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**The meaning of social inclusion to
people with enduring mental health
problems**

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

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in
Nursing**

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Abstract

The purpose of this qualitative research project has been to explore what social inclusion means to people with an enduring mental health problem. A review of the general literature on social inclusion revealed that little research has been conducted in relation to mental health, particularly in New Zealand. Even fewer studies have investigated the meanings that people with severe and enduring mental health problems place on their experiences.

A life story narrative approach was employed in order to explore the experience of social inclusion and enduring mental health problems. Data were collected by way of unstructured, individual interviews with five users of mental health services living in supported housing in a small rural New Zealand town. Thematic analysis was carried out on the narratives, identifying six major themes. The findings indicated that, for this group of service users, social inclusion means having someone to love, something to do and somewhere to live. They want relationships with family and friends, to engage in recreational or leisure activities, to be employed, to have financial security, and to have safe and comfortable housing. The major barriers to achieving these are stigma and discrimination.

New Zealand's mental health services have adopted a recovery approach to mental health. Whereas social inclusion has a broad political and social focus that places responsibility for reducing social exclusion on society, recovery focuses on individuals' personal journeys towards mental health and well-being. Despite international recognition of the value of social inclusion, New Zealand's mental health services have not yet embraced it, although policy advisory organisations such as the Mental Health Commission state its aims as desirable for services. However, the concept of recovery sits within the framework of social inclusion and is an integral part of it. Mental health nurses need to understand what social inclusion means to people who experience it, so that they are able to empower them to make a positive contribution to their community, as citizens, friends, family members, employees and neighbours.

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Chapter one: Introduction

1.0 Overview of the chapter

This chapter provides the background information which positions this thesis. It begins with an expression of my interest in the social inclusion of people with enduring mental health problems and an explanation of why I decided to investigate this topic. It provides definitions of social inclusion and recovery and explains how these two topics are linked. The research questions and aims are presented and I explain the terminology that I have used. Finally, this chapter concludes with an overview of the chapters that form this thesis.

1.1 Background to the study

This thesis explores the social inclusion experiences of people who have lived with mental health problems for many years. My interest comes from having worked as a registered nurse in the area of mental health for the past 17 years. The majority of this time has been spent working in a community home, with people who have a long history of mental health problems. For the past decade or so, mental health services in New Zealand have focussed on a recovery approach to mental illness (Mental Health Commission [MHC], 1998). A recovery philosophy has therefore formed and informed my mental health nursing practice. For this reason, I initially planned to base my thesis on the exploration of what recovery means to this group of long-term service users. However, when I embarked on the preliminary literature search, I found that recent international literature on mental health has had a shift in focus, from recovery to social inclusion.

Social inclusion incorporates people's personal journeys of recovery, but is a broader concept than recovery in that it aims to challenge societal norms and remove barriers for participation in all areas of society (Lloyd, Tse & Deane, 2006; Lloyd, Waghorn, Best & Gemmell, 2008; Morgan, Burns, Fitzpatrick, Pinfold & Priebe, 2007; Social Exclusion Unit [SEU], 2004). This paradigm shift is not seen in New Zealand's mental health literature, with very few explicit references to social

inclusion or exclusion and little research addressing people's experiences of it. I was therefore eager to explore this concept from the perspective of mental health service users within the New Zealand context. I hoped that by revealing the meanings of social inclusion embedded in people's stories, I would also discover the degree to which New Zealand's mental health services encompass the political and social concept of social inclusion.

So what is the significance of this study to mental health nursing? It is expected that, by understanding what social inclusion means to people with an enduring mental health problem, mental health nurses will be able to help service users develop plans that prevent relapse, promote wellness and extend their opportunities and potential within the community. People's stories of their experiences of mental illness will assist in exposing the deleterious impact of stigma, institutionalisation and social exclusion. This in turn will support the recovery vision in mental health services by challenging the barriers to recovery and social inclusion and show nurses how they can support individuals to make a positive contribution to their communities.

1.2 Social inclusion

The term 'social inclusion' originates from the antonymous term 'social exclusion', which in turn was developed from the previously dominant concepts of poverty, deprivation and marginalisation (Peace, 2001). With its background in the social policy of the French governments of the 1980s, the concept of social exclusion was adopted by the New Labour Government in the United Kingdom, and the Social Exclusion Unit was established in 1997 (Percy-Smith, 2000). Originally developed as a response to people on benefits who were unable to work, social exclusion policies were later widened to include people with mental health problems (SEU, 2003). They addressed issues such as the promotion of social participation and improvement of access to a broader range of community services.

At its simplest, social inclusion refers to somewhere to live, something to do and someone to love (Bonner, Barr & Hoskins, 2002). A more formal definition was

provided by Lloyd et al. (2006), who stated that “social inclusion involves being able to rejoin or participate in leisure, friendship and work communities” (p.1). The concept of citizenship is the key to ensuring that all members of society are able to have a socially valued role, social support and integration into the wider community. In contrast, social exclusion can be defined as “what can happen when people or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown” (SEU, 2003, p.4).

Sayce (2001) considered that this definition of social exclusion, with its focus on poverty and inequality, did not fully encompass the concept. This is particularly the case for people living with mental health problems. According to Lloyd et al. (2008), this group is among the most marginalised, socially isolated and excluded in society. Research has shown that while the reduction of poverty is important, service users identify being part of mainstream community groups and having meaningful relationships with friends and families as being of equal importance (Sayce, 2001). Morgan et al. (2007) supported this view when they stated that: “In most definitions of social exclusion, social relationships and networks are a central component, a key requirement for a fully participative and inclusive life” (p.479). It is also accepted that many of the barriers to mental health service users having an inclusive life, result from widespread stigma and discrimination against them (Peterson, Pere, Sheehan & Surgenor, 2006).

Despite international recognition of the value of social inclusion to the well-being of people with mental health problems (Sayce, 2001), Peace (2001) considers that social exclusion is a complicated and elusive concept, and suggested several negative implications of using it as a framework to guide social policy. These include labelling people and placing them into certain categories of exclusion. This has the potential of making moral judgements about people who are seen to be deviant or non-conforming. Ward (2009) expressed reservations about Britain’s social exclusion policies. She stated that: “The onus placed on certain, excluded

individuals, to integrate within the mainstream may also be experienced as a form of social control which limits, or seeks to limit, people's choices about how and where to live their lives" (p.242). Ward argued that social exclusion policies focus on inclusion interventions that aim to change individuals rather than questioning the structures within society that create their exclusion.

Although the concept of social inclusion has not been adopted by New Zealand's mental health services, significant changes and proactive policy-making have resulted in services comparing very favourably with other western countries (Lurie, 2005; MHC, 2007). Lurie noted that New Zealand's mental health policies and plans are "simple and straightforward" (p.99), focusing on the need to increase health status and decrease the prevalence of mental health problems. In addition, the focus of service development and delivery in New Zealand is the theme of recovery, an approach that is internationally praised for its progressive and client-centred qualities (Gawith & Abrams, 2006).

1.3 Recovery

As previously stated, New Zealand's mental health services have a strong commitment to, and focus on a recovery approach to mental health. Lurie (2005) considers that New Zealand has followed, and to some degree led, a worldwide change in direction in relation to mental health policy formulation, service design and delivery. The philosophical changes within mental health services that have resulted in the adoption of a recovery approach are due in most part to the rising influence of the service user movement. During the 1980s and 1990s, service user networks, advocacy, family and carer support groups were instrumental in raising awareness of the shortcomings of mental health services. These included the denial of users' rights and a lack of understanding of the impact that mental illness has on the lives of service users, their families and carers. These groups also highlighted the need for the participation of service users and their families at every level of a mental health service (MHC, 2002). The adoption of a recovery approach as the

guiding principle of New Zealand's mental health strategy addressed many of these issues (Lurie, 2005).

Recovery is a holistic approach to mental health that enhances social participation and helps combat social exclusion (Lapsley, Nikora & Black, 2002). In this context, recovery refers to the process of reconstructing a positive identity and growing beyond the limits that mental health problems impose (Curtis, 1997; Repper, 2000). The emphasis is not on eliminating symptoms but on managing one's illness. This means that recovery is not linear but involves growth, plateaux and setbacks, while learning to live in both the presence and absence of mental illness (Deegan, 1996).

A core element of recovery is personal responsibility (Curtis, 1997). This involves people taking an active role in their treatment so that they can take responsibility and be accountable for their mental illness and health (MHC, 1998). Consequences or outcomes of the recovery process include the appreciation that people with a mental illness are human beings with hopes, dreams and expectations like everyone else (Curtis, 1997). The premise is that by regaining rights and roles, a person is more able to make decisions and have hope for a productive and rewarding life (Deegan, 1996).

A fundamental defining attribute of recovery is hope (MHC, 1998). According to Deegan (1996), many people with a mental illness experience a deep sense of hopelessness and despair. They feel that they have no control over their environment, are not listened to by mental health staff and do not make any major decisions about their lives. This perception of being helpless leads to feelings of hopelessness and the inability to cope with everyday living. People must believe that change is not only possible but also attainable and that their lives can and will be better. Also central to recovery is the construct of empowerment (Young & Ensing, 1999). Finfgeld (2004) considers that people become empowered when they are viewed as individuals who are personally responsible and capable of growth and self-determination. Factors related to empowerment include personal power, self-

efficacy, self-esteem and having control over the future (Allott, Loganathan & Pulford, 2002). These attributes are seen to be more elusive for those people who have a severe mental illness.

Historically, it was accepted that people with a severe and enduring mental health problem had little or no hope of recovery (Kruger, 2000). However, Russinova (1999) cited several studies that showed that people can and do recover. In addition, when service users are included in a community which has a social consensus for recovery, their problems are less enduring (Sayce, 2000). Despite this, the very small percentage of people with an enduring mental health problem is still among the most excluded in society (Morgan et al., 2007; SEU, 2004).

Evans and Repper (2000) suggested that this may in part be due to the preoccupation within psychiatry of the traditional biomedical paradigm. Focusing almost all attention on individuals, symptoms and pharmacological interventions has all but eclipsed the social dimensions of people's lives, minimising their importance to recovery. Compounding this, are the longer-term or repeated hospital admissions that take the person away from his or her community for long periods of time. Bertram and Stickley (2005) pointed out that this leads to diminished social networks, resulting in a loss of roles, limited contact with friends and family and increased contact with health professionals and fellow service users. For many people, hospitalisation disrupts their lives to the extent where they lose their homes, their jobs and access to continuing education and training (SEU, 2004).

1.4 Social inclusion and recovery

So how are the recovery and social inclusion paradigms linked? The concept of recovery from mental health problems sits within the social inclusion framework (Sayce, 2001). They are complementary concepts and active participation in the community is an accepted indicator of recovery. However, whereas social inclusion has a broad political and social focus that places responsibility for reducing social exclusion on communities and society in general, recovery focuses on individuals'

personal journeys towards mental health and well-being. Davidson et. al. (2001) suggested additional dimensions of social inclusion that may not be explicitly addressed in a recovery paradigm. These include: “(1) social inclusion through friendship; (2) feeling like a worthwhile human being through meaningful activity, and; (3) hopefulness through an affirmative stance” (p.379). The degree to which these dimensions were evident in the literature on recovery is further discussed in Chapter three.

1.5 Research questions and aims

The purpose of this study was to explore what social inclusion means to people with an enduring mental health problem. In order to achieve this, the specific aims were:

- To interpret the meanings embedded in participants’ life stories in relation to social inclusion and exclusion.
- To explore how the social and political developments in New Zealand have impacted on their life histories and guided their illness experiences.
- To explore how mental health nurses can empower individuals to make a positive contribution to their community as citizens, employees, family members and neighbours.
- To develop a position from which mental health nurses can explore initiatives and strategies for social inclusion.

In order to achieve the aims stated above, this study asked the following questions:

- What does social inclusion mean to people with an enduring mental health problem?
- What facilitates social inclusion?
- What are the barriers to social inclusion?
- How do life stories reflect the social and political developments regarding mental health in New Zealand?

1.6 A reference to terminology

Within the literature, a number of terms were used to identify people who experience mental health problems. Gawith and Abrams (2006) suggested that how people identify themselves depends on their affiliation to a particular social, political or advocacy movement. The terms currently used include tangata whaiora (person seeking wellness), psychiatric survivors, service users, people with experience of mental illness and mental health consumers. The participants of this study did not show any preference to a particular term, so I made the decision to use the term ‘service user’.

A decision was also needed in relation to how to refer to people’s experiences of having a mental illness. Barnett and Lapsley (2006) found that their participants disliked the term ‘severe mental illness’ preferring instead the terms ‘severe mental health problems’ or ‘disabling mental health problems’. In order to avoid using a term with which participants of the current study may not be comfortable, I decided to use the term ‘enduring mental health problems’. While this suggests that people have had these problems for some length of time, it does not make judgements in relation to the severity of the problem, nor talk in terms of a specific illness or diagnosis. However, the terminology does at times reflect that which is used in other research reports. For example, if a particular study referred to ‘mental illness’, then I also used that term.

Finally, I used Barnett and Lapsley’s (2006) explanation to describe what I mean by ‘mental health services’. Mental health services in New Zealand provide crisis, acute, non-acute and specialty services, delivered in hospital, community and residential settings. Services run by District Health Boards and non-governmental organisations (NGOs) are staffed by people, often working in multi-disciplinary teams, from a variety of mental health professions and backgrounds.

1.7 Organisation of the thesis

Chapter one: This chapter has provided a background to my research project. It explains how and why I became interested in the social inclusion of people with enduring mental health problems. The research questions and aims are outlined and an explanation given for the terminology I have used. Finally, an overview is given of the chapters that form this thesis.

Chapter two: New Zealand's key documents (1994 – 2008) are presented. This historical overview is expanded through a discussion about how deinstitutionalisation and the development of community care have impacted on mental health services both internationally and in New Zealand. In addition, theoretical issues relating to the study are discussed.

Chapter three: A review of New Zealand and international research relating to social inclusion, exclusion and recovery is provided. Determinants of social inclusion are identified and discussed: stigma and discrimination; employment; material poverty; relationships and social networks; and partnerships in mental health.

Chapter four: The qualitative research design and the rationale for selecting this approach to the study are presented. The techniques used to select participants, conduct the interviews and analyse the data are explained. The ethical considerations are then discussed, along with how the quality and rigour of the study are maintained.

Chapter five: The findings of the study are presented as expressed through the themes that emerged from the participants' stories. The general trends from the data are identified and the themes and corresponding sub-themes relating to social inclusion are presented. Tracts of narrative are provided verbatim, giving representative examples of each theme. The chapter concludes with the

identification of themes that I had expected to see as indicated in the literature, but that did not emerge from the data.

Chapter six: This chapter discusses the findings, focusing on the first aim of the research project: to interpret the meanings embedded in participants' life stories in relation to social inclusion. In addition, the second aim is addressed: to explore how the social and political developments in New Zealand have impacted on people's life histories and guided their illness experiences.

Chapter seven: This final chapter reviews the findings of the study and addresses the final two aims: to suggest how mental health nurses can empower individuals to make positive contributions to their communities and to help develop strategies and initiatives for social inclusion. In addition, I discuss the degree to which New Zealand's mental health services encompass the political and social concept of social inclusion. Finally, the limitations of the study and suggestions for future research are presented.

1.8 Summary

People with enduring mental health problems are one of the most socially excluded groups in society (Lloyd et al., 2008). Despite acknowledgement that social inclusion is essential to mental health and well-being (Sayce, 2001), New Zealand's mental health services have not adopted the social inclusion paradigm. While not synonymous, social inclusion and recovery are closely linked. Whereas, recovery from mental health problems highlights people's personal journeys, social inclusion highlights the wider processes that place responsibility for removing barriers to participation onto society.

The next chapter presents an historical overview of New Zealand's key documents from 1994 to 2008. Deinstitutionalisation and the development of community care are discussed followed by the theoretical issues relating to the provision of mental health care and social inclusion.

Chapter two: Historical overview

2.0 Introduction

There have been significant changes within the policy development, planning and service delivery of New Zealand's mental health services since the early 1990s (MHC, 2007). The government's commitment to improving mental health services has been backed up with generous mental health funding that is a greater percentage of New Zealand's total health budget than most other countries (World Health Report, 2001). To understand how this came about and where social inclusion fits within New Zealand's current mental health services, it is important to consider the historical changes that have occurred from 1994 to 2008. This chapter presents these key documents, along with a discussion regarding deinstitutionalisation and community care. Finally, theoretical issues relating to the study are discussed.

2.1 Key New Zealand documents 1994-2008

First appearing in New Zealand in the early 1990s, service-user organisations and networks were led by Mary O'Hagan, the first chairperson of the World Federation of Psychiatric Users, and Pauline Hinds, founder of the Aotearoa Network of Psychiatric Survivors (Gawith & Abrams, 2006). Supporting the interests of service users and their families, peer support groups, advocates and carers were increasingly active in contributing to policy formulation, service development and delivery in all areas of the mental health sector. This had significant influence on many of New Zealand's key mental health documents (MHC, 2007).

In 1994 the National government followed the global trend of making strategic plans for the delivery of mental health services by releasing *Looking Forward: Strategic Directions of the Mental Health Services* (Krieble, 2003; Ministry of Health, 1994). This document outlined a community-based service model, while *Moving forward: the National Mental Health Plan for More and Better Services in 1997* (Ministry of Health, 1997) focused on providing the resources needed to implement the model. The findings of Judge Mason in the *1996 Mental Health Inquiry* (Mason, 1997)

identified several factors that were impacting negatively on mental health services in New Zealand. Inadequate resources, shortage of well-trained staff and lack of leadership at national level were making the management of good, effective care in the community extremely difficult. Judge Mason considered that the National Mental Health Strategy was not functioning as fully as it might have.

One of the key actions requested by the *Mason Inquiry Report* was that a Mental Health Commission be set up (Mason Inquiry Report, 1996). It was hoped that this would help infuse the sector with vision and purpose. Shortly after its establishment, the Commission released the *Blueprint for Mental Health Services in New Zealand: How Things Need to Be (1998)*. This set out in detail what resources were needed to establish the model outlined in *Moving Forward* and *Looking Forward*. The guiding principles of the *Blueprint* are the promotion of empowerment, participation, personal dignity and rights of all consumers and their families (MHC, 1998).

In 1998, *Like Minds Like Mine (LMLM)* was set up by the Mental Health Commission (Gawith & Abrams, 2006). It aimed to increase awareness about aspects of mental illness through media campaigns and programmes designed to inform and educate the public. Following on from this, *LMLM's National Plan 2003-2005* condemned the systematic exclusion of people with a mental illness from mainstream society and advocated for service users to play a central role in all areas of their health and illness. *LMLM National Plan 2007-2013* continued with this theme of countering stigma and discrimination and promoting the social inclusion of users of mental health services (Ministry of Health, 2007).

Designed to guide the second New Zealand Mental Health and Addiction Plan, *Te Tāhuhu, Our Lives in 2014* (MHC, 2004) produced service users' visions for their lives and mental health services. This document set a platform for social inclusion with its statement: "We want a society and whānau that value us as fully participating members, with the same rights and opportunities as other citizens" (MHC, 2004, p.8). *Te Tāhuhu* rose to this challenge with its commitment to

improving mental health over the next decade (Ministry of Health, 2005). Supplementing *Te Tāhuhu*, the action plan *Te Kōkiri* described how to provide recovery-focused services that meet the needs of service users, their family/whānau and their communities (Ministry of Health, 2006). The recommendations from these two documents were further prioritised in the discussion document *Destination: Recovery* (Mental Health Advocacy Coalition, 2008). Once again the focus was on recovery, advocacy and the rights of mental health service users.

