabilitative functions. Mothers interviewed spoke powerfully about the positive role that their children played in their ongoing recovery. The stories narrated by the mothers interviewed were full of reflection and growth from the experience of mental illness. Their suggestions for improvements in services gain strength as a result. The role of consumers as experts in their own care is given added importance by research which incorporates learning from the lived experience (Lapsley, 2005; Trivedi & Wykes, 2002).

Research set in the Aotearoa/New Zealand context has involved a process in which whanaungatanga or collaborative relationships have been imperative to the successful completion of the study. This is supported by literature which considers that building relationships that are meaningful, authentic and supportive is an important criterion for community research (Lincoln & Guba, 1985; Ochocka *et al*, 2002).

Principle

Recovery and strengths based approaches influence the design of studies which research and evaluate the experiences of living with mental illness.

7.8 The Strengths Of The Study

Ask women what they want.

Nettle & Phillips, 1996, p. 215.

The primary strength of the study is that it has heard and recorded the stories and experiences of mothers who live with mental illness in Aotearoa/New Zealand in the spirit of respectful partnership. There have been an increasing number of studies undertaken in New Zealand which have utilised firsthand experiences of consumers to describe life with mental illness (Fahy & Lysaght, 1999; Lapsley, Nikora & Black, 2002; Leibrich, 1999; Mental Health Commission/KITES, 2005). Most of these studies have utilised, as has this research, a qualitative methodology which involves a narrative perspective made up of the voices of people experiencing mental illness.

There has been a study completed on the experience of pregnancy, labour and the post-partum period for Maori women who experience mental illness (Semmens, 2006) and some studies which have focused on the experiences of children living in families experiencing mental illness. There are few, if any, previous qualitative studies which have employed in-depth interviews with mothers living with mental illness. This gap in research in Aotearoa/New Zealand provided the impetus to undertake the study.

The findings are congruent with international research where qualitative studies have asked mothers living with mental illness about their views and experiences. The themes which occurred in the literature review, and then in the findings chapter, were the acknowledgement of the importance of the parenting role, the reluctance to ask for help because of the fear that children will be removed purely on account of the mother's mental illness; the desire for services which are designed around the specific needs of mothers with experience of mental illness and the ongoing role of stigma and discrimination in the lives of mothers living with mental illness.

This study cannot claim to be conclusive of the views of mothers across the country but it can certainly claim to have provided an indication of the views, experiences and

ideas on service development of the women in the study. Overwhelmingly, it is a positive study in that it contains examples of women now living successfully alongside mental illness. Simultaneously it is populated with examples of the risk that untreated and unsupported mental illness has on individuals, children and the family. Mothers with experience of mental illness are as capable of raising their children as any other mothers but with targeted support, their stress would be ameliorated, the potentially adverse long-term effects on their children could be lessened and the mental health of the family/whanau and the community in which they live could be improved.

7.9 Limitations Of The Study

The size of the study is the first limitation. Whilst initially, it was planned to facilitate focus groups where the numbers participating would be greater, this did not prove possible so that eight individual interviews were undertaken instead. Nine women indicated an interest with one withdrawing after the first meeting citing concerns about the effect of the interview on her mental health. Time constraints did not allow for a long recruiting period so the researcher began the interview process with the eight women who were still interested.

Five out of the eight participants were recruited from within the consumer movement so there is a definite bias towards mothers who, it could be said, are evidence of the benefits from recovery influences and the subsequent development of peer support services. Their experiences may be vastly different from those of mothers who have not been involved in consumer initiatives. However, one of the other three participants reached a similar level of self-knowledge through further education. Although the sample may be biased, it is biased towards positive examples of mothers living with mental illness, because such examples build hope which is an essential component of the recovery influences of this study.

A further limitation is the lack of specific cultural input, especially as half of the study participants turned out to acknowledge Maori whakapapa. In the first design of the study, a partnership was planned with a hauora organization where a focus group would be held in the Whare Oranga and co-facilitated by one of the Maori community workers. Due to a number of circumstances discussed previously in Chapter Five, this proved impossible. Maori mothers were consulted as to the change and all were comfortable with their continuing involvement in the study. The issues raised were similar for all of the mothers. It is in the service design and delivery area where culture can be seen to have an impact. The experience of being a mother living with mental illness appears not to be all that different for women of different cultures, but diversity of response is paramount.