These papers and documents emphasised the central tenets of social inclusion, that all people should have the same opportunities to experience fulfilling and productive relationships and work experiences. However, the terms ‘social inclusion’ and ‘social exclusion’ were rarely used in New Zealand’s policy documents. In contrast, the terms featured prominently in some other non-mental health government documents.

In 2001 *the New Zealand Disability Strategy: Making a World of Difference* was released (Minister for Disability Issues, 2001). While this document was not specifically for mental health, it included people with mental health impairments and this group was included in the consultation process. The vision and aim was to change “New Zealand from a disabling to an inclusive society” (p.1). Social inclusion also formed the basis of the document *Social Inclusion and Participation: A guide for Policy and Planning* (Bromell & Hyland, 2007). This document set out the government’s vision for social inclusion and its priorities for social development. Although Peace (2001) and Ward (2009) expressed concerns about the unanticipated consequences of using the concept of social exclusion (see p.10), the approach has been adopted by the Ministry of Social Development (Bromell & Hyland, 2007).

Social Inclusion and Participation: A guide for Policy and Planning identified the key determinants of social inclusion and participation as belonging, inclusion, participation, recognition and legitimacy (Bromell & Hyland, 2007). In this context, ‘belonging’ refers to feeling connected to families and communities. The premise is

that sharing common experiences, aspirations, values and social attitudes within communities such as sports clubs and religious groups can reduce feelings of isolation and alienation. 'Inclusion' means having equal access to services, employment and social networks. 'Participation' enables opportunities to contribute to, and be involved in society, with the same citizenship rights as everyone else. 'Recognition' is an acceptance of diversity and acknowledgment that these differences make a positive contribution to community and national life. Finally, 'legitimacy' concerns people's rights to protection under the law and equal access to fair and reliable state services and community organisations.

The Social Report 2006, while referring less directly to social inclusion, defined social wellbeing as a sense of belonging and stated that: "Many New Zealanders experiencing disability face barriers to full participation in society" (Ministry of Social Development, 2006, p.18). New Zealand's policies and documents also promised to provide a fair and equitable health service to all members of its population (Hefford, Crampton & Foley, 2005). The raised political profile of Treaty of Waitangi issues and their relevance to contemporary life have contributed to a growing concern over the political, economic and social interests of Māori. Out of this has emerged an increased awareness of the implication that ethnicity and culture has for health and illness. Nowhere is this more relevant than in the area of mental health.

Despite this awareness, Māori have the highest levels of health disparities when compared to the non-indigenous population group (Bramley, Hebert, Jackson & Chassin, 2004). *Te Rau Hinengaro: The New Zealand Mental Health Survey* found that the Māori population has a 29.5% prevalence of mental disorder compared to 19.3% prevalence for non-Māori (Oakley Browne, Wells & Scott, 2006). As promised by Article 3 of the Treaty of Waitangi, Māori have the right to equivalent health status as Pākehā (Health Research Council of New Zealand, 1998). *The New Zealand Public Health and Disability Act 2000* endorsed this, with its objectives of reducing health disparities and facilitating access for all New Zealanders (Ashton,

2005). This can only be achieved through delivery of health services that are culturally appropriate, effective and responsive to Māori health needs.

The dominant biomedical model of health and disease practised in New Zealand is very different from the Māori perception of health and illness (Durie, 1994). For Māori, health and well-being is a much broader and far more holistic concept. An example can be seen in Te whare tapa whā model that identifies four dimensions necessary for good health: the family or whānau; the mental; the physical; and the spiritual dimensions. The spiritual dimension, taha wairua, is considered by Māori to be the most essential requirement for health. It includes religious beliefs and practices, as well as relationships with the land, lakes, mountains and reefs. The natural environment is integral to Māori identity and the lack of access to tribal lands is considered to contribute to ill health (Durie, 2004). As the prime support system for Māori, taha whānau or family is also essential for health and well-being and relates to the person's identity. When an individual is unwell, this reflects upon the whole family, often causing shame and guilt. In contrast to a western culture that holds independence in high regard, Māori place greater value on interdependence, relying on family support and help when needed (Durie, 1994). This collective ideology is very different from the individualism of western culture.

According to West, Park and Hakiha (2009), cultural safety, coined by Māori nurse Irihapeti Ramsden (Ramsden, 2002), occurs when a nurse provides effective care to a person from a different culture. In contrast, unsafe cultural practice diminishes or disempowers an individual's cultural identity. Nurses are more able to practise in a culturally safe manner when they adopt a recovery approach to mental illness. It assists them to work holistically, taking into account the individual's mind, spirit and body as well as the family, friends and social systems that are part of the individual's environment (MHC, 1998).

As previously mentioned, there was very little explicit reference to social inclusion or exclusion in New Zealand's mental health documents and policies. They did

however acknowledge the recovery concept as the focus of service development and delivery (Gawith & Abrams, 2006). In fact, Allott et al. (2002) suggested that in New Zealand, recovery-oriented services and practices are well advanced in comparison with other countries, driven as they were by the *Blueprint* document and its endorsement of the recovery approach (MHC, 2007).

2.2 Deinstitutionalisation and community care

In 1961, *the Joint Commission on Mental Illness and Health* published its recommendations for community alternatives for the mentally ill in New Zealand (McNabb, 1992). The Commission considered that community care was more desirable than hospital-based care, perhaps primarily as the provision of care in the community was thought to be cheaper (Barnes, 1997; Kelly & McKenna, 2004; Wilson & Dunn, 1996). However, it was recognised that people need family, friends, work and good mental health services in order to recover from a mental illness (MHC, 2005). In addition, coercion and lack of choice shaped the experiences of many people incarcerated in psychiatric hospitals (Lapsley et al., 2002; Lilja & Hellzén, 2008). A common part of the hospital experience was being isolated in locked rooms and forced to stay in hospitals that were characterised by cold environments devoid of intimacy.

Staff commonly used force to control people's behaviour and coerce them into acting in a way that was acceptable to the hospital milieu (Drury & Munro, 2008; Lilja & Hellzén, 2008). These experiences of isolation, coercion and fear shaped the relationships that people have with service providers. As Jarrett, Bowers and Simpson (2008) pointed out, forcing treatment on people who refuse it, has the potential of destroying trust and having a negative impact on therapeutic relationships. These ethically questionable coercive practices resulted in people largely viewing their inpatient experiences as unpleasant, unwanted and working against their recovery (Drury & Munro, 2008; Lapsley et al., 2002). Even those people who agreed to voluntary admission to hospital, often did so because of the pressure applied by relatives (Lapsley et al., 2002).

Replacing the *Mental Health Act 1969*, *New Zealand's Mental Health (Compulsory Assessment and Treatment) Act (MHA)* signalled major changes in the assessment and treatment of psychiatric patients (Department of Health, 1992). This followed a global trend of greater recognition of patient rights and minimization of inappropriate incarceration (Mellsoy, 1998). A significant change was the introduction of the Community Treatment Order which enabled the provision for people with serious mental illness to be treated in the least restrictive and enabling community setting. This legislation however, is not without its critics. As Gibbs, Dawson and Mullen (2006) pointed out, "New Zealand legislation permits the involuntary outpatient treatment of people with serious mental illness" (p.1087). Drury and Munro (2008) went so far as to suggest that, with the closure of psychiatric hospitals, the focus of mental health care in the community is on making clinical judgements that control people who may pose a threat to society. This has the potential for health professionals to base care and treatment on levels of risk to the community, as opposed to the needs and aspirations of the service user.

Wide-ranging problems became evident with the shift from institutional care to care in the community, largely driven as it was by fiscal rather than health policies (McMorland, Kukler, Murray & Warriner, 2008). Very little systematic planning resulted in a lack of affordable housing, supportive networks and well coordinated community programmes (Cripps, 1998). In addition, little preparation was given to people who were moved out of the institutions and into the community (Wilson & Dunn, 1996). They were not given training in regards to the social, financial and practical skills needed to cope with the stressors of daily living. This placed many ex-patients at risk of becoming targets of neglect, abuse, exploitation and prejudice.

According to Yip (2008), the problems created by insufficient health infrastructure and support networks may have been exacerbated by the fact that the concept of 'community' was ill-defined. Some may have viewed the community where patients were placed as a geographical area, groups such as families and relatives or the general public. Barnes (1997) considers that enabling people to participate within a

community should be the main objective of community care. However, in reality the care they received after leaving the psychiatric hospitals was largely 'community-based' rather than 'within the community' (Yip, 2008). The asylums gave many people a sense of community that was lost when they moved out of the old hospitals (Stickley & Shaw, 2006). This was especially the case for people who experienced many years of institutional care and who found the community to be a lonely, hostile and frightening place that failed to provide the feeling of security of the old asylums (Stickley, 2005). Lapsley et al. (2002) found that some of their participants reported relatively positive inpatient experiences, enjoying the company of fellow patients and viewing the hospital environment as a refuge and haven.

After the psychiatric hospitals were closed, access to in-patient services was severely restricted through fewer hospital beds and briefer admissions (Walsh, 2002). This meant that only the most seriously mentally ill were able to access in-patient services, raising the issue of safety on numerous occasions. Patients may have been discharged from hospital before they were ready or not admitted when unwell because of the demand on beds. Health professionals were aware that the safety of service users, their families and the community in general could be compromised because of this, but were not always equipped to deal with the problems (Cripps, 1998).

Health professionals working in psychiatric hospitals were trained in diagnosing and treating patients and had very few of the rehabilitation skills needed for the new mental health services (Cripps, 1998). There were extremely limited resources provided to educate the workforce or community groups and organisations about their roles in this very different environment. This changed treatment setting was particularly difficult for nurses to adapt to (Wilson & Dunn, 1996). Most nurses were trained within the hospitals and were used to working in teams within quite rigid hierarchical structures. When the process of deinstitutionalisation began, nurses needed to learn how to work autonomously in relationships with individual service users, while meeting both legislative and ethical requirements. For example, they

had to uphold Compulsory Assessment and Treatment Orders as mandated by the *MHA*, in addition to minimising harmful consequences both to the service users and to others (Department of Health, 1992). This had the potential to conflict with their moral obligation to promote the autonomy of service users, empower them to self-determination, and endeavour to reduce the impact of stigma and discrimination (Bonney & Stickley, 2008).

Despite the problems encountered with the move to the community and the critics of the care provided in the community, few people would dispute the institutional oppression and horror experienced by many ex-patients of the old psychiatric hospitals. This was acknowledged by the New Zealand government in 2001, when the Prime Minister and the Health Minister apologised to people who had received treatment at Lake Alice Hospital's adolescent unit ("Trust Helps Right Historic Wrongs," 2008). One hundred and eighty-three former patients received a share of several million dollars in compensation for receiving treatment described as violent, cruel and humiliating. This included receiving electroconvulsive therapy (ECT) and injections as punishment, and experiencing sexual abuse and violence. In addition, millions of dollars of patients' welfare benefits were appropriated by mental institutions during the 1970s and 1980s. While some of this money has been returned to its rightful owners, a large portion remains unclaimed. This has been placed into a charitable trust called 'Frozen Funds Charitable Trust', grants from which will be used to benefit people who used mental health and intellectual disability services. Many more people are yet to have their claims heard and are awaiting governmental recognition of the trauma they experienced over many years.

2.3 Theoretical issues

Although health and disease are represented in different ways, they are generally understood in New Zealand in terms of the biomedical model (Tamm, 1993). The biomedical model takes a scientific, disease-centred approach that is reductionist rather than holistic in character. Medicine has been strongly influenced by Cartesian dualism, the notion that the mind and body are two distinct entities that are linked

but are qualitatively different (Coward, 1993). The reductionism and dualism of the biomedical model have great significance for health care delivery, in particular, for mental health services. According to Fernando (1995), the focusing on small parts of the body and reducing health to mechanical functioning often results in health professionals seeing people as a disease rather than as human beings. This can lead to conceptualising of problems in terms of illness, causes and treatments, while neglecting the environmental, social, psychological and spiritual aspects of ill-health.

According to Laungani (2002), a predominantly symptom-orientated approach to mental illness is inextricably linked to the use of the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV)*, the official manual for psychiatric disorders (American Psychiatric Association, 1994). Commonly used by health professionals from New Zealand and all around the world, this diagnostic classification system helps construct what is considered to be normal and abnormal behaviour (Crowe, 2000). The assumption that a mental health diagnosis immediately confers abnormality, supports the individualistic biomedical paradigm which sees mental illness as a personal tragedy primarily coming from within the person. While mental health services continue to work within this biomedical framework, people need, in most cases, to have an official diagnosis of mental illness in order to receive treatment (Barnett & Lapsley, 2006). This means that the many social factors that are believed to determine how much people know, what they believe, and what they are capable of, are largely ignored (Lupton & Najman, 1995). However, a social model of mental health is more likely to make sense of service users' experiences and facilitate understanding of their health and illness (Lester & Tritter, 2005).

In contrast to the individual model of biomedicine with its emphasis on changing people so that they conform to society, social models draw attention to the disabling tendencies of society and seek to change them (Burchardt, 2004). The move to develop a social model of disability came in the United Kingdom in the 1970s, with

the realisation that disability is centrally structured by social oppression that prevents equal participation in community life (Lester & Tritter, 2005). Originally limited to physical conditions, this perspective locates disability in the environmental barriers created by social structures, policies and practices (Beresford, 2000).

According to Burchardt (2004), the social model makes an important distinction between impairment and disability. Whereas impairment is attributed to an individual, a disability results from an oppressive relationship between people with impairments and the rest of society. However, there is disagreement as to the degree to which impairment causes the societal restrictions that constitute disability. Some proponents of social disability models view disability as being entirely imposed by society, whereas others suggest that the impairments themselves play a role in how disabling individuals' experiences are (Thomas, 2004).

Whatever one's view on the role that impairments play in causing disability, it was originally agreed that they referred only to physical impairments (Barnes, 2007). Despite their interest in how social oppression, discrimination and exclusion impacted on their environment, people with mental health problems were initially excluded from these disability activist groups. Although the social model of disability is now an inclusive concept that encompasses all sections of the disabled community, mental health advocates have continued their relatively separatist fight for fair, equitable and respectful treatment (Sayce, 2001). In New Zealand, they have particularly focused on driving a recovery approach to mental illness. However, the social model of disability explicitly underpins *the New Zealand Disability Strategy* and shows how its principles fit very well with social inclusion (Minister for Disability Issues, 2001).

It is important to remember that there are significant differences between physical conditions such as blindness, paraplegia and diabetes and serious mental illnesses such as schizophrenia (Davidson et al., 2001). Mental illnesses are characterised by

symptoms that fluctuate, periods of impaired judgement and varying levels of functioning, whereas other physical conditions often remain stable. Planning and policy making for the mental health sector must therefore reflect the unique challenges faced by mental health service users if they are to have socially inclusive lives. The adoption of a broad conceptual framework of social inclusion, based on a disability paradigm should be the goal of both mental health services and society in general.

2.4 Summary

This chapter provided an historical overview of the mental health and social policy documents that have informed New Zealand's mental health service provision from 1994 to 2008. Major health reforms in New Zealand, coupled with paradigm shifts in mental health care and provision have resulted in changed conceptualisations of mental illness and recovery from illness. The closure of the old psychiatric hospitals and the move to care in the community has created new challenges for both mental health professionals and service users. A discussion of theoretical issues has led to the suggestion that these challenges would be better met by applying a social model of mental health care as opposed to the biomedical model currently employed. It has been established that, while New Zealand's key mental health documents made few explicit references to the term 'social inclusion', they did contain many of the central tenets of inclusion such as recovery, the importance of relationships and the countering of stigma and discrimination. The Ministry of Social Development further expanded the social inclusion concept, with its emphasis on ensuring that everyone has the opportunity for employment and meaningful activity (Bromell & Hyland, 2007).

The next chapter provides a literature review of relevant research and documents from New Zealand and overseas. The focus is on literature that relates to social inclusion and exclusion and their determinants, stigma and discrimination, employment, material poverty, relationships and social networks and partnerships in mental health.

Chapter three: Literature review

3.0. Introduction

“At the heart of any social inclusion initiatives and strategies is the belief that people with mental health problems can make a practical and positive contribution to their community as citizens, employees and neighbours” (Stickley, 2005, p.14). When people experience social exclusion they are unable to fulfil these roles through having poor access to community services and activities, and barriers to employment and social opportunities (Sayce, 2000; SEU, 2004). In this chapter, New Zealand and international research is evaluated. Consideration is given to the determinants of social inclusion and exclusion; that is stigma and discrimination, employment, material poverty, relationships and social networks and partnerships in mental health.

Health related electronic databases were searched for relevant literature. These included CINAHL, Medline, Web of Science, EBSCOhost, Health Source/Academic Edition, Jstor, ERIC and Psychinfo. Limiting the search to research conducted after 1990, key words used were *social inclusion/exclusion, enduring/chronic mental illness, psychosis, deinstitutionalisation and recovery*. The articles reviewed were evaluated firstly to provide a theoretical perspective relating to social inclusion that focused on mental health service users’ experiences. Secondly, the literature was assessed in order to elicit how well it captured the essence of social inclusion and exclusion as it related to those experiences.

3.1 New Zealand research

There were several studies that referred to issues and aspects of social inclusion and exclusion, although the concept was not explicitly identified as such. Integral aspects of social inclusion such as recovery, the determinants of recovery, relationships, stigma, discrimination and employment are therefore identified and examined.

The recovery process was the focus of the Mental Health Narratives Project (Lapsley et al., 2002). This substantial bicultural qualitative study described the recovery journeys of 40 people and their experiences after recovery from mental health problems. The significant themes that emerged from the data included the individual determinants of recovery: hope; esteem; agency; relationships; and transitions in identity. While this study explored people's first hand experiences of mental illness, the characteristics of the participants differed markedly from those of the present study. They no longer used mental health services, were considered to be 'recovered' and were not taking psychiatric medication. In addition, the participants had a variety of diagnoses ranging from depression, bipolar disorder, anxiety disorder and schizophrenia to drug and alcohol dependence and personality disorder. Despite this diversity of participant characteristics, the theme of the Mental Health Narratives Project was similar to much of New Zealand's mental health literature. That was: "A recovery orientation would enhance social participation and combat social exclusion" (p.2).

Similarly, Barnett and Lapsley (2006) concluded that employment, education and social support from family/whānau and friends support recovery from mental health problems. In this study of 40 young adults who had significant contact with mental health services, stigma and discrimination were identified as the main barriers to recovery. Mental health discrimination was further explored in a survey undertaken as part of the Like Minds, Like Mine project (Peterson et al., 2006). This survey had 785 responses from people self-identified as having experienced mental illness. These people reported wide-spread discrimination against them, with the most commonly reported as that by friends and family (59%) and a fear of being discriminated against (46%). The conclusion drawn was that discrimination limits social inclusion of people with a mental illness. The researchers acknowledged that the method used in this study created an important limitation. The written questionnaire did not allow participants to elaborate on the information that they provided. This meant that their responses lacked detail, possibly omitting important factors that had impacted on their experiences of mental illness and discrimination.

In contrast, *Fighting Shadows* (Peterson et al., 2008) used 11 focus groups to carry out an in-depth investigation of what self-stigma means to people with experience of mental illness. Findings of this research included showing the association between self-stigma and discrimination, and how these two concepts have the potential to impact on low self-esteem and self-doubt. Once again the term ‘social inclusion’ was rarely mentioned. However, social withdrawal and isolation was discussed as well as the relationship that self-stigma and discrimination have with social exclusion.

Peterson (2007) conducted a study that focused on the employment experiences of 22 people with experience of mental illness. The title *I Haven’t Told Them, They Haven’t Asked*, was a quote from one of the research participants. This comment referred to the decision that people must make in regards to disclosing their experience of mental illness to employers. It highlighted issues of discrimination in the workplace, identified the positive aspects of employment and showed why social policy should target removing the barriers to employment. In this way, the study made a direct link between employment and social inclusion. However once again, aspects of social inclusion were discussed but not explicitly identified as such.

As evident by these five studies, there is very little New Zealand mental health research that specifically used the term ‘social inclusion’ and few studies that explored the first hand experiences of people who have enduring mental health problems. However, the studies referred to issues of social exclusion such as stigma and discrimination, unemployment and lack of social support. Alongside this, all the studies considered New Zealand’s ethnic diversity and thus the cultural components of and contributors to recovery from mental health problems.

3.2 International research

In direct contrast to the New Zealand literature, there were several international studies that explicitly dealt with mental health and social inclusion (Davidson et al., 2001; Evans & Repper, 2000; Gould, 2006; Lloyd et al., 2006, 2008; Morgan et al.,

2007; Parr, 2000; Sayce, 2001; Stickley, 2005; Stickley & Shaw, 2006). Parr (2000) reported a study from the United Kingdom that investigated how the social geographies of mental health had changed with deinstitutionalisation. The study was mainly 'covert ethnographies' conducted in a drop-in centre for people with mental health problems. The report described drop-in centres, along with residential homes, as "semi-institutional places" (p.229) that promoted both social inclusion and exclusion. While behaviours were observed and reported on, the focus of the study was the norms and culture of the centre. As a result, the voices of the attendees were largely unheard and their life stories were not told or examined.

Conversely, a recent study by Lloyd et al. (2008) used structured interviews to investigate the social support, stigma experiences and community integration experienced by 26 people who attended a psychiatric rehabilitation service in Brisbane, Australia. The interviews were analysed to provide quantitative data that assessed the reliability of a social inclusion measure for people with psychiatric disabilities. Alongside the quantitative component of this study, the views of service users were incorporated, which provided insight into what aspects of social inclusion were important to them.

There were several qualitative studies that incorporated service users' experiences of mental illness. They highlighted the impact that stigma, work and recovery have on people's day-to-day lives. Arguably one of the most relevant to this review was a hermeneutic phenomenological study of 45 people with serious and persistent mental illness (Bradshaw, Armour & Roseborough, 2007). This was a comprehensive examination of people's recovery over a three year period, culminating in the identification of five essential themes, four of which involved reintegration: into the community; with friends and family; with the case manager; and with oneself. While this study discussed social inclusion, the majority of the findings were presented in terms of 'reintegration' into the community. Sayce (2000) considers that these two concepts should not be used interchangeably as they are two quite different concepts. She cited Tom Shakespeare, who suggested that

reintegration implies that, in order to be accepted, the person has to change to fit the system. On the other hand, social inclusion means that the system needs to change in order for the person to fit in.

Following on from the four themes of reintegration identified in the study by Bradshaw et al. (2007), the fifth theme tied the previous four together by identifying the barriers to social inclusion. Although all participants reported that they wanted more social connection and inclusion in the community, they struggled to make friends, lacked educational and job opportunities and did not have sufficient financial resources to afford good housing, transportation and leisure activities. The study concluded that despite individuals' best efforts and willingness to reintegrate socially, the community's response to mental illness made it very difficult for them to do so.

Similar results were found in an exploratory study conducted in Norway by Granerud and Severinsson (2006). Seventeen participants, all with a diagnosis of a psychiatric disorder, reported a sense of loneliness, struggled financially, experienced shame, had a fear of exclusion and had to struggle for equality. They felt marginalised, alienated and did not have a sense of belonging in the community. Not having a job and being alone for several hours each day meant that the days passed slowly and time had little meaning for most participants. Although it examined aspects of social inclusion such as employment and social networks, this study did not fully encompass the broad concept of social inclusion. While it identified the barriers to social inclusion from the voices of the participants, it failed to acknowledge society's responsibility in ensuring that no-one is excluded. Although mental health workers have an important role to play in facilitating social inclusion, it is the responsibility of the community as a whole to combat exclusion.

Browne, Hemsley and St. John (2008) also focused on the role of mental health professionals as well as the individual aspects of recovery. This two-part Australian study of eight service users explored the recovery needs, in particular the housing

needs, of people following their discharge from hospital. It found that quality, stable housing helped develop social networks and access to resources that support recovery from mental health problems. Limited money, stigma and discrimination, and poor social networks all worked together to restrict service users' ability to live where and how they chose.

According to Goodwin and Kennedy (2005), suitable housing has historically been prioritised over employment for people with a mental illness. Following discharge from hospital, long-stay patients often found they had less to occupy them and were less able to make meaning out of their lives than when they were in hospital. However, in the last decade there has been a resurgence in the value placed on work for people with mental health problems. Goodwin and Kennedy's research, involving 50 participants, found that people with a severe and enduring mental illness rated psychosocial work functions as highly important. In contrast to the research of Browne et al. (2008) and Granerud and Severinsson (2006), Goodwin and Kennedy explicitly acknowledged the service and policy implications of viewing work as a valued social role. As such, the political and societal obligations to further the social inclusion of people with enduring mental health problems were highlighted.

A social inclusion agenda was also seen in a recent study by Borg and Kristiansen (2008). Following the phenomenological tradition, it explored the meaning of work for 13 people recovering from severe mental distress in Norway. This study concluded that work means the same to people with mental health problems as it does to people in general. In addition, Borg and Kristiansen found that work was a crucial part of social inclusion goals in that it was associated with increased self-confidence and self-esteem, raised social status and a sense of belonging. The statement: "recognising all people as fellow human beings with citizenship rights" (p.521) created an indisputable link to the concept of social inclusion.

Green, Hayes, Dickinson, Whittaker and Gilheany (2003) supported the importance of strategies to combat social exclusion through their exploration of mental health service users' experience of stigma. In-depth interviews were conducted in which 27 participants reported both overt discrimination and fear of stigma. The researchers suggested that by discovering the nature and impact of stigma from the perspective of service users' lived experience of mental health problems, service users themselves would be more able to develop coping strategies to combat stigma. In addition, mental health services would be better equipped to support their clients in dealing with stigma and to encourage communities to behave in a non-stigmatising, socially inclusive manner.

3.3 Stigma and discrimination

People with mental health problems face widespread stigma and discrimination in a number of key areas of their daily lives (Peterson et al., 2006; Sayce, 1998, 2000; Schulze & Angermeyer, 2003). Sayce (1998) criticised the language used in much of the literature relating to stigma and discrimination, specifically the use of the word 'stigma'. She referred to a personal communication with Judi Chamberlain who stated that: "the concept of 'stigma' is itself stigmatising. It implies that there is something wrong with the person, while 'discrimination' puts the onus where it belongs, on the individuals and groups that are practising it" (p.331). New Zealand's Mental Health Commission supported this view stating that: "Whereas stigma attaches to the consumer, discrimination results from actions of others" (MHC, 1997, p.16).

Many people report discrimination against them in education, employment, housing, parental rights, health services and leisure activities as well as that generated by friends and family (Peterson et al., 2006; Sayce, 1998). According to Kelly and McKenna (2004), one reason for discrimination is that the public often view the appearance and behaviour of many people with a severe and enduring mental illness, as unusual, strange or even deviant. This engenders fear and apprehension, especially amongst people who have limited knowledge about mental illness and

have little contact with people with a mental illness. Media portrayals of mental health service users as being unpredictable and violent, add to the discrimination that results in negative perceptions within the community (Read & Law, 1999).

3.31 Structural discrimination

In order to broaden understanding of the discriminatory processes directed at people with mental illness, Corrigan, Markowitz and Watson (2004) differentiated between discrimination at a structural or institutional level and that based at an individual level. Individual discrimination refers to the behaviour or actions of individuals or small groups in the context of social relationships. At this level, discriminatory behaviour commonly comes from friends, families, neighbours as well as from mental health professionals. On the other hand, structural or institutional discrimination involves “imbalances and injustices inherent in social structures, political decisions and legal regulations” (Schulze & Angermeyer, 2003, p.306). The strongest form of structural discrimination is perceived as that emanating from mental health services.

According to Krieble (2003), New Zealand’s mental health services continue to use an outcome-based framework in which outcomes are measured against a biomedical model of illness. This means that the focus is on diagnosis and symptomatology, as opposed to quality of life, recovery and other social and economic issues (Bertram & Stickley, 2005). Compounding this are the patriarchal assumptions that have traditionally permeated mental health services (Crowe, O’Malley & Gordon, 2001). It is often believed that service users do not have the judgement, knowledge or intellect to make decisions about their treatment but that professionals do. Specific examples of structural discrimination within New Zealand’s mental health services are identified by the Mental Health Commission (MHC, 1997). These include insufficient professional contact time, difficulties in accessing help in crisis situations, inadequate early intervention and community based services, overemphasis on drug-related treatments and lack of training for both professional and untrained staff.

Corrigan et al. (2004) suggested that mass communication sources help perpetuate structural discrimination through portraying people with mental health problems in a negative light. A constant theme of the news media is that ‘the mentally ill’ are dangerous, violent, unpredictable and incompetent (Kelly & McKenna, 2004). These misrepresentations excite fear and false impressions that confirm the myths surrounding mental illness (MHC, 1997). Playing a major role in maintaining this stereotype are the negative perceptions endorsed by the film industry (Read & Law, 1999). People with mental health problems are often characterised in movies as ‘homicidal maniacs’ or ‘incapable misfits’.

3.32 Multiple discrimination

According to Sayce (1998), the discrimination faced by people with a mental illness is compounded by other categories of discrimination such as race, ethnicity, or gender. This multiple or layered discrimination is evident in how New Zealand’s Māori population have been treated (MHC, 1997). Mental health services have not always been appropriate or adequate, nor were they designed to meet the needs of Māori. For women, gender-based discrimination may also be layered on top of the discrimination that results from having mental health problems (Van Den Tillaart, Kurtz & Cash, 2009). Women are likely to have more difficulty than male service users in accessing employment, health care, education and safe housing.

3.33 Labelling and self-stigma

A mental health diagnosis in effect ‘labels’ people, putting them at risk of being rejected, avoided or physically attacked (Wright, Gronfein & Owens, 2000). However, perhaps the most negative effect of a mental health diagnosis may be on people’s self-image. They may come to view themselves in terms of the negative cultural meanings associated with mental disorders and people who have them. In addition, some people with a mental illness diagnosis start believing in the negative stereotypes about themselves (Ministry of Health, 2007). Otherwise known as self-stigma, this internalised stigma is yet another barrier to full participation in society through significant loss of self-esteem and confidence. This in turn may lead people

to become isolative due to the fear of being rejected or shunned by the community (Link, Struening, Neese-Todd, Asmussen & Phelan, 2001).

Peterson et al. (2008) suggested that if empowerment involves wanting to have a positive effect on one's community and having positive self-esteem, then self-stigma can be defined as the opposite of empowerment. Their study *Fighting Shadows: Self-stigma and Mental Illness* suggested that the only way to minimise the negative effects of discrimination and self-stigma is to socially include people with a mental illness. If people with mental health problems are treated the same as every other citizen, they would have the opportunity to view themselves as valued members of society. This is especially important when people want to join or re-enter the work force.

3.4 Employment

Employment is a major determinant of social inclusion (Evans & Repper, 2000). It not only gives people financial security, but also provides opportunities to make new social contacts and to raise feelings of self-esteem, a sense of purpose, social status, and overall quality of life (Russell & Lloyd, 2004). Mental health services users have far more limited opportunities than the general population to find employment and to retain it (Evans & Repper, 2000). Jensen et al. (2005) reported that only approximately 27% of people with experience of mental health problems in New Zealand are in full-time employment. Duncan and Peterson (2007) cited several sources that show that this rate is similar to that in both the United Kingdom and the United States of America. Rates of unemployment however can vary according to the severity of the mental health problem and may be higher than 85 % for people with a severe and enduring illness.

Internal barriers to employment include a lack of training and education, poor self-confidence and self-esteem and lost opportunities through episodes of mental illness (Russell & Lloyd, 2004). The widespread discrimination and negative stereotypical attitudes against mental illness are external barriers that arguably have the most

significant impact on people's access to employment opportunities. While research showed that mental health service users identified work as a major determinant of their recovery, a large proportion remains unemployed (Lapsley et al., 2002; SEU, 2004).

Health professionals may also deter people from pursuing employment goals through their continued focus on symptoms and impairments rather than on strengths and abilities (Evans & Repper, 2000). In many cases, low expectations and negative assumptions among mental health professionals, lead them to consider that mental health service users are not fit to work and will never have the ability to find and sustain employment (Lloyd et al., 2006). In addition, mental health professionals may still view work as a form of treatment, as opposed to it being an entitlement and a right as a citizen. These negative attitudes on the part of health care professionals mean that they do not generally view employment as a key objective for people with mental health problems (SEU, 2004).

As evident in Chapter two of this thesis, there was little focus in New Zealand's policies and documents on employment and social exclusion, especially in regards to mental health issues. This is in contrast to the policies of the United Kingdom and the establishment of the Social Exclusion Unit (SEU, 2003). However, Peace (2001) suggested that the focus on the employment-oriented policies of the 1990s created greater exclusion for already excluded groups. For example, some employers were reluctant to employ people with mental health problems who had gained the reputation of being unreliable workers because of their inability to sustain full-time jobs.

There are several different models of employment programmes designed to assist people with experience of mental health problems to access and keep jobs (Duncan & Peterson, 2007). In New Zealand, the most common and effective approach is supported employment (Morris & Lloyd, 2004; Peterson, 2007; Waghorn & Lloyd, 2005). These services assist people to plan their careers and identify their vocational

interests, to approach potential employers, and to support them in applying for and retaining work (McLaren, 2004). However, for optimal effectiveness of supported employment programmes, vocational and mental health services must be integrated (Duncan & Peterson, 2007; McLaren, 2004). Despite the proven efficacy of integrated services, a New Zealand survey of supported employment services found that none of those surveyed were integrated (McLaren, 2004).

Morris and Lloyd (2004) suggested that many people are denied rehabilitation opportunities due to the separation of mental health services from vocational services. For integration to occur, mental health workers have to prioritise vocational rehabilitation in order to help service users manage their symptoms and medication, facilitate early interventions and provide after-hours services that do not interfere with the person's working hours (McLaren, 2004). Furthermore, the Mental Health Commission (2001) recommended that collaboration occurs between employee health care and welfare services and management departments within a business. There should also be collaborative relationships between Work and Income New Zealand (WINZ) and clinical and supported services (McLaren, 2004).

Many people with experience of mental health problems are on invalid or sickness benefits and consider that some WINZ policies and practices create further barriers to them moving into paid work (McLaren, 2004). Stand-down periods when a person leaves a job, loss of income when working more than 15 hours a week, and a lack of consistency in how WINZ employees interpret people's entitlements, all contribute to many people being reluctant to return to the workforce. This is especially the case for people who have had the security of a WINZ income for many years and who are unsure of their ability to sustain a job in light of their mental health problems. Sayce (1998) suggested that a scheme of reducing benefit disincentives would assist people with severe difficulties in returning to work, without the fear of being left with a net loss of income.

3.5 Material poverty

According to Waghorn and Lloyd (2005), people with mental health problems are among the most economically marginalised groups in society. Although social exclusion involves a great deal more than simply being poor (Sayce, 2001), long-term poverty promotes income inequality and material disadvantage through unemployment, financial exploitation and long-term reliance on financial assistance (Bradshaw et al., 2007; Kelly & McKenna, 2004; Lapsley et al., 2002; Peace, 2001). Limited financial resources mean that people are often unable to join community clubs or participate in meaningful and recreational activities (Young & Ensing, 1999). Lack of money for transport can limit people's ability to attend appointments, visit friends and family, and to gain and sustain employment (Bradshaw et al., 2007).

Although persistent poverty has a significant impact on social exclusion, Ward (2009) suggested that the British government had approached social exclusion in terms of material disadvantage in order to reduce the country's welfare burden. The conceptions of social inclusion employed by the New Labour government tended to focus on individuals and their inability to be included. Rather than seeking to remove the social and cultural barriers to social inclusion, the emphasis on the individual and on outcomes, drew attention away from the exclusionary practices of discrimination, stigmatisation and negative social attitudes that create those barriers.

3.6 Relationships and social networks

It is widely recognised that having supportive relationships and social networks is essential for mental well-being. It is also acknowledged that people with experience of mental health problems have difficulties in establishing and maintaining these relationships (Lester & Tritter, 2005; Pejler, Asplund & Norberg, 1999; SEU, 2004; Stickley, 2005). Lapsley et al. (2002) pointed out that breakdowns in relationships often triggered episodes of mental ill health. In addition, the meaningful roles that people have in society are extremely important (Stickley, 2005). The onset of mental health problems and periods of hospital admissions can severely restrict people's

ability to fulfil these social roles, to resume them when discharged from hospital and to maintain them as they travel through their personal recovery journeys (SEU, 2004; Stickley, 2005).

Having supportive and understanding relationships with family members is considered necessary for recovery from mental health problems (Lapsley et al, 2002; Young & Ensing, 1999). People have a wide variety of understandings of what constitutes 'family'. This can range from immediate family such as parents, brothers and sisters, to wives, husbands, partners and children. For Māori, 'family' is a much broader concept, encompassing a greater variety of categories and groups (Durie, 1994). While the term 'whānau' is typically understood to mean 'extended family' or 'family group', Metge (1995) pointed out that Māori use the term to refer to small family units consisting of one or two parents, to spouses and children adopted from outside immediate family, to descendants of relatively recent named ancestors, to tribal descent groups, and finally to groups who, while not directly related, interact and gather together for a common purpose.

The term 'friend' and the concept of 'friendship' also mean different things to different people (Boydell, Gladstone & Crawford, 2002). It can refer to acquaintances and short-term superficial relationships, or to deeply committed and long-lasting relationships. Friendship is considered to be a normal and important aspect of people's social lives which can contribute significantly to overall quality of life (Boydell et al., 2002; Bradshaw et al., 2007; Lapsley et al., 2002; Repper, 2000; SEU, 2004; Young & Ensing, 1999). Boydell et al. cited numerous studies from psychiatric literature that highlighted the significance social networks have on mental wellbeing, social functioning and recovery. Despite this, many people with experiences of mental health problems report difficulties in making friends and maintaining friendship networks (Lapsley et al., 2002).

Some people find that relationships with friends are more meaningful and supportive than those with family members (Young & Ensing, 1999). However, many others

report disruption to friendships through repeated cycling from hospital to home, and the discrimination associated with mental illness (Boydell et al., 2002; Bradshaw et al., 2007; Pejler et al., 1999). The feelings of loneliness and isolation that this engenders, may in part be why people value the support and friendship they receive from other service users (Boydell et al., 2002). Although socialising with people without mental health problems is seen to be more normalising, being with people who have similar problems can offer a level of understanding and acceptance that is difficult to find elsewhere (Lester & Tritter, 2005). Alongside this, some people feel so excluded from the community that they believe that friendship is only possible with fellow service users (Stickley, 2005). Peer support programs have been set up throughout New Zealand to help people establish friendships and develop broader social networks (Gawith & Abrams, 2006). These groups are owned and run by service users and are seen as an effective way to support people in their recovery and to improve social inclusion.