A further limitation may be that the random recruitment did not throw up any participants with an ongoing experience of psychosis or schizophrenia although one mother initially diagnosed with schizophrenia before she was re-diagnosed with bipolar disorder. Parenting alongside the experience of psychosis and/or schizophrenia may provide yet another perspective to the experience of motherhood and mental illness.

7.10 Reflections On The Study

The reflective practitioner is well placed to become the reflexive researcher, using reflexivity to understand and make sense of research findings.

Fuller & Petch, 1995 cited in Atkinson, 2005, p. 425.

Undertaking research informed by participatory action research models in the sense that the role of the researcher changes from that of expert to that of facilitator and supporter felt like a natural process for the researcher. Having worked alongside consumers who were developing early forms of peer support services for many years and with many years' experience in the maternal mental health field, the subject and the process of the research fitted with my personal and professional profile.

Social work skills such as sensitive interviewing, good listening combined with counselling-type attributes such as warmth and empathy, it has been noted, are well utilised in qualitative research (Atkinson, 2005). The data collection process was the most enjoyable part of the research process for this reason. For the researcher, this was a humbling process because it involved sharing both the positive achievements but also being witness to experiences of suffering and discrimination.

Research in which partnerships and participation are encouraged also brings with it responsibilities in the form of seeking to do the best job in communicating the views of the participants of the study because of the close nature of the relationships developed throughout the research process. Research relationships take time and energy to get right, and the time-consuming nature of this process was something that emerged during the research activities. The advantage of such an approach is that the researcher does feel like a member of the team which is aiming to get the stories of mothers living with mental illness out to a wider audience.

The mothers participating in the study welcomed the opportunity to participate and seemed to be pleased to have the opportunity to talk about their lives as mothers living with mental illness. Most expressed a desire that changes to service delivery might occur as a result of their experiences and suggestions.

7.11 Conclusion

The findings of this study reflect the direction of key strategy documents and recent reports in the health and mental health area. The research has relevance both nationally as a support document to the various projects being undertaken and locally as a pointer to some possible changes in services.

This study reflects the findings of international research and its conclusions support the contention that the experience of mothers living with mental illness is similar across countries and cultures. Best practice models that emphasize integrated, family-focused services fit comfortably alongside both Maori and Pacific Island models of health and into an environment in which recovery and strengths approaches are promoted.

CHAPTER 8 CONCLUSION: TRANSLATING FINDINGS INTO ACTION

The challenge for service providers is to reduce the gap between currently available services and optimal services. The eventual cost of our current neglect will be substantial.

McLean, Hearle & McGrath, 2004, p. 343.

8.1 Introduction

The basic aims of this research have been firstly to record the experiences of mothers living with mental illness and secondly, to specifically ask them what was helpful to them in their recovery process, and what additional services or service changes they would recommend. The role of the mental health consumer in critiquing services is well established as part of recovery approaches within the New Zealand mental health scene (see Chapter Two) and such feedback has had some success in modifying services to better meet the needs of consumers.

The literature review established both the environment in which mothers with experience of mental illness parent (Chapters Two & Three) and introduced what is already known, both internationally and in Aotearoa/New Zealand (Chapter Four). The main themes from the literature were the invisibility of mothers living with mental illness when searching for accurate data; a pervasive fear of losing custody or access to children; that experiences of stigma and discrimination were commonplace and led mothers to be reluctant to ask for help; poverty was a significant stressor to many mothers and finally, the value of being a mother was emphasized as a way to increase self-esteem and a tool for recovery.

The qualitative methodology was influenced by elements of Critical Theory, feminism and Kaupapa Maori models as these approaches privilege giving 'voice' to marginalised groups. The data collection was through in-depth interviews and the data was interpreted utilising a thematic analysis. The findings were concentrated into a number of principles which form the basis for the following recommendations.

8.2 Recommendation One

The first recommendation is one which will provide the foundation for all other recommendations to arise from this study and that is:

That accurate and meaningful data is collected within the current, national Mental Health Information systems to record the number of adults who use mental health services who are parents and their parenting arrangements for their children. Parents need to be supported to maintain contact with their children within a range of circumstances so the means to collect all-inclusive information is paramount.

8.3 Recommendation Two

Integrated, family-focused services for all parents living with mental illness are developed which utilise early intervention approaches.

The views of the mothers interviewed support the literature. They concur that the most relevant services for families living with mental illness are those which are not bounded by the current parameters which separate the provision of mental health care into age-related categories, and child welfare agencies from health and mental health providers. Research suggests that the separation of services into independent units reinforces a fragmented approach to the needs of families living with mental illness and conversely, interagency co-operation is enhanced where there are more integrated service structures (Baistow & Hetherington, 2004).