3.7 Partnerships in mental health

There is an increasing recognition of the importance of working in partnership with service users, government and non-government services, and community organisations (McMorland et al., 2008; Russell & Lloyd, 2004). This partnership working allows for appropriate and effective use of resources, provision of continuity of care and sharing of innovative ideas (Ministry of Health, 2005). While the United Kingdom has used the themes of collaboration and partnership to guide initiatives to tackle social exclusion (Tett, 2005), partnership relationships in New Zealand have evolved within the policy framework of recovery (McMorland et al., 2008).

New Zealand's commitment to working in partnership is seen in the documents *Te Tāhuhu* and *Te Kōkiri* (Ministry of Health, 2006, 2007). These strategic plans proposed building effective partnerships between mental health service users, the Ministry of Health, clinical provider services, and NGOs. In addition, they acknowledged the importance of having proactive partnerships between justice,

corrections, education, housing, employment and social service agencies in order to meet the social and economic needs of service users. Arguably the most important group to consider when discussing partnership working within mental health is service users (Gawith & Abrams, 2006). Tett (2005) suggested that they should play a significant role in shaping what services are available and how they are delivered. Gawith and Abrams gave evidence of service user involvement in New Zealand when they pointed to Consumer Advisors being in paid employment, the establishment of Consumer Councils, peer support services, and the employment of service users as consultants, educators, researchers and policy makers.

Working in partnership with service users is also important at grass-roots level (Crowe et al., 2001; Sayce, 2000). To support and assist in their recovery from mental health problems, many service users want to take an active role in their treatment (MHC, 1998). Crowe et al. found that community mental health nurses had an important role in the delivery of mental health care that service users wanted and needed. Nurses are in a position to work together with service users in the development of treatment plans that reflect individual choice and informed consent. For this to happen, service users must have received information with regards to treatment options, potential benefits and adverse effects.

3.8 Summary

It has been established that social inclusion and well-being are inextricably linked (Sayce, 2001). Strategies that help increase social inclusion include “facilitating access to roles, responsibilities, relationships and communities” (Repper, 2000, p.575). It has also been acknowledged that people living with mental health problems are among the most socially excluded groups in society (Lloyd et al., 2008). Despite this awareness, there is little New Zealand literature that deals specifically or explicitly with the social inclusion or exclusion of people with mental health problems.

However, the common aspects of recovery evident in the literature incorporated the three dimensions of inclusion that Davidson et al. (2001) identified as being inadequately addressed in a recovery paradigm. Friendship, meaningful activity and hopefulness are addressed in both New Zealand's key documents and research on service users' experience of mental health problems. While current international research also addressed these aspects, most studies had in general a much broader focus, taking into account the responsibility that society has for ensuring that no person is excluded. Social inclusion and exclusion were dealt with far more explicitly. Although this may be partly due to the terminology used, it appears that society's obligation to promote social inclusion within mental health is more readily recognised internationally than it is in New Zealand.

The research gap that this study aimed to fill lay firstly in the fact that there is a paucity of research in relation to people with experience of enduring mental illness. Secondly, first-person accounts of recovery from severe mental health problems and social inclusion are very few (Borg & Kristiansen, 2004). Finally, social inclusion and exclusion as they relate to the experience of enduring mental health problems have not been explicitly explored in New Zealand. This indicated that it was important and relevant to conduct research that reflected the multicultural diversity of New Zealand's mental health service users, their experiences of an enduring mental health problem and social inclusion.

The following chapter presents the qualitative research design used in this study. It gives the rationale for selecting this approach, the techniques used to select participants, conduct the interviews and analyse the data. Finally, the ethical considerations and maintenance of the quality and rigour of the study are discussed.

Chapter four: Research design and methods

4.0 Introduction

In accordance with the literature, Sayce (2001) defined social inclusion as “improved rights of access to the social and economic world, new opportunities, recovery of status and meaning and reduced impact of disability” (p.122). This study aimed to understand what social inclusion means to people with an enduring mental health problem by exploring people’s experiences of social inclusion and their perceived barriers to it. This chapter describes the qualitative exploratory method and the narrative approach that was used and provides the justification for the selection of this methodology. It discusses how and why the participants were selected, along with the ethical considerations of the study. Details of how the data were collected, analysed and interpreted are given.

4.1 Design

4.11 Qualitative exploratory method

Nursing researchers are increasingly using qualitative research designs to describe, explore and explain human behaviour, experiences and beliefs (Bailey, 1996; Burnard, 1991; FitzGerald & Field, 2004). Quantitative studies measure and quantify phenomena in order to produce objective knowledge that examines cause and effect relationships, while qualitative research is interested in people’s experiences and the subjective meanings they place on them (Carr, 1994; Harris, 2004). Selecting which design should be used for a particular study involves determining the style and format that can best answer the research question and aims, as well as whose perspective is to be the focus of the study. As the present study aimed to give voice to the views of mental health service users and to allow an in-depth exploration of their experiences, a qualitative exploratory method was considered to be the most appropriate.

The qualitative methodological approaches that are commonly used in health sciences include grounded theory, ethnography, phenomenology and life story narratives (Grbich, 2004). Ethnography originates from social and cultural anthropology and provides detailed information that holistically describes and interprets behaviour, activities and social relations within a particular cultural setting (Holloway & Todres, 2003). The central goal is to discover and understand the social and cultural patterns that guide, inform and explain people's behaviour and experiences. The theory of symbolic interactionism informs methodology by taking the perspective of those being studied within the context of their culture (Crotty, 1998). Data are generally collected using participant observation and in-depth interviews. Researchers can spend several months or even years getting as close as possible to the participants and becoming immersed in their worlds.

Although ethnography enables a rich and complex picture of the culture of interest, I had two reservations about its use for this study. Firstly, as Grbich (2004) pointed out, the data collection and analysis are extremely labour-intensive and therefore outside the constraints of available resources for this study. Secondly, the main focus of ethnography is on how people are situated within and between institutional structures and their spatial and symbolic boundaries (Sandelowski, 1998). While I was interested in the meanings that people construct about their cultural and social situations, I particularly wanted to hear their personal narratives of living with an enduring mental health problem. For these reasons I discounted ethnography as the preferred methodology for this research project. The next methodology I considered was grounded theory.

According to Grbich (2004), grounded theory differs from ethnography in that it focuses not on the relationships between people and institutional structures, but on the relationships that people have with each other that lead to action and interaction within a particular setting. Grounded theory was developed by Glaser and Strauss in the 1960s and involves the development of theories that are informed by events and people's interactions (Holloway & Todres, 2003; Sandelowski, 1998). Sandelowski

pointed out that the researcher reformulates the data and only presents that which supports the theory. Critics suggest that this linking data to existing theories is overemphasised (Grbich, 2004) and this is the main reason I decided against using grounded theory. I wanted a data-driven approach that searched for individual understandings and meanings, with the voices of the participants driving the study. The next step involved considering whether phenomenology would provide the means to achieving this goal.

As an approach to research enquiry, phenomenology seeks to reveal the essence of a phenomenon through the eyes of those experiencing it (Holloway & Todres, 2003). There are two forms of phenomenology, descriptive and interpretive (Polit & Beck 2006). Descriptive phenomenology, developed by philosopher Husserl, proposes that researchers separate out or 'bracket' their preconceived ideas, past experiences and emotions in order to provide careful descriptions of human experience. Heideggerian phenomenology on the other hand utilises an interpretive approach, allowing researchers to examine, interpret and understand participants' rich descriptions of their reality and experience. Polit and Beck pointed out that this approach emphasises the everyday experiences of people and how they are involved in and united with the world. As opposed to the bracketing of descriptive phenomenology, Heideggerian researchers acknowledge their assumptions and preconceptions and use them to further understand the participants' worlds.

In many ways an interpretive phenomenological inquiry is well placed to explore the thoughts and feelings of people with an enduring mental health problem. Arguably the biggest problem, and certainly the most controversial, is the question of rigour in phenomenological nursing research (de Witt & Ploeg, 2006). According to Draucker (1999), Michael Crotty alleged that while many nursing researchers purport to use Heideggerian philosophy, their interpretation of the methodology and of the data fails to reflect this philosophy. Darbyshire, Diekelmann and Diekelmann (1999) however refuted this, arguing that Crotty misunderstood Heidegger's work and therefore presented a narrow and misguided viewpoint. These contradictions have

led to a great deal of confusion surrounding the use of phenomenological approaches and highlighted the challenges that novice researchers face in sorting out a methodological conundrum (Caelli, 2001). I therefore decided against using phenomenology and considered life story narrative as the methodology to use.

Life story narrative focuses on people's personal experiences, looking back at particular life events as they recall them, and highlighting the meanings they place on the connections between their experiences and the social and cultural context of their lives (Grbich, 2004). My interest lay in the connections between the experiences of having an enduring mental illness, social relationships and the processes that help or hinder social inclusion. I therefore considered a life story narrative to be the most appropriate approach to use for this study.

4.12 Life story narrative

Narrative inquiry is used as a framework for collecting and understanding data that enables participants to give voice to their experiences (Gaydos, 2005; Kelly & Howie, 2007; Kohler Riessman, 1993; Sandelowski, 1991). A narrative approach assumes that people tell their stories of personal experiences in order to know, understand and make sense of their world (Casey & Long, 2002). As Kohler Riessman (1990) stated, "language is the major cultural resource" that people use to create meaning (p.1195). While narrative research can reveal how participants construct explanations about their cultural and social situations, there is a lack of consensus about what constitutes a narrative and what terminology is appropriate for life-story narrative (McCance, McKenna & Boore, 2001; Sandelowski, 1991). Although some authors propose that a narrative differs from a life story (Ward, 2005), others use the terms 'personal narrative', 'personal story', 'life story', 'life history' and 'life journey' interchangeably (Gaydos, 2005).

Notwithstanding this debate, McCance et al. (2001) suggested that life stories are based around a plot that provides the cultural context of the story. The narrator is the chief actor and this person identifies their significant others and the roles they all

play in the development of the storied plot. For the purpose of the present study, I treated the terms narrative and life story as synonymous, adopting the definition of a narrative as a story. I wanted the participants to focus on their lives as lived and the meaning they make of their personal experiences. For this reason, I asked them to tell me the stories of their lives. This gave them the opportunity to begin their stories where they wanted, to develop the plot in whatever way they chose and to represent past events and actions as they wished.

Life stories are particularly appropriate for examining the experiences of marginalised social groups whose voices are often unheard by those who hold more dominant positions in society (Kohler Riessman, 1993). Despite the debate surrounding the terminology that is used, there can be no disputing the value of narrative approaches within the area of mental health. Three notable New Zealand research projects used the stories of service users to describe and explore experiences of mental illness, employment and recovery (Barnett & Lapsley, 2006; Lapsley et al., 2002; Peterson, 2007). These studies honoured the experiences of the people who participated, by listening to their voices and giving credence to their words. This was also the case in several overseas studies that collected narrative data (Borg & Kristiansen, 2004, 2008; Browne et al., 2008; Casey & Long, 2002; Diaz-Caneja & Johnson, 2004; Granerud & Severinsson, 2006; Pejler et al., 1999). While focusing on the stories of people who have experienced mental health problems, these studies varied in the method of data collection as discussed in the following section.

4.13 Data collection

Browne et al. (2008) and Granerud and Severinsson (2006) used focus groups to collect their data. Focus group interviews enable researchers to explore what people think, how they interact in a social context and the diversity or consensus within the group in relation to a particular topic (Grbich, 2004). The ability of focus groups to provide information about the interaction of complex factors is seen in the study conducted in Norway by Granerud and Severinsson. They explored the experiences

of people with mental health problems and their ability to integrate socially into a community. The findings reflected the multifaceted and complicated nature of the topic as well as the diversity in the meanings that people made of their experiences.

Browne et al. (2008) also used focus groups to determine the recovery needs of people who are living with mental health problems. This study highlighted how a focus group method was able to explore a variety of opinions and views and to give group members the opportunity to clarify and qualify these views. A further advantage of focus group interviews is that they generally enable the collection of large amounts of data relatively quickly and easily (Grbich, 2004). This means that they are usually considered to be cost-effective, both in terms of the financial resources needed and the researcher's time.

However, as with all research methods, focus group interviews have limitations that may result in them not always being the method of choice (Grbich, 2004). Group interaction can be affected by the personal characteristics of participants, especially if they have a relationship with each other outside the group. Some people may be more forceful and talkative than others, and some people may be reluctant to discuss sensitive issues in a group context, especially those that carry social taboos. It is likely that the data generated consist of public rather than private views, as participants will only discuss what they are prepared to say in front of other people. Participants may not voice their true thoughts and ideas in a group setting and existing relationships can influence responses within the group. These limitations persuaded me that a focus group method would not be appropriate for the present study. The alternative was to conduct individual interviews.

Pejlert et al. (1999) conducted a narrative study in which they used semi-structured individual interviews to collect the data. Although the study had a predetermined list of questions, the researchers invited open-ended responses and asked further probe questions that encouraged clarification and elaboration. There were quite specific research questions relating to the participants' experiences of living in a home-like

setting, their key care provider and the care they received. Having some structure to the interview may have been necessary, due to the participants often responding with concrete and short sentences. In this case, an unstructured interview format may not have generated the narratives required to answer the research questions. However, Kohler Riessman (1993) suggested that in some instances, unstructured interviews may give greater control to the participant and therefore encourage more free-flowing narratives. Lapsley et al. (2002) supported this view, suggesting that structured interviews, along with questionnaires and surveys, have the potential to detract from a full exploration of people's subjective experience.

The narrative study of Lapsley et al. (2002) explored people's first hand experiences of mental illness and recovery from it. They used unstructured interviews to generate valuable and insightful data about a wide range of aspects relating to people's experiences of recovering from disabling mental health problems. Despite these variations in how the narrative data were collected and the limitations of each method, the focus of all these studies was personal experience from the perspective of the participants as expressed through their stories.

4.14 Summary of design and data collection considerations

To summarise, I chose a life story narrative approach for this research as I decided that it would best answer the research questions and meet the objectives of the study. Data were collected using unstructured, individual interviews. I considered that this method had the potential to provide an in-depth understanding of what social inclusion meant to people with an enduring mental health problem. How the data were analysed and interpreted is discussed in section 4.6, page 67.

4.2 The qualitative researcher

In all qualitative research the researcher is the primary instrument of data collection and strongly influences the presentation and interpretation of the data (Finlay, 2002; Schensul, Schensul & LeCompte, 1999). Dickson-Swift, James, Kippen and Liamputtong (2007) cited several sources that identified the numerous challenges

researchers face throughout the qualitative research process. These challenges are often compounded when the research involves sensitive issues or when the participants are vulnerable or marginalised. Johnson and Clarke (2003) suggested that in many cases, this is a result of inexperience and lack of training. In fact this unpreparedness may mean that some neophyte researchers are unable to surmount all of these challenges, especially when the research involves sensitive issues such as HIV/AIDS, chronic pain, sexual abuse and mental health problems.

4.21 The challenges

For some researchers, their lack of experience and training mean that the challenges begin at the very start of the research process (Johnson & Clarke, 2003). Having to access potential participants, make the initial contact and establish rapport, can create feelings of anxiety. These difficulties often continue throughout the data collection process. When participants share their personal stories in an interview situation, researchers may feel that they need to reciprocate by telling something about themselves (Dickson-Swift et al., 2007). This self-disclosure has the potential to increase rapport and trust and to lower the hierarchical position of the researcher (Liamputtong & Ezzy, 2005). However, the challenge for the researcher comes from knowing what, when and how much to disclose (Dickson-Swift et al., 2007).

In the process of trying to establish empathic rapport and build a trusting relationship, the boundaries between the researcher and the participant can become blurred (Dickson-Swift et al., 2007). Some participants may have difficulties in differentiating between the person as a researcher and the person as a friend (Johnson & Clarke, 2003). The researcher may also become emotionally attached to the participant and find themselves in a relationship that moves beyond that of participant and interviewer. This then creates issues around how and when to terminate the research relationship and the potential for the researcher to feel guilty about leaving a relationship that both parties have come to value.

4.22 A dual role: nurse researcher

The dual role of nurse and researcher of qualitative studies can be problematic, especially when the participants are aware that the researcher is also a nurse (Johnson & Clarke, 2003; Robley, 1995). Robley pointed out that the ‘nurse role’ is likely to be more familiar to people than that of a research role and this may lead to participants interacting with the nurse researcher simply as a nurse, not as a researcher. Fowler (1988) however, suggested that the dual role of nurse researcher is not two distinctive roles, but rather “a *single role* with dual aspects” (p.110). Fowler also considered that from an ethical perspective, the nurse aspect must always take precedence over that of the researcher. This compounds the difficulties faced by nurse researchers, as participants may have different expectations of nursing care than what they can practically expect from nursing research (Johnson & Clarke, 2003).

The nurse researcher also has a commitment, not only to the nursing profession, but to the research project, the ethics committee who approved it, and the educational institution that supports it. This can create conflict when the ethics of protecting the participant clash with their role as data collector (Johnson & Clarke, 2003). Nurse researchers can feel guilty when they are unable to assist participants, or give an opinion about an aspect of nursing care (Patterson, 1994). Guilt may also come from ‘using’ people as a means to further knowledge instead of viewing them as individuals whose health needs are paramount (Robley, 1995).

4.23 Reflexivity

“Reflexivity can be defined as thoughtful, conscious self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself” (Finlay, 2002, p.532). According to Hewitt (2007), reflexivity is an integral component of qualitative research that should be incorporated in the research project from its conception, through data collection, analysis and interpretation. Finlay asserts that being reflexive involves researchers continually challenging and examining their research-

participant relationships, their roles within the research process, their biases and assumptions, and the cultural values, attitudes and influences that they bring to the research project.

However, being reflexive can create its own problems and potentially skew the findings of a research project (Finlay, 2002). In an attempt to maintain a reflexive stance, researchers may become so preoccupied with their own emotions and experiences that they block out the voices of the participants. Criticisms such as these can be challenged by maintaining a balance between self-indulgence and self-awareness, and undertaking reflexivity only to the point where it remains useful and fulfils some purpose. Despite these concerns, I made every attempt to maintain a reflexive stance throughout this research project.

4.3 Methods

4.31 The Setting

The research setting was a privately owned community home located in a small rural New Zealand town. There are 15 residents, 10 women and five men with an age range of 45-74 years. Four are Māori, 10 are New Zealand European and one is Asian. All 15 residents have a history of long-term institutionalisation. The average length of time living in the home is 10 years. The home is an old house with large common areas and single bedrooms. Most of the residents are in need of guidance and help with their daily activities such as showering and cleaning as well as with medication and financial management. While they are encouraged to be responsible for keeping their bedrooms clean and tidy, doing their personal laundry and assisting with common tasks around the home, there are cooks and cleaners employed to perform the majority of this work. There is one registered nurse employed and she has the dual role of manager and nurse of the home.

4.32 The Researcher

I have worked as a registered nurse for over 35 years, the last 17 of these in mental health. I am currently employed as the manager and registered nurse of a home very

similar to the one that was the setting of this study. While located in different rural towns, both homes are owned by the same person and I am therefore acquainted with the home and the residents. However, I do not have any responsibility for, and am in no way involved in treatment or any other aspects of day-to-day care in the home. Despite this, my familiarity with both the participants and the setting raised several issues that needed consideration.

A close and interactive relationship such as this can provide rich and meaningful data, making the research more insightful and valuable (Roper & Shapira, 2000). An insider is more likely to gain access to the setting, be familiar with the nursing practice and get co-operation from the staff. However, Hanson (1994) argued that it can be difficult for researchers in familiar settings to see others' viewpoints and perspectives. This was particularly relevant in my case as I have a long-term relationship with two of the participants. I had worked with them several years ago and although I have not been involved in their care for the past eight to ten years, we know each other very well. It was therefore essential that I maintained a reflexive stance, from the very beginning of the project through to its completion.

Before starting the data collection process, I declared all my preconceptions and prior assumptions in order to isolate their effect and minimise the risk of them influencing the findings of the study. I continued to lay out my assumptions throughout the data collection and analysis stages by way of keeping a self-reflexive journal. These were not objective observations, but reflections and thoughts about my feelings and experiences. According to Patterson (1994), the memoing of reflexive remarks enables the researcher to stand back from the research situation in order to see things in a fresh way. However, journaling my impressions and experiences were not in themselves sufficient to minimise all risk of the participants suffering adverse consequences from the project.

As suggested by Johnson and Clarke (2003) and Patterson (1994), I put strategies in place to deal with any blurring of boundaries and role conflict before I entered the

field and began collecting the data. These included defining my role as nurse researcher by openly identifying myself and my role to the residents and to the staff. I explained that I would not deal directly with any participants' requests or concerns unrelated to the study but would refer them to either the manager of the home or to the staff on duty. In addition, the participants were reminded that they were taking part in a study, and were given every opportunity to discuss the research, my role as the researcher and their role as participants.

4.33 The Participants

The participants were selected using purposive sampling. This involves judging which people have the required knowledge and willingness to share their experiences (Fetterman, 1998). Further inclusion criteria were that they could speak and understand English, had a psychiatric diagnosis and had the ability to communicate clearly and be able to read. An informal meeting was held at the home to provide information and invite participation. The staff and residents were given verbal and written information detailing the purpose and aims of the study, a brief description of how it would be carried out and what would be done with the results (see Appendix A). In addition, an information sheet about the study was made available for the family/whānau of prospective participants (see Appendix F).

Of the 15 residents who attended the pre-selection meeting, five volunteered to participate in the study. All met the criteria for inclusion in the study and I expected that five participants would provide sufficient data to answer the research questions (see Table 1, page 60 for participant characteristics). Informed, written consent was obtained from each individual who agreed to take part in the study and who fully understood the nature of the research and their part in it (see Appendix B). I explained to the participants that the interviews would be audio-taped and obtained authorisation for the use of the tape transcripts from each participant (see Appendix C).

Table 1. Characteristics of the participants

Age range	Between 56 and 75 years old. Average age 62.80 years
Gender	3 females and 2 males
Ethnicity	2 Māori and 3 New Zealand European

4.4 Ethical considerations

The research project received ethical approval from the Northern Y Regional Health and Disability Ethics Committee. The study followed the basic ethical principles set out in the *Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants* (Massey University, 2006). The most relevant to this study and group of participants were: respect for persons; informed and voluntary consent; and respect for privacy and confidentiality. Although gaining informed consent from participants is mandatory (Roper & Shapira, 2000), it is of particular importance when seeking the consent of vulnerable people such as people with a mental illness (Liamputtong & Ezzy, 2005). There must be full disclosure of information concerning the study in language that is clear and simple. This helps to ensure that the participants understand exactly what they can expect to happen and what they are consenting to. It must include the purpose of the study, the expected risks and benefits and how the results will be used.

Even though the inclusion criteria for this study included being able to read, it was necessary to read the information and consent forms to each prospective participant. This allowed even more opportunity for them to ask questions and give an indication through the discussion, that their consent was truly informed and voluntary. Participation in the study was entirely voluntary and there was no coercion to take part. People were reassured that they would not be penalised if they declined to participate or withdrew from the study. They were also assured that their treatment or their lives would in no way be adversely affected if they decided not to participate. This was all discussed again with the participant before beginning each individual interview. All consent forms were stored securely in the control of the

supervisor of the study and will be held for ten years, after which time they will be disposed of under the supervision of the supervisor.

McEldowney (2002) pointed out that in qualitative research it is not possible for participants to remain anonymous as they are known to the researcher. While this was the case in the present study, every effort was made to maintain the privacy of the participants and the confidentiality of information obtained about them. No identifying material was attributed to the participants, including the geographical location, the name of the home, the names of family and friends and the staff of the home. Transcribed data referred to the facility as 'the home' and each resident was called by a pseudonym of their choosing. Ensuring that no participant could be identified was paramount. All transcripts were stored on a CD-Rom. Audiotapes and computer files were stored securely and were only accessible to myself and my supervisor. Audiotapes and computer files will be held at Massey University for ten years, after which time they will be destroyed under the supervision of my supervisor.

Even though ethnicity data were not being collected and the focus of this research was not ethnicity, two Māori participants participated in the study. While the study adopted a mainstream approach, the methodology incorporated a clear commitment to the Treaty of Waitangi and in particular to the principles of partnership, participation and protection. A Kuia with expertise in mental health was consulted about how best to incorporate tikanga (doing things the proper way) into participant selection, the collection and storage of data, as well as the dissemination of the results. She was available to clarify or explain the information sheet and consent forms to the participants. Finally, the Kuia was asked to review the analysed data of the two Māori participants. This was done in order to confirm that things of cultural significance were recognised and that interpretations and assumptions made about the data were correct.

No payment was made to the participants. The time and place for the research was negotiated with the participants so that they did not incur costs such as transport and therefore did not need any reimbursements. However, in accordance with Māori tikanga, a small gift or koha in the form of a \$30 gift voucher was given to each participant at the completion of the interviews.

4.5 Collecting the data

Conversations with the participants were the primary data collection source for the study. I had initially planned to use a two stage narrative interview process, with narrative interviews being followed by analytic interviews. While the ideal would have been for each participant to have two sequential individual interviews one or two weeks apart, I recognised that this may not have been possible and that the interview timetable needed to be flexible. Some participants may have refused a second interview, have been unwell at the time of the scheduled interview or may simply not have felt up to the task at the time. There are two main reasons for having interviews on separate occasions. Firstly, the risk of the participants becoming tired and not wanting to continue if the interview goes on for an extended period of time is minimised. Secondly, it allows the opportunity for a preliminary analysis of the first stage of interviews, so that clarification, elaboration and feedback can occur at the second phase. Checking back with the participants also minimises the risk that their stories are misinterpreted.

In order to elicit free flowing narratives, I planned to use the unstructured interview format recommended by Kohler Riessman (1993). While I aimed for minimal interruption, it was important that the participants were aware that I was interested in their stories (Ward, 2005). In addition, Pejler et al. (1999) found that their participants with schizophrenia often responded with short and concrete sentences. Kohler Riessman suggested that if this occurs, the researcher may need to intervene with prompts such as: “Can you tell me more about that?” or “And then what happened?” It is expected that this would not interrupt the telling of the narrative, but would open topics for further conversation and assist the participant to continue

with his or her story (Kelly & Howie, 2007). Furthermore, in their study of women with dementia, Shenk, Davis, Peacock and Moore (2002) found that it was necessary at times to co-construct their stories over time. This involved: “Question-and-answer and affirmation-reaffirmation sequences between the woman and her conversation partners” (p.410).

The final problem I anticipated in the data collection process related to a participant becoming anxious or distressed through the recollection of painful memories (McEldowney, 2002). If this occurred the interview could either be paused or stopped entirely and rescheduled for another time. Although one participant asked for the tape to be turned off, this was because he wanted to tell me something that he did not want to be recorded.

With an awareness of these issues uppermost, I prepared for the first stage of the interview process. The scheduling of the interviews was in itself fraught with difficulties. One participant was admitted to hospital just prior to the arranged interview time and another person asked to postpone the scheduled appointment on two occasions, saying that she didn't feel up to talking to me at those particular times. A third person, who originally volunteered to participate, changed his mind and withdrew from the study. However, two weeks later he said that he wanted to talk to me after all. Yet another participant was experiencing problems with medication, resulting in having to postpone the interview on more than one occasion. Due to these delays it took over three months to complete the initial five interviews.

Each interview took place in a small private lounge at the home. Before beginning I reminded the participants about the purpose of the study and discussed the other issues raised in the consent forms that each had previously signed. They were told that they may ask to have a break or stop the interview at any time. Finally, they were reminded that the interviews would be taped and that they could ask to have the tape stopped or paused at any time during the interview. For each participant I began with a standard request such as: “I would like you to tell me the story of your

life. I am particularly interested in what it has been like for you living with mental health problems.” Each interview lasted for between 30 and 60 minutes, and just as the duration of the conversations varied quite considerably, so did the ease with which the participants told their stories.

Although I aimed for free flowing narratives with minimal interruptions on my part, this only happened for two of the interviews. Of the other three, one participant responded with short and concrete answers. There were frequent lengthy pauses throughout the interview and the participant needed a great deal of prompting to continue. Prompting was also necessary in two other interviews. These involved the participants with whom I have a long-term personal relationship (see page 58). This familiarity may have caused them to be somewhat distracted from telling me their life stories. Both women expected a response from me after most of their comments and if not given readily, would pause, look enquiringly at me until I either verbally responded or nodded.

Only one person asked for the tape to be turned off (see page 63). This man also asked for several breaks, to have a cup of tea, a cigarette and to use the toilet. Added to the interruptions of this interview was the fact that he wanted the door of the room left open, resulting in noise from the passage and other residents coming in and out of the room. This meant that the conversation was somewhat disjointed as it took some time to pick up the thread of the narrative when it was resumed. I made the decision to terminate one interview when a woman appeared tired and reluctant to continue. There were no reports from staff of any distress after the meetings, although one participant reported feeling quite upset after reading the transcript of the interview. She said: “it was upsetting to read but I am coping with the past”. Before the end of the interview all participants were asked if they wanted a copy of the tape and/or a transcript of their conversations. Three people initially said that they would like a copy of the transcript and no-one wanted a copy of their tape.

Immediately after each interview I made notes of my thoughts, reflections and impressions. This included my overall impressions of the content of the narrative, the manner of their telling and reflections on my research approach and my reasoning behind it. This not only served as a memory jog for the analysis and interpretation process but perhaps more importantly, it allowed me to take a reflexive stance to the study. As Neville (2005) pointed out, reflexivity in the research process is essential in that it assists in showing how the researcher influences and informs the study. By giving details about how the data are collected, analysed and interpreted, the researcher's preconceived ideas and assumptions are exposed and open to critical examination.

After each interview was completed, the narratives were transcribed verbatim by a person employed to do so. This person signed a confidentiality agreement before beginning the transcriptions (see Appendix D). However, this process did not go as planned. Several of the interviews were extremely difficult to understand and took far longer to transcribe than the time I had allowed. In addition, there were several large tracts of narratives from some of the interviews that the transcriber was unable to follow and which I had to complete. Once transcribed, I conducted a preliminary analysis of the life story interviews. This involved scrutinising the narrative in order to identify the key themes and meaningful units relating to social inclusion, social exclusion, and the experiences of having an enduring mental illness.

I then embarked on the second phase of the study by endeavouring to arrange a time to meet again with each participant. I had planned to conduct a semi-structured interview seeking further conversation to clarify and elaborate on topics discussed during the narrative and to check that details of their life story were correct. The second interview with the first participant was carried out as planned. While I had a list of questions based on the preliminary analysis, these questions mainly related to the clarification of areas of the transcript that neither the transcriber nor I could understand. On the man's request, the second interview was not audio-taped. Instead, we read through the transcript together as I took notes. The notes were the

participant's words which he verified as we went through the interview. However, this interview was the only one that was conducted in the second phase of the study and there was only one other participant who had the opportunity to verify the transcript of the first interview.

The second participant indicated that she had nothing more to say and that she did not wish to talk to me again. The third participant was eager to talk to me again but was admitted to hospital before the meeting could be scheduled and was very unwell for some weeks. I returned the transcript of the first interview to the fourth participant. This was returned to me with numerous amendments, including changes to what I had said. There were several spelling corrections, in particular people's names. Despite this, the changes did not alter the essential understanding of the narrative and I doubted that a second interview would give me any more information about the woman's experiences of having an enduring mental health problem. This was also the case for the final participant. The initial interview was comprehensive in its content and I believed that further clarification was unnecessary. This participant originally stated that he wanted a copy of the transcript once it was completed. However, he then had a change of heart and said that this was not necessary and that all he wanted was a summary of the final report.

Although the methodology used was a departure from what I had planned, the reflexivity used in the research process led me to consider that the changes were appropriate and responsive to the needs of the participants. As Schensul et al. (1999) pointed out, these types of qualitative methods require the researcher to be flexible and react to any and all responses. In addition, I believed that despite the reduction in the number of interviews, there was sufficient data that related to the research topic of social inclusion. I was confident that the information I had collected would allow me to answer the research questions and meet the objectives of the study.

4.6 Data analysis and interpretation

As Ayres and Poirier (1996) pointed out, “each story has a meaning to the teller of the tale, to the listener, and to the researcher” (p.163). Furthermore, this meaning cannot be separated from the context in which the story is presented, is not fixed or static and has no wrong or right interpretation. This creates the challenge when conducting research within an interpretive paradigm, to derive meanings from the data which are not only trustworthy but true to the uniqueness of each individual’s story. Once the words are transcribed and turned into ‘text’, the researcher has several decisions to make in order to interpret the data faithfully. Initially, it is necessary to decide what part of the story they will tell, and how they will tell it (Koch, 1998; Mello 2002; Sandelowski, 1998). The researcher is not expected to be an impartial observer as in empirical, positivistic approaches, but rather a subjective and reflective author of other people’s voices and perspectives (Savage, 2000). In order to achieve the aim of giving voice to the participants’ experiences, I needed to select an appropriate method of data analysis.

I initially considered narrative analysis, a technique well suited to studies that use stories to describe and understand human experiences (Kohler Riessman, 1993, Sandelowski, 1991). While examples are seen in the studies by Casey and Long (2002) and Pejler et al. (1999), these two studies employed different forms of narrative enquiry. Casey and Long explored how one man made sense of his experiences of mental health problems. The data analysis involved “discovering or developing the plot that gives meaning to the person’s story as it moves through time towards an outcome” (p.605). Pejler et al. on the other hand analysed narratives of lived experiences of mental illness in regard to content and form, identifying key topics in order to organize the content into meaningful groupings. These variations led to some degree of confusion on my part, not helped by the diversity of frameworks for narrative analysis proposed by numerous researchers and cited by McCance et al. (2001). Given that there was no clear guidance for the use of these frameworks, and the fact that I am a novice researcher, I discounted using narrative

analysis for this study. I then considered whether thematic analysis would be an appropriate method to use.

During the process of conducting the literature review, I found several studies that used thematic analysis (Borg & Kristiansen, 2004, 2008; Browne et al., 2008; Granerud & Severinsson, 2006). The two studies by Borg and Kristiansen used unstructured interviews to collect narrative data, the first on helping relationships in mental health services, the second on the meaning of work for people recovering from severe mental distress. Browne et al. conducted their thematic analysis on narrative data collected from focus groups, as did Granerud and Severinsson. While these studies described differing step-wise procedures of identifying themes and categories, they used a systematic process that enabled their readers to assess the analyses for quality and rigour.

Having no set method and a lack of detailed guidance for analysing narrative data can be a major concern for novice researchers (Fraser, 2004; Priest, Roberts & Woods, 2002). While some suggest that each researcher should develop their own data analysis method, Kelly and Howie (2007) pointed out that inexperienced researchers may need to follow a set procedure. For this reason, I elected to use a thematic analysis that was guided by the detailed and systematic process suggested by Burnard (1991), which in turn was developed out of grounded theory literature. The process I used involved seven stages.

The first stage in the analytic process involved the writing of notes and memos immediately after each interview (Burnard, 1991). Stage two involved reading the interview transcripts several times while listening to the audiotape. This allowed me to reconnect with the participants' stories, gain full immersion in the data and become totally familiar with people's experiences. While doing this, I made notes on general impressions and patterns that related to the research aims, as well as referring back to my journal notes and memos.

Stage three, involved 'open coding', making headings or categories and writing them in the margin (Burnard 1991). These described all aspects of the content of the interview and accounted for most of the interview data. Examples of headings that I developed at this stage included 'being in hospital for long periods of time', 'getting unwell', 'previous treatments' and 'things that are different and have changed for the better'. In the transcripts there were numerous references to being in hospital and being unwell. Although they were largely viewed as unhappy and unpleasant experiences, they were seen as being in the past, with the present being much better.

The aim of stage four was to reduce the number of categories within the data by combining similar units of meaning into broader categories (Burnard, 1991). To do this, I read through the marginal notes and grouped similar headings together. An example of this was combining the headings listed above into a single category entitled 'things that are better now'. This process was repeated until I had a list of key themes that captured the patterns of experiences of all five participants. Stage five involved defining each theme and deciding exactly what was going into each of them. Stage six occurred once I was sure that I had been as inclusive of the data as possible. It involved assigning each theme a different coloured highlighting pen and marking the sections of data that related to the corresponding theme. These sections of data were then copied and pasted into a word document created for each theme. These documents were examined and sub-themes developed.

In stage seven, I selected a narrative passage that was representative of each theme. This final stage enabled me to link each theme to existing theory or research in the discussion which takes place in Chapter six. To carry on the example used earlier, a participant talked about being in a psychiatric hospital for many years and how unpleasant that experience was. This was then used to highlight how people with an enduring mental health problem were institutionalised for long periods, resulting in them being excluded from their communities and families. The themes were then compared with each other across the stories in order to identify consistencies and diversity in the participants' experiences.

I experienced a considerable degree of difficulty in carrying out the data analysis and interpretation, largely due to my lack of research experience and my nursing background. These factors led me to make nursing judgements about, and conduct assessments on what the participants recounted in their narratives. Instead of faithfully reflecting the voices of the participants and reporting what they said, I constantly found myself forming opinions about their mental status and reasons for their experiences. Maintaining a self-reflexive journal assisted me to stay focused on the aims and objectives of the study as well its data quality and rigour.

4.7 Data quality/rigour

The fact that narratives are negotiated and nonlinear creates a challenge when ensuring that research findings are valid and true (Mello, 2002). Holloway and Todres (2003) noted the dispute concerning the terms ‘validity’ and ‘reliability’ in reference to qualitative research. While some consider that these terms, originating from the field of quantitative research, are adequate, others suggest that they are totally inappropriate for non-empirical research (Polit & Beck, 2006). As Sandelowski (1991) pointed out, the stories that are often told in qualitative studies are representations that vary each time they are constructed for telling. It is therefore not ‘truth’ that the researcher wants to understand, but the meaning of people’s experiences. This means that efforts to apply criteria such as consistency and reliability to qualitative research may be misguided.

In response to this criticism, Koch (1998) suggested alternative ways of maintaining rigour and assessing the trustworthiness of a qualitative study. Being especially appropriate for a narrative approach, the criteria of transferability, credibility, and dependability were used to ensure that the present study was trustworthy and rigorous. Transferability “refers to the extent to which the findings from the data can be transferred to other settings or groups” (Polit & Beck, 2006, p.336). While I do not claim that the findings from this study can be generalised, I expect that by providing sufficient descriptive data about the participants and their home, readers will be able to judge how applicable the data are to other contexts. In addition,

transferability means that the findings of this study should relate to those of other studies with similar research questions and participants. For example, Browne et al. (2008), Granerud and Severinsson (2006) and Pejler et al.(1999) conducted studies involving people with mental health problems and explored their experiences of recovery, social integration, housing and community care. These participants, contexts and research questions were similar to those of the current study and thus the findings may also be similar.

To achieve credibility, enough detail is given about methods and processes for readers to have confidence in the way I have carried out interpretation and analysis, and I acknowledge that there could be other trustworthy interpretations besides mine (Ayres & Poirier, 1996; Polit & Beck, 2006). Although not all the transcripts were returned to the participants, the people who did receive a copy verified that the data were consistent with their experiences. This increased the credibility of the study (Polit & Beck, 2006). The final criterion, dependability, can also be achieved by making the research process visible (Bailey, 1996; Koch, 1998). In order to minimise the risk of error or fraud and increase its dependability, I maintained a decision trail that documented all the methodological and analytic decisions I made, and my rationale for making them.