It has already been stated that there is a lack of a family focus in adult mental health services and that children of parents with mental illness who have support needs but are not mentally unwell often have difficulty in accessing CAMHS which may well have the required family focus. It is recommended that a COPMIA service be considered an essential component of a family-focused service, potentially lessening the possibility of the stigma that attaches itself to a child or young person as a client of a MH&AS. The best practice examples of such a service are from Australia and are both CAMHS-based and also involve partnerships with NGO providers (Cowling, 1999).

Interagency collaboration is the key to effective support for families living with mental illness, but the extent of collaboration is influenced by the way in which health and social services are organised. Organizational and geographical separation of services leads to “a lack of shared discourse about the family” (Baistow & Hetherington, 2004, p. 367) and makes informal contact and consequent information sharing that much more difficult. Rigid professional boundaries, ignorance by various health and child welfare professionals about each other’s roles, and the lack of a shared knowledge base around mental illness, child welfare/development and family issues also work against the ‘whole of family’ approach.

The provision of early, expert interventions has the potential to make a significant difference to families living with mental illness (both children and parents). Services in Germany and Scandinavia and the best practice examples in Iowa and New York State in the United States committed the most intensive resources, at the earliest possible stage with families, rather than wait until the crisis point was reached, as is the experience of many parents in New Zealand.

Family-focused services may be designed in many different ways but the design needs to encourage collaboration, integration and information sharing. Some of the groundwork may already be being laid in the form of pilots and the development of primary health initiatives which may more easily integrate the physical and mental health care of mothers, fathers, children and family/whanau. A further means to encourage integration and collaboration is the basis of Recommendation 3.

8.4 Recommendation Three

The experience of living with mental illness from the perspective of mothers is incorporated into the education of health and social services professionals.

The spread of information about life with mental illness involving the direct experience of consumers is considered to be an essential part of combating stigma by raising awareness. It has been claimed that recovery must be led by consumers and informed by their unique lived experience of mental illness (Mental Health Commission, 2007).

The participants of this study gave many examples of discriminatory behaviour from professionals with whom they were involved, ranging from midwives to mental health professionals and CYF social workers. It has been suggested that a woman's ability to retain custody of her children is often critical to her recovery (Zemencuk *et al*, 1995) but it is also true that mothers living with mental illness are reluctant to ask for help as they fear the involvement of outside organizations will lead to the loss of their children. At the same time, helping mothers living with mental illness to maintain custody and contact with their children benefits both mothers, through increased self-esteem and personal growth, and their children through a strengthening of the family bonds (Mowbray et al., 1995; Sands, 1995). Exposing other health and social services professionals to recovery and strengths-based approaches to mental illness may assist those professionals to view their roles with families living with mental illness in a more positive and active fashion.

8.5 Recommendation Four

All services working with mothers living with mental illness recognise the long-term and interconnected effects of trauma and abuse and organise appropriate treatment and education.

This study supports the recognition by the report, "We Need to Talk" (2007) of the importance of the wide availability of talking therapies, which are important in treating trauma and its long-term mental health consequences.

Fowler (2000) found that for some people, making the connection between their life experiences and their previously incomprehensible symptoms could have a therapeutic effect. The identification of a trauma history in women living with mental illness is essential, especially as untreated traumatic memories may have an adverse effect during pregnancy and labour and influence parenting style. Whitfield, Dube, Felitti, & Anda (2005. p806) state that: "The effects of childhood and adulthood trauma are treatable and preventable...Finding such a trauma-symptom or trauma-illness association... may help patients by lessening their fear, guilt or shame about their possibly having a mental illness".

8.6 Recommendation Five

Existing mental health services explore more flexible ways to give practical support to both parents and their family/whanau living with mental illness.

Mothers interviewed rated support as both the most important means to cope with motherhood and mental illness, but also the area in which more could be done. Suggestions for a more flexible home-based support service and the development of varied, flexible and long-term respite options for both individuals and families would be relatively easy to take up even within current structures. Ultimately, if such support services could be based within a family-focused service or within a primary healthcare setting, their utilisation would contribute to the social inclusion of those experiencing mental illness.