4.8 Summary

This chapter presented the methodological underpinning of the study and detailed the design that I used. I have justified the use of the qualitative methodology as well as the positioning of the project within an interpretive paradigm. An outline of the characteristics of the participants has been given and an explanation of how they were selected. The ethical considerations have been discussed and details of the data collection, analysis and interpretation given. In addition, I have outlined the problems that I encountered when doing both the data collection and transcriptions, and provided the rationale for not following the planned methodology. Finally, I have discussed how data quality and rigour have been maintained.

The following chapter presents the findings and shows how the participants' life stories have answered the research questions: what does social inclusion mean to people with an enduring mental health problem?; what facilitates social inclusion?; what are the barriers to social inclusion?; and how do life stories reflect the social and political developments regarding mental health in New Zealand? As an introduction to their stories, the background of each participant and a brief outline of their life experiences are given. I discuss the general trends that emerged from the narrative data as well as what I anticipated from the literature but did not find in the narratives. The themes and sub-themes relating to social inclusion, social exclusion and recovery are identified.

Chapter five: Research findings

5.0 Introduction

This chapter presents the findings of the research project, beginning with the background information of each participant. This includes the length of time they have lived at the home, their significant relationships both past and present and the main focus of their narratives. The rationale for giving this information is to locate the participants' stories within the context of each of their lives. Following on from this, I briefly discuss the general trends from the data. The themes and the corresponding sub-themes that emerged during the course of the analysis are then identified and a working definition of each theme is given. Tracts of narrative are presented verbatim, providing representative examples of each theme in the voices of the participants. In order to maintain confidentiality, all references to the participants are made using their chosen pseudonym. In addition, any other proper names are either changed or omitted so that no person or place can be identified. Ellipsis points are used to indicate any material that has been omitted from the original quotations. Finally, I briefly discuss the themes that I had expected to emerge but did not. A fuller discussion about these will take place in Chapter six.

5.1 The participants

5.11 *Steven*

Steven is a 62 year old European male, born in New Zealand. He has resided at the home most weekends and public holidays for the past three years. His current wife (pseudonym Mary) also lives at the home. According to Steven, Mary's family and Mental Health Services did not want the couple living together on a full-time basis as their previous life together was characterised by serious social, financial and emotional problems. They spent some time living in a car and there were reports of physical and emotional abuse between the couple. For this reason Steven lives in a flat on a different site, but spends each weekend at the home with Mary. His first admission to a psychiatric hospital was at the age of 14 ½ following what he describes as a 'breakdown'. He has since had numerous admissions, spending long

periods of time as an inpatient. Steven's story largely focussed on the jobs he has had and what jobs he would like to do in the future. He talked of having real hope for the future, of getting employment and making the most of opportunities to learn new skills. His relationships centre on his wife and her family. He made several references to mental health professionals who have helped him in the past.

5.12 *Monica*

Monica is a 57 year old Māori woman. She has been a resident at the home for 13 years and has a long history of severe and enduring mental health problems. At the time of the interview Monica was unsettled and distracted, making her narrative disjointed. Even with prompting, she gave short and concrete responses. The only relationships she spoke about were with her blood relatives, with little mention of friends, acquaintances or mental health professionals. She talked about being unwell but was reluctant to speak about her experiences of being in psychiatric hospitals.

5.13 *Jo*

Jo is a 64 year old Māori woman born in New Zealand. She has spent many years in psychiatric hospitals and has never been married. When not in hospital, Jo lived in various supported accommodation, residing at this home for the past 13 years. She continues to have two or three admissions to hospital each year. Jo put off the first two scheduled interviews, saying that she didn't feel up to talking to me at that particular time. However once the interview started, Jo was reluctant for it to end. She was also eager to talk to me again but before the second interview could be conducted, she was admitted to hospital. Relationships with family, caregivers, mental health professionals and friends featured prominently in Jo's narrative and she seldom referred to previous employment. She avoided all mention of what it was like in hospital, even to the point of saying that what happened in hospital was 'secret'. Activities seemed to be important to her and she talked a great deal about sewing and knitting and going to the flea market and the fun day. However, she also talked about the things that she used to enjoy but can no longer do such as reading, watching TV and playing the piano.

5.14 Priscilla

Priscilla is a 56 year old European woman born in New Zealand. Although still married, she has not lived with her husband for many years. She has two children and three grandchildren. She has spent long periods of time in psychiatric hospitals and most of her adult life in supported accommodation, the past 10 years in this home. In the past few years she has rarely been admitted to hospital, however was discharged from a psychiatric unit one week before the interview. Except for her last admission, Priscilla did not talk much about her experiences as an inpatient. She did however talk a great deal about the circumstances of her becoming unwell and the process of being admitted to hospital. Most of her narrative revolved around her family, both the support she has had from them as well as their lack of support when she needed it. She also talked a lot about money, being ‘ripped off’, and what things have cost her.

5.15 Gordon

Gordon is a 75 year old European man born in New Zealand. His wife died by suicide several years ago and he has one son and two step-sons. His first admission to a psychiatric hospital was when he was 17 years old. He has lived at the home for approximately five years. His narrative was punctuated with references to ‘social upset’ and he gave this as a reason for each of his numerous admissions to psychiatric hospitals. He also spoke at length about the jobs he has had over the years, suggesting that employment and the money earned from this, is extremely important to him. There were few references to recent contact with family and it appeared that he is estranged from his son and step-sons.

5.2 General trends

The aim of thematic analysis is to gain a deeper understanding of the meanings inherent in the data and it is assumed that it is reasonable to compare what one person says with the utterances of other people (Burnard, 1991; Kelly & Howie, 2007). These comparisons highlight differences and diversity and the resulting patterns and trends form a comprehensive picture of the individuals’ collective experience. The general patterns of this study related in most part to gender

differences between the participants. For example, the narratives of the two men were dominated by their previous employment history and they both talked a great deal about the numerous jobs they have had over the years. In contrast, the three women spoke very little about paid employment and usually only mentioned previous jobs in response to being asked about them. Whereas the men focused on their work, the women paid far more attention to relationships and roles. The relationships they talked about were mostly in terms of immediate family, but they also included care-givers and friends.

5.3 Themes relating to social inclusion

The following six themes emerged from the data of the five participants:

- social upset
- relationships
- finances and money
- keeping occupied
- violence and abuse
- things are better now

These recurrent themes, along with their corresponding sub-themes, were woven throughout the transcripts. For each theme I provide verbatim statements that clearly capture the essence of the participants' experiences. This thematic analysis served to integrate these findings into the understanding of social inclusion and what it means to people with an enduring mental health problem.

5.31 Social upset

The participants identified social reasons for becoming unwell and having to go to hospital. No-one spoke in terms of having an enduring mental health problem although some people referred to having a 'breakdown' and others talked about 'becoming ill'. Sub themes of social upset were: 'critical incidents'; 'major life events'; and 'other stressful events'. An example of a critical incident was when Gordon's wife succeeded in taking her life after three unsuccessful attempts:

And there she was, standing up on a ladder...and she was just hanging there

Priscilla also had two extraordinary experiences resulting in her becoming unwell and having to be admitted to a psychiatric hospital:

The gun accidentally fired off and someone got hurt...I was put in ...Hospital children's ward

What made me really sick in the 70s is that I got involved in the strike

Major life events also impacted significantly on the participants' ability to remain well and stay out of hospital. One of these events was Priscilla having twins:

Had twins, no support...I had them at home for two weeks but I couldn't cope

Priscilla's most recent admission was precipitated by the death of her aunty from whom she had received a great deal of support over the years:

The shock of losing Aunty...

Gordon's partner left him, an incident that he said made him unwell:

And she was gone, so another social upset

Major marital problems contributed to Steven becoming unwell:

My first wife gave me a hard time with smashing dishes, she was an alcoholic

Participants identified other events and circumstances as triggers for becoming unwell. For example, Steven said that he could not cope when his wife was not with him:

Ran into a bit of trouble when Mary wasn't there to cook a meal

I couldn't look after Mary, so when Mary went back to hospital that's when I crashed

Gordon suggested that he was in hospital for reasons related to physical health:

I was just feeling buggered. I was just physically overworked

Priscilla also discussed contributing factors for her becoming unwell, specifically the relationship with her husband:

He had a bad habit of making me feel very, very, very mentally sick

Finally, Steven identified other factors that led up to his problems:

I had nowhere to live...I lost the house because I'd cross-leased it. That's when I lived in the car for about six or seven months, till they picked me up and I went into the isolation ward
I'd go boozing...but when I drank I'd get sick

5.32 Relationships

All participants spoke a great deal about relationships. They also talked about the roles that they played within these relationships: mother, father, son and daughter. Another role mentioned by one participant was that of being a mediator and advocate. Common to all but one person was the fact that they had, or have had at least one family member with a mental illness. These included three spouses, one mother and a step-daughter. Sub themes included: 'family'; 'friends and acquaintances', including other residents at the home; and 'caregivers and health professionals'. All five participants spoke about their family members repeatedly throughout their narratives. As mentioned previously, Gordon's wife died by suicide. He suggested that his actions may have contributed to her taking her life:

My wife was a manic depressive...I think she'd been in hospital about 17 times...at one stage we were both in there together...she attempted suicide about three or four times. She committed suicide, hung herself in the garage
She'd been in hospital and I had a one-night stand with a sheila from a massage parlour and she might have found out about that

Gordon often mentioned his sister, and the support she gave him when he was younger:

I had my 17th birthday there (in hospital) and my sister sent me over a cake
My sister paid my fees
I was going to head for the back road for my sister's farm. I was going to stay there for a while

However, he also talked about having little recent contact with his immediate family:

I haven't seen my son for about 13 years, it might be more...I haven't seen my grandson either since he was about this high

My brother's supposed to come over and see me but...I haven't seen him for quite a while. My sister and brother-in-law haven't been over for a while

Priscilla talked about the contact with and the support she has had from family members:

I was never so glad to see Mum...Dad had to take me for psychiatric shock treatment

I spent two days there (hospital)...my mother-in-law got me out

I had to go to my son's wedding

Since Mum died we've got closer, me and my sister. Since we went to Australia we've become big buddies

In contrast, she talked about the times when her family did not help or support her:

My brother-in-law wouldn't let his wife help...he wouldn't let anybody else help me either

Priscilla mentioned the difficulties she experienced when her husband became unwell:

(My husband) getting ill made me very ill too.

Priscilla said that she failed in her role as a mother as she was often unable to care for her children:

I had to put them into Karitane. I had them at home for two weeks but couldn't cope

I kept giving them up to family because I couldn't cope

Afterwards I felt very bad, like a failure because I couldn't look after my own kids. Imagine what it was like for a mum to give up her kids

I knew that I'd have to give up my kids and that was hard

Monica spoke about her mother a great deal. She suggested that her mother was very strict and that she too had some mental health problems:

Quite strict on me...she was pretty strict on me

She was getting sick, and I was sick too

*My mum...she used to tell me that my dad was well-known...she mentioned
Elvis Presley...yeah, my dad's Elvis*

She said that since her mother's death she has not had a great deal of contact with her whānau:

They're too busy with their lives, they come now and then

Jo mentioned occasional visits from a few members of her whānau. She made no mention of ever having had contact with her parents:

*I come from a big family, a broken home...I think they weren't looking after
us properly. I had two foster mothers in my life*

My sister used to come...not very often but she'd come

My foster brother would come for a while...and my aunty

I don't know where they all live now

Family featured prominently in Steven's story, in particular his different partners.

*She was one of my partners, but she went back to her husband so I couldn't
get married*

The first wife I married was unsuitable so I divorced her and married Mary

The only family Steven talked about in the present day was his wife and her family:

My stepdaughter, she's had a breakdown too, and now she's got married

Mary's mother really likes me- I get on well with her mother

Mary's family didn't want me living with her

While there were numerous comments about family members, there were few made in regards to friends and acquaintances. Jo talked about a 'fun day' held recently at the home:

And my friend, we did it together

Another was made by Steven when speaking about his current living situation:

I enjoy living here, I like the people here

Priscilla spoke about advocating for other clients while in hospital:

*There was me being mediator for the residents, and the staff thanked me for
it, being an advocate. I try to be the advocate here*

However, she complained about a fellow resident at the home:

He's always telling me what to do, say and think

Gordon too spoke about another resident:

He won't open the bloody shed for me half the time

Finally, Steven qualified his previously recorded positive comment:

Sometimes they get me rarked up

The final sub-theme of the relationship theme was 'caregivers and health professionals'. Three of the participants mentioned this group of people several times. For example, Gordon talked about the community mental health nurse involved with his care some years ago:

She walks in and she says "the police are out there, you're going back to hospital". I rang her...and I said "you've put me in a hell of a spot being over here"

Steven spoke about health professionals he met while in hospital:

They were both staff members...they were important as they gave me direction and helped me. They were good men

The social worker there...I used to do her gardens and lawns

He talked about a time when mental health professionals prevented him from living with his wife:

The hospital... didn't want me living with her so they put me in another home

Priscilla talked about the support she had from the manager of the home when she recently planned a trip to Australia:

She said that if I didn't make up my mind and go she was personally going to put me on the plane. And I went all the way there and came back with a bottle of wine for her. She thought I was Christmas for that

5.33 Finances and money

The subject of finances and money was prominent in all of the participants' interviews. For the two men, this was mainly in relation to paid employment and the financial independence that this gave them. The women however only spoke about

their previous jobs in passing. All but one participant mentioned being cheated or having things stolen from them in some way or other. While some people spoke about the costs of things and the financial restrictions in their lives, two women suggested that they had enough money to spend on different things. Sub themes were: 'paid employment'; 'being cheated'; and 'money troubles'. Gordon spoke about several jobs that he has had over the years:

I had a good job in the dairy factory...I also worked in the bush for 20 odd years, cutting down trees. I worked for ... on the reconstruction of the mine. When that job finished I had to rush around and see if I could get hold of work...there wasn't much work

Steven also has had several different jobs:

*A job working for the dairy company, then I found another job at the... I discovered that I could work for myself- I had about 15 lawns and five gardens- self employed
I couldn't do my job- I was doing pamphlets and all sorts of thing.
Did that for three years, cleaning up the hill side, went to the sawmill and did some stuff with saws, worked in a dairy factory in ...
I worked as a cleaner...picking persimmons.
Working on a cow farm, driving tractors and feeding out cows making hay, he gave me good wages and I worked there for three years as farm hand, and thoroughly enjoyed it*

Steven stated that his employment days were not over and that he hoped to return to the work force sometime in the future:

It's never too old to learn a new trade

Of the three women, only Priscilla made more than a passing reference to previous employment:

I worked for ... Insurance, I gave up my job at ... because I needed psychiatric treatment. I worked for ... and then I got married

Four participants said that they had been cheated in some way or other. This was not only having money and possessions taken from them, but also the inability to get

what they thought they were owed and being taken advantage of. This was the case for Gordon:

*I was on an unemployment benefit...and should have gone on a sickness benefit...I didn't know I could've gone on a sickness bloody thing
He couldn't pay \$50 a week rent, he painted a room...and charged me about \$1500 and it didn't even want painting*

Similarly, Steven said that he was cheated out of a decent wage while working in hospital:

I worked at the dairy farm at ... Hospital and only got one pound a week

Priscilla made direct accusations against a care giver from several years ago:

*He was stealing my money...because I had to pay back \$5000 he booked up.
He ripped me off from Social Welfare and they made me pay it back*

Jo made allegations against the same care giver and also complained that she had her possessions stolen while in hospital:

He stole some of my money too. They sent me back and never gave me my money back. He said "I'll get some things if you sign this" and I never got no jolly things

When I was at ... hospital I had heaps of lovely things- they all got stolen

Money troubles were evident in most of the narratives. Gordon's interview in particular had many references to the financial problems that he experienced over the years:

I didn't have much money...and I was fishing mad so I borrowed some money off a land agent to buy this boat. I paid \$2000...then sold it for about \$1500 and I had to pay back the \$500 that I owed. It was tough going because there was not much work around

I promised him \$2000 in my will but I didn't have \$2000 to give him

They stopped my petrol allowance

I drew out \$14, I'll probably have to buy another lighter soon

Jo talked about the struggle to have her own nice things:

We were pretty poor so we didn't get much

I've saved up since then. I've got clothing in there

In contrast, Priscilla talked about having enough money to help her family financially:

I saved up all my pennies and helped my son pay for his wedding and all sorts

Gave her a couple of hundred more and put it in her bank account for her

I gave him enough money and got him to buy guttering

Monica also spoke about having financial resources:

I'm waiting for my lotto so I can move into the house...I've already won it, but I was too sick to realise what was going on with it

5.34 Keeping occupied

Keeping occupied and having something to do was a dominant theme within all narratives. For the two men this mainly took the form of paid employment over the years. As the money they received for this appeared to be their driving motivation, paid employment was placed in the 'finances and money' theme. For the women however, the emphasis was on unpaid work, organised activities (clubs and groups), personal interests and hobbies. Sub themes were: 'unpaid work'; 'clubs and groups'; and 'hobbies and interests'. All but one person talked about doing unpaid work. Jo pointed to her unhappiness with the chores that she had been expected to do:

At ... Hospital we used to go down to the garden and take a shovel, wheelbarrow, rake and work in the gardens, in the rain, in the frost

I set the table sometimes...dishes, I hate it

Steven however stated:

I was lucky enough to do a cow shed at the time at the farm- I did that for seven years at ...Hospital before I got out

Gordon also said that he liked to keep occupied:

The other day I wanted to do some work, raking up some leaves

Monica was the only person who spoke about doing voluntary work:

I did volunteer police work

Gordon is the only participant who belonged to a community club and he talked about the problems he had experienced:

I had a bit of trouble at the bowling green...when I was on a bit too much medication...I touched this lady on the back of her shoulder...she walked off. (The president) called me after the game and said "you've been touching these women up"

Monica stated that she attended an activity centre set up specifically for people with mental health problems:

We do cooking and art work and kapahaka

Before coming to the home three years ago, Steven also attended a training centre for service users:

I soon developed new skills and went and did some lessons...we did some cooking and we did some cooking classes

Participants identified numerous interests and hobbies. Also mentioned were things that they used to be able to do, but no longer can. Gordon's focus was on activities that he did several years ago:

Shoot rabbits like I did...

I was going fishing and walking around and getting pipis and they took me out to do crafts

Jo identified several interests that she enjoyed:

Flea market...every second week in the month...I love going

A bit of knitting...we had a fun day here. I won a prize

I make bags. We have sewing once a week...

Along with the activities that Jo still participated in, she made several comments about the things that she no longer was able to do:

I used to be a book worm before I got sick. I was always happy, satisfied if I had a book and some chocolates

I can't even concentrate on television. I used to like watching Emmerdale Farm and Home and Away

I can't play it anymore (the piano). I gave it up when I got sick of practising every day

Steven talked about his numerous interests:

I was always interested in flowers and gardens

One of my other interests is to learn to cook, to learn to cook more

I am looking forward to Tuesday next week as we are doing art

I like animals- cats, I like cats. We've got a nice cat here

5.35 Violence and abuse

All participants talked about violence and abuse that they had either experienced or perpetrated. The majority of the abuse was carried out by family members. Sub themes were: 'being abused'; and 'being violent'. Gordon cited the majority of incidents that involved committing a violent or aggressive act:

I had this de-facto...she came towards me and I put my foot out... and I gave her a push and she fell over

This Māori guy wasn't putting the timber in the right places and I got angry with him, tipped him upside down

I picked a woman up outside in the car park...I put my arms around her and went to pick her up

I grabbed hold of the trousers and tore them...she'd never seen me like this and so she ran next door and rang up the bloody police

I shot him (the dog) inside the porch...

Priscilla said her violent behaviour was due to her being unwell:

Very ill...I went to court after burning part of the house down

Being abused was an experience common to the majority of people. Gordon talked about the harsh treatment he received from his father:

The old man gave me a hell of hiding with a bloody stick

He hit me over the head once with a stick and it nearly blinded this eye

Gordon also talked about his wife and the abuse she received:

She'd been sexually assaulted by her father when she was 12 years old

Priscilla spoke about her husband but did not give any details about what he had done:

He wore me down until I got sicker and sicker and sicker. I'm terrified of him after what he did

Jo showed me the scar on her face that a foster mother had given her:

A lady hit me across the face with a lump of firewood when I was about three

5.36 Things are better now

There were numerous references to the past being worse than the present. The participants suggested that this was largely due to past treatments such as antipsychotic medications and being in the old psychiatric hospitals. Most participants mentioned at some stage of the interview that they had experienced some pretty awful times but that things had changed and were now a lot better. The sub-themes were: 'being sick'; 'being in hospital'; 'previous treatments'; and 'things are different now'. Four of the five participants spoke at least once during their interview about being unwell and the most common terms they used were 'ill' and 'depressed'. Gordon however made no reference to being unwell himself, but talked about his late wife having a psychiatric diagnosis:

My wife was a manic depressive

Priscilla mentioned several times about being ill, but this mainly referred to her recent admission to hospital:

I've been very very ill...Quite frightening to see me that ill. I haven't been like that for a very long time

That was a horrific memory, made me very paranoid

I was very heavily depressed

Jo also spoke about being unwell, but this was several years ago and she made no mention of her recent admissions to hospital or the lead up to them.

I was very very depressed when I was younger.

Very very down and depressed and I've been homesick as well

All five participants spoke a great deal about the length of time they spent in psychiatric hospitals. Although few details of their experiences were offered, most

said how unpleasant it was for them and how much they disliked being there. Gordon had numerous admissions, the first one being the longest:

I spent 9 months over at ...Hospital

Priscilla focused on how unpleasant hospital was:

It had things that would frighten anybody

And in those days we lined up just like...against the wall. We weren't allowed to talk, do anything but to sit there all day...It was horrible

Monica made only one statement about hospital and this combined the prolonged duration of her admissions with how much she disliked the experience:

Been in and out of ...Hospital for quite a while. Terrible. They kept taking me back to ... Hospital. For a while, quite a while I've been there

Jo also linked the length of time she spent in hospital with her hatred of it:

Half my life I think ...it was ghastly...then I hated it...terrible place

Steven only spoke about the length of time he spent in hospital, with little indication of how he felt about being there:

I've been in and out for 25 years, I've been in and out of hospitals. Some long stays, some short

I did that for 7 years at ...Hospital before I got out

There were too many patients and not enough room, they were in the corridors and offices, there was no space in the bedrooms

Only three of the five participants talked about previous treatments that they had received. However, all three made negative comments about those mostly medication-related treatments. Gordon talked about past medication:

I was on a bit too much medication

I was on Melleril and I don't know what I was going to do

Priscilla spoke about past treatment:

And then got I shock treatment. That wasn't very pleasant

Steven also talked about past medication and treatment:

Got back on injections- which I think are rather painful

Had Melleril, that was the worst, didn't agree with me at all

No I managed to avoid that (shock treatment), I think because I behaved myself

Steven gave an example of having no choice about the treatment he received:

I never should have come off the pills- doctor put me off

Gordon however, talked about how he recently negotiated the dose of his medication with the psychiatrist:

The doctor said "you are a bit overactive, I'm going to increase your Modecate to 37.5". I said I wasn't on 37.5 18 months ago, I was on 20 I found out later on that he only made it 25 so I was quite happy

The final sub-theme of this theme related to how things had changed over the years and how they were now quite different. All the participants inferred that the differences had improved their lives and that things were better for them now than they had been in the past. Priscilla focused on the improved treatment she recently received in hospital:

*Now it's different, they've either got to look after the patients, or no job
It was definitely different from what it's like now, from how we were all treated in the 60s*

Two participants talked about feeling better than they did in the past. Monica stated that:

It's alright, actually. I'm doing alright now

Jo also suggested that life was better now:

Never mind I don't get homesick any longer now

Both male participants made direct references to being happy. Steven made particular mention of how much he liked the home:

*I've found lots of good things about (the home)
Well, I feel there is opportunities out there for me
I do enjoy living here, I like the people here*

Gordon stated that he was content with his current life:

So I'm quite happy now except now I have to wait until Thursday before I play bowls

5.4 What I expected but was not supported by the data

I took a data-driven approach to the thematic analysis performed, as opposed to a theory-driven or prior research-driven approach (Boyatzis, 1998). That is, the themes were constructed inductively from the raw information given by the participants. Having decided on this approach, I aimed to avoid forcing the analysis of the data into the pre-existing themes of social inclusion. Notwithstanding this goal, I was always aware of the themes identified in the literature: ‘discrimination and stigma’; ‘employment’; ‘housing’; ‘loneliness’; and ‘relationships’ (Barnett & Lapsley, 2006; Browne et al., 2008; Goodwin & Kennedy 2005; Peterson et al. 2006). I was therefore conscious of the issues from the literature that did not emerge from the data analysis.

With stigma and discrimination being so prominent in the literature about social inclusion (Green et al., 2003; Lloyd et al., 2008; Peterson et al., 2008), I expected that there would be explicit references to them in this study. However, this was not the case and there were no reports of being discriminated against. Indeed, Steven expressed a relatively positive comment about stigma:

I hear the odd bit of stigma...a lot of people seem to accept us the way we are

He attributed this acceptance in the most part, to the *Like Minds, Like Mine* television campaign:

The ads by John Kirwan the rugby player relate to where I was. They are good because they make people aware of other people with the same experience, of going into hospital

In contrast, Gordon mentioned being treated differently:

They always made fun of me

My father came home and said “...they reckon you’re mad”

I was married to her for three months and her mother found out that if I wanted a holiday I could go to hospital and have a holiday...she didn’t like that

Jo made numerous statements about how silly and stupid she had been, and still was:

I was stupid. I used to do some silly things

Granerud and Severinsson (2006) found that a sense of loneliness was dominant for most of the participants in their study on the social integration of people with mental health problems. However, at no time did the current participants talk about feeling lonely. In fact the opposite was the case for Steven when asked if he was lonely in a flat on his own:

No, I'll always have contact with people. I think it will work quite well.

It was expected that the participants would say more about their experiences of being in a psychiatric hospital, especially considering the prolonged length of time that each of them had been hospitalised. While there were several comments about how unpleasant and distressing the participants found them, few details were given about their experiences. Some suggested reasons for the differences between my findings and those from previous studies are further discussed in the following chapter.

5.5 Summary

This chapter presented the key findings of the study as expressed through the themes that emerged from the participants' stories. In order to minimise the dislocation of these themes from the life stories, background information of the five participants, Gordon, Steven, Priscilla, Monica and Jo was given. The general trends from the data were identified and the themes and corresponding sub-themes presented. Taking the perspective of the participants was maintained by using their words to give examples of each theme. Chapter five concluded with a brief discussion of the themes related to social inclusion from previous research that I expected to emerge, but that did not.

In the next chapter, discussion of the findings takes place. This discussion centres on the first aim of this project: to interpret the meanings embedded in participants' life stories in relation to social inclusion and exclusion. Chapter six also addresses the

second aim: to explore how the social and political developments in New Zealand have impacted on their life histories and guided their illness experiences. The final two aims of this thesis, those that relate to implications for nursing practice, are addressed in the final chapter of this thesis.

Chapter six: Discussion

6.0 Introduction

The central aim of the present study was to gain an understanding of what it has been like for people living with an enduring mental health problem and their experiences of social inclusion. This chapter discusses the findings of the study in terms of the six emergent themes that were presented in Chapter five. Each theme is presented individually, along with a discussion of how it links to the literature and previous research on social inclusion and exclusion. Following this, issues that were expected but not raised by the current data are discussed and reasons for their absence suggested.

6.1 Themes of social inclusion

In order to explore what social inclusion means to people with enduring mental health problems, a thematic analysis was carried out on the narratives of five participants. As a result of this analysis, six major themes were identified:

- social upset
- relationships
- finances and money
- keeping occupied
- violence and abuse
- things are better now

6.11 Social upset

The naming of the first theme ‘social upset’ came about through a conversation with Gordon before the start of the data collection phase of the study. When reading the ‘Participant Information Sheet’, Gordon said that he did not have ‘an enduring mental health problem’ but that all his problems came about through ‘social upset’. Gordon repeated the term several times during the interview, referring to incidents that had occurred and that led up to him becoming unwell. While he was the only

person to use the term 'social upset', the other four participants identified social events and incidents that caused them to become unwell. While not explicitly stated in the interviews, it was implied that had these 'social upsets' not occurred, then neither would the ensuing 'breakdown' or admission to hospital. The social upsets that precipitated a mental health crisis included critical incidents such as death by suicide, major life events such as births and bereavements, and other stressful events such as drinking too much alcohol and having nowhere to live.

Similarly, the study by Lapsley et al. (2002) described the onset of mental ill health in terms of stressors and critical incidents. Many of these events involved breakdowns in partner relationships and lack of supportive social networks, which in turn frequently provoked a sense of shame and failure. While these findings were very similar to those of the present study, there were some differences. Unlike the people spoken to by Lapsley et al., the current participants did not identify loss of jobs, physical health crises or identity conflicts as triggers for mental ill health. However, common to both studies was the prevalence of the importance that relationships had to people's mental health.

6.12 Relationships

As expected from the literature search, relationships were prominent in participants' stories of their experiences. It was evident from the data that having a mental health problem impacted not only on the lives of the people with the problem, but also had immediate consequences for the life experiences of their family and friends. The literature emphasised how meaningful relationships with family, friends, care givers and health professionals were vital if people were to recover from mental illness (Bradshaw et al., 2007; Repper, 2000; Young & Ensing, 1999). The most commonly spoken about relationships in the present study were those with immediate family: spouses, partners, parents, brothers, sisters and children. The participants talked about the emotional and sometimes financial support they had received from their families. In addition, they showed how they had been assisted in accessing resources, been transported to treatment facilities and how someone advocated for

them when receiving treatment. However, family relationships had not always been without conflict.

Within the narratives, participants gave several examples of the lack of support from family members as well as traumatic and stressful incidents that had occurred. It appeared that relationships with spouses, partners and siblings had helped create situations resulting in the person needing to be hospitalised. This was either because they did not get the support they needed or because their mental health problems were exacerbated by a breakdown in relationships. These findings were consistent with those of Lapsley et al. (2002). From their research on narratives of recovery, they found that the strain caused by living with someone with a mental health problem often limited their ability to be supportive. Peterson et al. (2006) consider this to be a type of rejection, which in itself is a form of discrimination. Their survey on mental health discrimination in New Zealand found that this lack of support from family members was the most often reported form of discrimination experienced by service users. Despite these relationship conflicts, the importance that the participants of the present study placed on family contact and support was evident.

Young and Ensing (1999) presented a different viewpoint in their study. They found that people with mental health problems spoke more about their relationships with other service users than they did about those with family members. Relationships with other service users were considered to be more meaningful, supportive and accepting than those with parents, brothers and sisters. In addition, relationships with non-biological family members were reported to be more positive than those with original biological family members. In other words, people felt that they had more support from spouses and children than they did from family-of-origin relationships.

The participants in the present study however, reported greater levels of stress and trauma arising from the relationships with their marital partners. This lack of spousal support may have partly been due to the fact that all the spouses had experienced mental health problems themselves. Young and Ensing (1999) found that people

with mental health problems often formed relationships with other service users. This may have resulted from being in psychiatric hospitals for many years and therefore separated from their original families. People were also immersed within the mental health system and may have felt so excluded from their communities that they believed they could only have intimate relationships with other service users (Stickley, 2005).

Having an enduring mental health problem has taken its toll on the marital relationships of the current participants. Of the five participants, three had either been married or were currently married but did not live together on a permanent basis. This separation was reflected to some degree in all other family relationships. Most people spoke about having little contact with their family members, stating that people were busy with their own lives and did not visit them very often. Despite the intermittent contact with immediate family members and the history of conflict, it appeared that these relationships were valued more highly than those with friends and acquaintances. This was made evident by the surprisingly few comments that they made in regard to friendship.

There were only five statements about having friends or acquaintances, most of which referred to fellow residents of the home. While two of the comments were positive, the other three were not, with people talking about dissension amongst the residents. These findings were in accord with other studies. For example, Pejler et al. (1999) conducted a study on 14 people with mental health problems who lived together in a group home. They found that many of the stories expressed how difficult it was to live together with so many people. They talked about being irritated by the other residents, as did the participants of the present study. Although Peterson et al. (2006) and Lapsley et al. (2002) reported some positive and supportive friendships, they also found that rejection by non-family members and disruption to friendship networks was common, as was the distress and pain that this caused service users.

The impact that health professionals and carers had on recovery from mental health problems is well documented, with supportive and helpful relationships being highly valued (Barnett & Lapsley, 2006; Borg & Kristiansen, 2004). Despite this, ambivalence was evident in the relationships that people had with health professionals and carers. The coercive care and treatment that many people experienced, in particular when incarcerated in the old psychiatric hospitals, may have resulted in a continuing distrust of service providers (Drury & Munro, 2008; Jarrett et al., 2008). Past experiences may have contributed to the negative comments made by one participant in the present study, in regards to the community mental health nurse, the social worker and the manager of the home. Conversely, two other people spoke highly of several people involved in their care. These findings were mirrored in a study by Pejler et al. (1999) who found that while most people described care providers as ‘good’, some people thought they were too dominant or harsh.

A study by Crowe et al. (2001) explored how well the needs of service users were met by community mental health nurses. The service users were generally very satisfied with the care they received and found that support from their key worker nurse was vital in helping with their recovery journey. There were however some areas of dissatisfaction that related to not receiving adequate time with their nurse and not always receiving enough information. This study also emphasised the importance of developing a partnership between service users and nurses, findings similar to those of Peterson et al. (2006). They found that people reported discrimination against them by mental health professionals who sometimes trivialised their concerns and gave them poor treatment. Browne et al. (2008) also had conflicting reports about mental health professionals, with positive comments interspersed with less favourable ones such as: “some mental health professionals were deceitful and scheming” (p.406).

Although the majority of these comments cited from the literature referred to developing and maintaining relationships in the community, the influence that

mental health professionals had on service users within psychiatric hospitals cannot be underestimated (Bertram & Stickley, 2005). Longer-term admissions led to increased contact with nurses, doctors, occupational therapists, social workers, and other service users, and less contact with friends and family. This diminution of social networks may have contributed to the erosion of all roles except that of ‘a mental patient’. Stickley (2005) discussed the value that everyone places on having social roles and suggested that their loss may also occur when people are unable to establish a meaningful position in their community.

All the people in the present study talked implicitly about their roles as employees, sons and daughters, brothers and sisters, and friends. However, one of the more direct references was made in regards to being a mother. For this woman, having to leave her children in the care of other people and being unable to perform this role, was one of the most distressing consequences of having an enduring mental health problem. This finding corresponded to those from other studies. For example, Diaz-Caneja and Johnson (2004) and Peterson et al. (2006) found that many women with long-term mental illnesses lost custody or access to their children, especially during times of illness relapses. Discrimination against them and lack of support from family members and health and social services often hindered these women from performing their role as mothers.

The final role spoken about in the relationship theme was that of being a mediator or advocate for other service users. While the growth of consumer advocacy groups in New Zealand over the last two decades has been significant (Gawith & Abrams, 2006), the findings of this study suggested that individual service users also take personal responsibility for this role. This was supported by Lapsley et al. (2002), whose findings illustrated that many people with experiences of having mental health problems want to give something back to other service users. They often encouraged people to take an active part in their recovery, advocated for improvements in service delivery, and offered a level of support and acceptance that they could not get from anyone else (Lester & Tritter, 2005; Young & Ensing,

1999). As Tal, Roe and Corrigan (2007) pointed out, some service users seek to change the role of other people with mental health problems from that of ‘mental patient’, to the normal social roles that many in society aspire to. The ability to perform these roles also depends to some extent on having a degree of financial security.

6.13 Finances and money

It was evident from previous research that the economic consequences of having an enduring mental health problem are significant (Browne et al, 2008; Lapsley et al., 2002). The participants of this study were no different in that they made frequent references to financial issues, exploitation and having money troubles. I included employment in the finances and money theme, as I considered that having a paid job was intrinsically linked to a person’s financial resources. While it was expected that employment would feature strongly in a study related to social inclusion, it was surprising to find such a marked gender difference in the relative importance that people placed on work. From the narratives of both men, it appeared that paid work was the major focus of their lives. Conversely, the women made few comments about their previous jobs, and when they did it was usually as a result of being directly questioned. This gender difference was not evident in any of the reviewed literature or previous studies on social inclusion or recovery.

Apparent in the literature however, are the numerous benefits of paid employment. As Borg and Kristiansen (2008) pointed out, work is highly valued by most people. It improves health and psychological well-being and has social, economic and political benefits. Work may be even more important to people with mental health problems, a group that often experiences social devaluation, exclusion and feelings of low self-esteem. Being in paid employment can give people financial security and a sense of purpose and belonging, important determinants of social inclusion (Evans & Repper, 2000). It provides greater opportunities for social interaction, and contributes to feelings of self-worth and personal status (Russell & Lloyd, 2004).

Despite these obvious benefits, there are high levels of unemployment among people with enduring mental health problems (Duncan & Peterson, 2007; Evans & Repper, 2000; Goodwin & Kennedy, 2005; Jensen et al., 2005). According to Tal et al. (2007), this rate may be as much as three to five times higher than those without a mental health problem. A suggested reason for this high level of unemployment is that people are discriminated against both while looking for a job and while they are within a job (Peterson et al., 2006). Furthermore, Lapsley et al. (2002) found that most people were unable to continue as normal with their jobs or careers once they became unwell, and several people either lost or left their jobs when their mental health worsened. This finding was reflected in the present study, with some people stating that they could not continue with their jobs, either because they were too unwell, because they were admitted to hospital or because their jobs did not facilitate retention.

An expected consequence of unemployment is low financial resources. For many people with mental health problems this may result in poverty, hunger and homelessness (Brousseau, 2009; Kirkpatrick & Byrne, 2009). The present participants made several references to the costs of things and how they could not always afford to have or to do what they would like. While the basics of life may be taken care of, they wanted to have nice things, to belong to community clubs and groups and to join in with recreational activities (Young & Ensing, 1999). Bradshaw et al. (2007) found that almost everyone spoke about the financial binds that impacted on all areas of their lives. Many people reported being unable to drive because they could not afford the insurance, being unable to engage in many leisure activities due to their expense, and having to get food from their families when they could not afford to purchase their own.

What little financial resources people have can be restricted even further by theft, fraud and exploitation. Almost all the current participants spoke about being financially exploited or cheated in some way. This ranged from not being told one's benefit entitlements, to direct theft of possessions and money. Kelly and McKenna

(2004) and Browne et al. (2008) suggested that this is a relatively common occurrence for people with enduring mental health problems. They cited several examples of people being exploited by unscrupulous people, and it appeared that the participants of the present study were equally vulnerable, despite the protection of being in a residential home.