Such support needs to be proactive not reactive, occurring within an early intervention response to the stressors of parenting alongside mental illness, rather than as part of a crisis package. Support that assists family/whanau is an integral part of this recommendation. Family members who provide help are often alienated through fear, ignorance, or the strain of unsupported care. Again, a family-focused approach to supporting all members of the family living with mental illness is pivotal.

8.7 Recommendation Six

That further research is undertaken into the views and experiences of a larger group of parents living with mental illness, particularly those experiencing psychosis or Axis II disorders.

This study has provided an insight into how a small group of mothers live with mental illness. Further research is recommended which considers the needs of a larger group of both mothers and fathers living with mental illness throughout Aotearoa/New Zealand. Some form of triangulation would be useful by perhaps beginning with a survey tool followed up by a combination of focus groups and individual interviews in a variety of settings. A partnership of Maori, Pakeha, Pacific Island and Asian researchers working together is another suggestion to look at the impact of culture on the experience of motherhood and mental illness and subsequent service design.

The six recommendations represent the gathering together of the experiences and suggestions of the mothers interviewed into six categories, all of which are considered necessary to construct services which may better meet the needs of mothers who parent whilst living with mental illness. It is clear that if outcomes are enhanced for women, those efforts will most likely to be repaid in an improved level of mental health within the general population.

Some recommendations (trauma-informed services and a more effective partnership with A.C.C. plus a range of flexible, practical assistance) could be integrated into whatever system currently exists. There is a clear need for advocacy to training providers with respect to the provision and integration of relevant training courses. The collection of simple data may be possible within the current development of PRIMHED but again, its inclusion needs to be promoted by interested parties to the Ministry of Health as being essential.

The recommendation of family-focused services, as in the best practice examples from the United States and Australia, will require major changes in how we currently deliver mental health and child welfare services in Aotearoa/New Zealand. Most mental health and child protection services in the twenty-first century are still focused on risk, rather than support for the mothering role of women living with mental illness. It is apparent that clinicians can no longer assume that having a mentally unwell parent places a child at risk (Human Rights & Equal Opportunities Commission, 1993). In researching family conditions that promote resiliency, Rutter (1979; 1985; 1990) found that a favourable home environment alongside a stable, cohesive family, a good relationship with one or more parents and positive parental role models made a difference. The movement towards greater investment in early interventions focused on all parents with young children, is based on international research demonstrating the effectiveness of such interventions in changing behaviours and achieving good outcomes. The evidence is also available for the efficacy of such interventions with families living with mental illness. Children will be the beneficiaries of the work done with their parents.

The key to achieving optimal services for mothers living with mental illness is a family-focused service into which a range of health, mental health and child welfare professionals has input. Such a service fits closely with current Kaupapa Maori, Pacific Island and Asian models of health in which the family is the primary focus for intervention rather than the individual. Such a service, if placed within a community setting, would promote social inclusion and thus work to lessen stigma and discrimination. There is no one right way; services need to be designed by the communities they serve to meet their needs.

The experiences of the mothers interviewed for this study attest both to the vital role that parenting could play in recovery, but also to the stress involved in being an unsupported parent living with mental illness. Most, through a combination of education and reflection, are now able to offer their experiences to others through peer support and advocacy, and to give voice to the notion that most parents living with mental illness can parent successfully, usually with only a little additional support. The amazing journey of these women who have coped, often with very little support but now offer support to others, is truly a manifestation of recovery in action – to live and to parent well in the presence or absence of the symptoms of mental illness.

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**APPENDIX I
ADVERTISEMENT**

**"In her Shoes" The Experience of Mothers living with Mental
Illness.**

HAVE YOU HAD AN EXPERIENCE OF MENTAL ILLNESS?

HAVE YOU USED MENTAL HEALTH SERVICES?

ARE YOU A MOTHER?

**WOULD YOU BE ABLE TO VOLUNTEER AROUND TWO HOURS OF YOUR TIME
TO TAKE PART IN A FOCUS GROUP WITH OTHER WOMEN OR AN
INDIVIDUAL INTERVIEW, TO TALK ABOUT YOUR EXPERIENCES?**

**ASSISTANCE WITH THE COSTS OF TRANSPORT AND CHILDCARE CAN BE
ARRANGED.**

**HI, MY NAME IS LESLEY WATKINS. I AM A MASTERS OF SOCIAL WORK
STUDENT AT MASSEY UNIVERSITY, CURRENTLY UNDERTAKING MY THESIS
WANTING TO HEAR THE STORIES OF MOTHERS WITH EXPERIENCE OF
MENTAL ILLNESS WITH THE AIM OF IMPROVING SERVICES.**

**PLEASE CONTACT ME VIA GILL DOMS @ CAN TRUST (TEL: 07 5798382) OR
DIRECTLY (MOB: 021 1674074), LEAVE YOUR DETAILS AND I WILL
CONTACT YOU TO TALK ABOUT THE STUDY.**

THANK YOU

APPENDIX II

"In Her Shoes" – The Experiences Of Mothers Living With Mental Illness

Information sheet

September 2006

You are invited to take part in a study which aims to gather the stories of mothers with an experience of mental illness in the hope that the information collected will guide the development of more effective support services. Your participation is entirely voluntary.

Researcher:

My name is Lesley Watkins. I am currently a part-time Masters of Social Work student at Massey University with a background in mental health social work. I am undertaking my thesis in 2006/2007.

How to contact the researcher

I can be contacted by

telephone on 021 167 4074.

My postal address is P.O.Box 158, Whakatane.

Email: lesleywatkins@xtra.co.nz

I can also be contacted via Gill Doms @ CAN Trust, tel :(07) 579 9890.

My supervisors for this research are:

- Dr Carole Adamson, School of Sociology, Social Policy & Social Work, Massey University, Private Bag 756, Wellington. Tel: (04) 8012794 ext: 6481. Email: C.E.Adamson@massey.ac.nz
- Barbara Staniforth, School of Sociology, Social Policy & Social Work, Massey University, Private Bag 102904, North Shore Mail Centre, Auckland. Tel: (09) 4140800 ext: 9084. Email: B.L.Staniforth@massey.ac.nz

What is the Research about?

This is a study aimed at hearing the stories of English-speaking mothers with an experience of mental illness. (Mental illness is defined as a psychiatric or psychological condition regardless of cause such as schizophrenia, depression, bipolar illness, anxiety, personality disorders and/or adjustment disorder or other conditions). I would like to hear what their views and experiences are in relation to being a mother with an experience of mental illness and what these experiences might suggest in the way of improvements to support services. There has been much international research in this area but little has been undertaken in Aotearoa/New Zealand. I will be interested in whatever similarities and/or differences emerge when I compare my findings with those obtained internationally.

What will the participants be invited to do?

I am planning to interview women individually where this is their preference. The interviews will last between 1½ - 2 hours and will take place at the CAN Trust at 1250 Cameron Road, Tauranga or at another convenient location. Refreshments will be available and assistance with the cost of transport and childcare is available from the researcher.

The interview will be stimulated by the following questions:

- "How does your mental illness affect your ability to be a mother?"
- "How does being a mother affect your mental illness?"
- "What has helped you being a mother with experience of mental illness?"
- "What suggestions can you make for changes to mental health services which you think might give you more support?"

The interview will be audiotaped and the tapes will be transcribed by the researcher. You have the right to request that the recording is stopped at any time during the interview. After the interview I will contact you with the edited transcripts and invite you to discuss with me any points that you may wish to correct.

As I have worked in Eastern Bay of Plenty Mental Health Services for many years, in the event of a participant who is known to me wishing to be interviewed, I will request that one of the Consumer Reference Group (2-3 consumers who are assisting me with the study) assess the process around how the potential participant has become involved checking that there has been no undue pressure exerted to participate. You have the right to ask questions about the research at any time during the research.

How will confidentiality and anonymity be kept?

Participants will be expected to sign a consent form. All personal identifying details will be removed during the writing up of the interviews. All information collected will be securely stored in a locked cupboard in the researcher's office for 10 years. Information collected from the interviews may be shared with the researcher's supervisors.

What will be the role of the researcher?

As this study is exploring personal experiences of both mental illness and motherhood, I have prepared a list of resources/contact people for participants to assist if any issues arise during or after the study. If I am concerned in any way about your mental health during the interview, I will discuss these concerns with you. If I am seriously concerned, I may make contact with the Mental Health Services in Tauranga. This will be done with your full knowledge. A letter about the research will be sent to local Mental Health Services so that they will be aware of possible consequences for participants.

Your Rights

Results from the interviews will be published as part of the thesis process and may be presented at future conferences or submitted to any reviews of the needs of mothers with experience of mental illness. If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact the Health & Disability Advocate, Emma Ngawhare on (07) 577 1715 or 0800 423 638 (Mid/Lower North Island).

This study has received ethical approval from the Northern Y Regional Ethics Committee.