6.14 Keeping occupied

Listening to the experiences of the participants suggested very clearly that being active and keeping occupied was important to them. This finding was not unexpected in light of the literature and previous research. Lloyd et al. (2006) suggested that purposeful day-time activities were one of the basic necessities of life and that people who participated in community activities had better health outcomes than those who did not. Active participation in social clubs and groups gave people purpose and a sense of belonging, which in turn often promoted faster recovery from mental health problems (Granerud & Severinsson, 2006). This was supported by Borg and Kristiansen (2008) who found that keeping occupied did not necessarily mean being in paid work, but involved participating in any activity that was perceived as useful.

The perceived usefulness of unpaid work does not necessarily guarantee that people will enjoy performing it. While most participants in the present study appeared to enjoy the opportunity to do chores and voluntary work, one woman most certainly did not. She talked about duties given to her, both while she was in hospital and at the home, that she did not like doing. The fact that the chores were assigned to her could perhaps explain her dislike of them. Lloyd et al. (2006) pointed out that for psychosocial rehabilitation programmes to be helpful, they must be customised, driven by service users' needs and goals, and based on people's choice. When given a choice, the current participant identified other activities that she enjoyed, such as sewing and going to the flea market. Another interesting finding was that only one of the five participants belonged to a local club. The literature suggested reasons

why people with mental health problems do not access organised community clubs and groups.

The first of these relate to the financial barriers that many people with mental health problems must deal with. Several studies have found that in many cases people did not have enough money to join clubs, participate in enjoyable leisure activities or even engage in a lot of 'normal' recreational activities (Granerud & Severinsson, 2006; Stickley & Shaw, 2006; Young & Ensing, 1999). This lack of involvement in the local community lowers self-esteem and feelings of self-worth and increases isolation and social exclusion (Granerud & Severinsson, 2006). The second reason relates to the stigma and discrimination perpetrated by some people in the community (Peterson et al, 2006; Stickley & Shaw, 2006). Bertram and Stickley (2005) suggested that stigma and discrimination in local communities can result in "a general *culture of tolerance*...rather than acceptance" (p.392). People may therefore prefer to stay at home rather than become involved in groups where they do not feel welcome and included.

An alternative to mainstream activities is activity and training centres set up specifically for people with mental health problems. One participant in the present study talked about attending a training centre in the past, while another person currently attended an activity centre. Both people made positive comments about their experiences and appeared to welcome the opportunity to learn new skills. The literature however had conflicting opinions of the benefits of these mental health-specific services. Granerud and Severinsson (2006) found that people who attended a day centre highly valued the support and motivation that they received and were convinced that it enabled them to become more active and involved. On the other hand, Bradshaw et al. (2007) found that their respondents "strongly aspired to participate in non-ill communities and activities" (p.40).

Studies by Bonney and Stickley (2008) and Stickley and Shaw (2006) also suggested that people wanted to be involved in activities that did not have a mental health

focus and that social inclusion and recovery were fostered through accessing mainstream facilities and activities. Stickley (2005) supported this view, arguing that attending groups specifically set up for mental health service users are in themselves discriminating, and can promote stigmatisation and reinforcement of the ‘mental patient’ role. While the alternative is to join existing clubs in the local community, people may have difficulty accessing these social activities.

Within the data of the present study were several comments about things that people used to enjoy doing but were no longer able to do. This in part may be due to interests that change with age, age-related conditions, and impairments in attention and concentration that are related to the person’s mental health problem (Davidson & Stayner, 1997). In addition to financial and social barriers, Lapsley et al. (2002) proposed other reasons for reductions in functional ability. They found that many people complained that medication made them forgetful and tired, unable to focus on anything and feel like a ‘zombie’. Similar results were found by Borg and Kristiansen (2008), with people complaining that the side-effects of medication made them feel drowsy and emotionally flat. Medication can also cause people to make unusual, involuntary movements that often draw attention to them (Lester & Tritter, 2005; Stickley & Shaw, 2006). This in turn can reinforce the perception that people with mental health problems are different, deviant and potentially dangerous (Kelly & McKenna, 2004; Read & Law, 1999).

6.15 Violence and abuse

There is a public perception that many mental health clients pose serious risk to society through their unpredictable and violent behaviour (Read & Law, 1999). This predominant stereotype was not supported by the current data, in which only one man reported committing acts of aggression and one woman a single act of arson. These findings were not surprising considering that people with a mental illness are no more violent than the general public, and commit only a small percentage of murders in New Zealand (MHC, 1997; Read & Law, 1999). According to Kelly and McKenna (2004), public attitudes towards mentally ill people may have become

more enlightened as people move out of psychiatric hospitals and into the community. While some suggest that increased contact with people with mental health problems may reduce stigmatised attitudes, public tolerance of mental illness is constantly threatened by exposure to stereotypical ideas, resulting in continued hostility towards them in communities (Tal et al., 2007).

The media portrays mentally ill people as violent, dangerous and criminal-like (Tal et al., 2007). The film industry tends to represent them as homicidal maniacs, a view reinforced by print media coverage that highlights the unpredictable and sometimes irrational behaviour that some service users display (Read & Law, 1999). Perhaps even more disturbing is a report that found high levels of negative stereotypes against service users existed among the very people who were there to help them, mental health professionals (Tal et al, 2007). This same report however praised New Zealand's 'Like Minds, Like Mine' project, stating that it is a "unique national and institutional initiative" that is a successful anti-stigma campaign (p.554). It is therefore hoped that the attitudes of both the public and mental health professionals in New Zealand are more tolerant, accepting and based on more accurate information.

The majority of the participants spoke about either being abused or the abuse of someone they knew. This included physical assault, sexual abuse and possibly emotional abuse. Most of the abuse occurred during childhood and was performed by family members. These findings were very similar to the New Zealand study by Lapsley et al. (2002), in which almost half their participants mentioned physical or sexual abuse, with several people experiencing both. Their stories illustrated what Barnett and Lapsley (2006) called "precursors to later mental health problems" (p.17). Most people felt that growing up in an abusive and violent family environment significantly contributed to the mental health problems they experienced in later life. These findings differed from those of the current study in which there were no comments suggesting that people blamed their current mental health problems on childhood abuse. Although all participants talked about previous

experiences of adversity and trauma, there was a pervasive feeling of optimism throughout the majority of the narratives.

6.16 Things are better now

Although the five participants struggled with mental health problems for many years, they gave the impression that they were reasonably content with their present situation, that things were better than they had been in the past, and that things would continue to improve in the future. This however was not to say that their journeys towards recovery had been easy or without difficulties and conflict. The terminology that people used did not always convey these hardships, with illness often expressed in relatively mild terms such as ‘being sick’, ‘depressed’, ‘homesick’ and ‘having a nervous breakdown’. The terms ‘psychosis’ and ‘schizophrenia’ were not used and the only time a psychiatric diagnosis was mentioned was in relation to a person’s wife being a ‘manic depressive’. This was very surprising considering that the participants had been immersed in a mental health system that supported a biomedical paradigm and embraced psychiatric diagnoses and labels (Crowe, 2000; Laungani, 2002).

Service users would have been given an official diagnosis, or perhaps a multitude of diagnoses, from the *DSM-IV* classification system (American Psychiatric Association, 1994) and would be familiar with the terminology used by mental health professionals. Over the years, they had most likely been called a ‘schizophrenic’, been told that they had a ‘psychotic illness’ or ‘delusional disorder’ and been asked frequently if they were ‘hearing voices’. It was therefore expected that people would have used these terms when telling their stories, as people had in previous research. For example, Lapsley et al. (2002) found that people spoke about being given a psychiatric diagnosis in terms of the stigma and shame the label bestowed on them, and the despair and hopelessness that having a supposedly ‘incurable’ mental illness engendered. These findings were reflected in a study specifically about being named ‘mentally ill’ by Hayne (2003). In this study, people talked about feeling that a psychiatric diagnosis meant that they had lost their

identity and had been given a "...kind of a living sentence..." that would impact on the rest of their lives (p.725).

While the current participants did not talk specifically in terms of having a mental illness, there were several references to being unwell and the events that had led up to hospital admissions. However, people did not talk to any great extent about their experiences of being in hospital except to say that they were largely unpleasant and distressing periods of their lives which they described as 'horrible', 'terrible' and 'ghastly'. This was particularly surprising considering their numerous admissions and the fact that they all spent extended periods of time in hospital, especially in the early years of their lives. This variance in what information was expected and what was actually obtained may have been due to the length of time that had passed since these long-term hospitalisations. The majority occurred several years ago and so memories of the experiences may not have been as vivid as they once were. On the other hand, people may have felt that they had moved on and put those periods of their lives behind them.

Another proposed reason is related to the methodology used. The narrative approach that was adopted, invited people to tell their stories in which ever way they chose. Therefore they may not have wanted to rekindle what, from all accounts, were mostly unhappy and distressing memories. This was not the case in a study by Lilja and Hellzén (2008), which asked people to describe recent experiences of psychiatric inpatient care. The semi-structured format encouraged people to speak about specific aspects of being in both institutional care and acute psychiatric care. As expected, these people spoke at length about their experiences, which were largely seen as being negative and not conducive to recovery. They felt that psychiatric hospitals were frightening, lonely places in which people were seen as a disease rather than individuals with unique goals, dreams and needs.

The findings of Lapsley et al. (2002) were very similar, with largely negative experiences of hospitalisation being reported. People described feelings of being

controlled by medication and confined and isolated in a hostile environment. In light of these traumas, perhaps it was not surprising after all that the current participants chose not to talk about their experiences. They were a group of people who were on average 15 to 30 years older than the participants of the two previously cited studies. This meant that the conditions they endured in hospital two to three decades earlier could well have been markedly different than those reported by Lapsley et al. (2002) and Lilja and Hellzén (2008).

The seemingly intolerable environment of psychiatric institutions led to grave concerns about the care and treatment of the mentally ill (Kelly & McKenna, 2004). This in turn led to the closure of psychiatric hospitals and the international phenomenon of deinstitutionalisation. As in many western countries, the deinstitutionalisation process dominated mental health care restructuring in New Zealand during the 1970s (Joseph & Kearns, 1996). The plan was to shift the locus of treatment from large psychiatric institutions to small-scale community-based facilities. It was hoped that this would address the numerous concerns relating to the conditions of the hospitals. In the current study, Steven talked about the overcrowding which resulted in having beds in the corridors and offices because there was no room in the bedrooms. Furthermore, Priscilla spoke about how patients were lined up in a row against a wall, not allowed to talk, but simply to sit there all day. These practices could have contributed to what Kelly and McKenna (2004) described as ‘Institutional Neurosis’, an illness that is “...characterised by loss of interest, lack of initiative and apathy” (p.377).

The *1992 Mental Health (Compulsory Treatment and Assessment) Act* (Department of Health, 1992), with its provision for people to be treated in the least restrictive environment, enabled the ideological shift towards community mental health treatment (Joseph & Kearns, 1996). The goal was to reduce the negative social effects of institutionalisation by reintegrating people back into society, ideally into the communities they originated from (Wright et al., 2000). Despite the critics of the institutional oppression, some service users identified positive aspects of the old

asylums (Stickley, 2005; Stickley & Shaw, 2006). Those people who lived in a psychiatric hospital for many years came to view it as their home, had a feeling of belonging and were provided with a sense of community. For many people, the closure of the hospitals resulted in their feelings of safety and security being replaced with stigma, discrimination and loneliness, rather than the increased social inclusion that was the primary goal. For better or for worse, the restructuring and reform of the mental health services in New Zealand had a direct impact on the lives of the current participants.

Whether they occurred in a psychiatric hospital or in a community-care setting, three of the current participants made negative comments about previous treatment that they had received. They complained about being on too much medication, about how painful the injections were and how unpleasant ‘shock treatment’ was. Although the side-effects of medication were not specifically mentioned, two people talked about a particular drug not agreeing with them. Gawith and Abrams (2006) pointed out that people with a mental illness had historically been denied the right to make even the most basic decisions about all aspects of their lives. Not the least of these was the right to decide what psychiatric treatment they were given as well as the right to refuse treatment.

As Borg and Kristiansen (2004) found, service users were given little opportunity to talk about their treatment options or to discuss what supported their recovery and, perhaps more importantly, what did not. As a result, numerous service users complained about ECT (shock treatment) and the different drug therapy regimens that they had received (Lapsley et al., 2002; Lester & Tritter, 2005). The side-effects of medication caused particular distress, with many people complaining about how they impacted negatively on their ability to function on a daily basis and on their quality of life (Lester & Tritter, 2005). Despite these difficulties, or perhaps because of them, all five people in the current study talked about the present being better than the past.

Several people mentioned that things were different now and it was implied that these differences were positive and that the changes were welcome. After a recent admission to hospital, Priscilla spoke about how the conditions of the ward were different and much better than those of the old psychiatric hospital. She talked about the staff having to listen to the patients and treat them with respect. Also evident in the narratives was the fact that people were content and happy with their current living situation. As would be expected, previous studies have found that people preferred to live in boarding houses rather than be in hospital and that people had higher rates of hospitalisation when they lived in poor quality housing (Kirkpatrick & Byrne, 2009). However, there were conflicting reports of people's satisfaction with living in supported housing.

Some people were more satisfied with, and tended to have better mental health outcomes when living independently than they did living in supported housing (Browne & Courtney, 2007). In addition, while some people complained of feeling isolated and lonely in group homes, other people preferred supported housing to alternative housing situations (Kirkpatrick & Byrne, 2009). These differing opinions suggested that people's satisfaction depended on what other choices they had, the quality of the housing and the social environment of the home. It seemed that the satisfaction that the people in the current study expressed about their home, contributed to them remaining hopeful and optimistic about their lives.

The participants did not explicitly state that they had hope or that things were better now than they were in the past. They did however express contentment and satisfaction, albeit in varying degrees, ranging from being 'happy' to 'alright'. It seemed that people felt they had more control over their lives than they did previously, that they had more choices and were able to make decisions for themselves. An example of this was seen in Gordon negotiating with the psychiatrist about the dose of his medication. It was encouraging to hear comments such as this in light of the disempowerment that many people with mental health problems had experienced in the past. (Lapsley et al., 2002; Peterson et al., 2008). Optimism was

also seen in the comments made in regards to returning to work, learning new skills and looking forward to engaging in leisure activities. Although there were a few relatively minor complaints about other residents, it seemed that in general people were happy with the social interaction within the home, and did not experience feelings of loneliness or isolation. This optimism and hope is a state of mind that many people consider essential for their recovery from mental health problems (Lapsley et al., 2002; Ochocka, Nelson & Janzen, 2005).

6.2 Issues relating to social inclusion that did emerge from the data

Chapter five listed the issues related to social inclusion that were identified in the literature search but that did not emerge from the current data (see p.90). It was expected that the participants would talk more about their experiences of being in a psychiatric hospital. This was discussed at some length in the theme ‘things are better now’. Also discussed in the same theme were feelings of loneliness that many other service users experienced but that the current participants did not. As there were almost no explicit references to stigma and discrimination in the narratives, it was not identified as a theme that emerged from the data. However, the literature identified stigma and discrimination towards people with mental health problems as being one of the greatest barriers to social inclusion (Lapsley et al., 2002; Peterson et al., 2006; Stickley & Shaw, 2006). For these reasons, stigma and discrimination is further discussed, and an explanation of why people did not talk about them explicitly in their narratives is suggested.

Stigma and discrimination in some form appeared in the majority of the six themes from the data, albeit implied as opposed to openly talked about. It was seen in the relationships that people have with family members and friends and acquaintances. However, the participants did not equate rejection through lack of support with being discriminated against, as did Peterson et al. (2006). Neither did they view the disempowering practices of health professionals as discrimination (Bertram & Stickley, 2005). There is a stereotypical assumption that service users are irrational, lazy and unreliable people whose judgement is impaired (Crowe et al., 2001; Lester

& Tritter, 2005; Tal et al., 2007). This can lead to health professionals denying people's rights, treating them with disrespect and not allowing them to make decisions for themselves. In addition, having low expectations of service users' recovery and telling them that they have a poor long-term prognosis, further disempowers them and adds to their feelings of despair and hopelessness.

Still within the 'relationship' theme, discrimination was seen in people's inability to perform life's natural roles. For example, Priscilla was unable to be a mother to her children through being denied support and assistance by family members and service providers. It appeared that people considered that having a mental health problem made her incapable of caring for her children. Rather than helping her, she was sent back to hospital. Once again, this lack of support was a form of discrimination that was not perceived as such by Priscilla, who blamed herself for what she saw as her failure to care for her children.

Discrimination and stigma were pervasive in the theme of 'finances and money', with several examples of being exploited and defrauded. Kelly and McKenna (2004) suggested that financial exploitation and victimisation is part of the larger problem of stigmatisation, because people with mental health problems are seen as being 'easy targets' and vulnerable. While there was no reported discrimination in the area of employment, the chequered employment histories of the participants suggested otherwise. Conversely, overt discrimination was evident in the theme 'keeping occupied'. An example of this was when the president of a bowling club accused Gordon of acting inappropriately towards female members of the club. According to Gordon, he had done nothing wrong and considered that the allegations were based largely on a misunderstanding. This however showed that the public still perceive mental health service users as being unpredictable, the predominant stereotype that perpetuates stigma and discrimination (Read & Law, 1999).

According to Sayce (1998), stigmatised attitudes towards users of mental health services are prevalent in communities, as evident in 'nimby' (not in my back yard)

campaigns. While these campaigners may say that they accept people with mental health problems into their communities, they will not have them living on ‘their’ street, attending ‘their’ clubs and groups or having the children go to ‘their’ schools (Tal et al., 2007). This is only one example of how difficult it is to change negative attitudes. While laws and legislation may limit discrimination in the sense of unfair treatment towards people with mental health problems, confronting and changing negative attitudes or stigma is a far greater challenge (Sayce, 1998).

A positive finding of the present study was that there was no evidence of the ‘nimby’ phenomenon in the small rural town in which the home was located. This may be due to the fact that the home had been there for several years, initially as a private hotel and then as a boarding house for both mental health service users and non-service users. During the process of deinstitutionalisation, service users began to outnumber other people in the home, until in the early 1990s it became a registered ‘psychiatric’ home. However, this was a gradual process that did not attract the attention of the local community. Further tolerance and acceptance was generated through networking with other services and groups, and inviting members of the local community to join in activities and celebrations within the home.

As stated previously, an unexpected finding of this study was that the participants did not refer to themselves as having a mental illness. In fact, Gordon specifically denied having an ‘enduring mental health problem’, stating instead that all of his problems come from ‘social upset’. Lapsley et al. (2002) pointed out that being given a psychiatric diagnosis labelled people as being mentally ill which in turn engendered stigma and shame. There are two suggested reasons why the participants of this study did not talk in terms of a diagnosis or being mentally unwell. Firstly, they may not have wanted to internalise the shame associated with mental illness, preferring instead to think of their mental health problems as being a result of external events or circumstances outside of their control. Secondly, by not acknowledging to other people that they have a mental illness, they may be attempting to avoid the discrimination and stigma that a psychiatric diagnosis

bestows. On the other hand, they could be denying that they themselves are ill, or that they hold stigmatised views about mental illness.

Self-stigma of people with mental health problems occurs when they believe the negative stereotypes that others hold about them (Ministry of Health, 2007). This can manifest itself in low self-esteem, loss of confidence and a fear of being rejected (Link et al., 2001). A possible example of self-stigma was how Priscilla felt when being unwell prevented her from looking after her children. She stated that she was a ‘failure’ as she could not be a mother to them. In addition, Jo referred to herself on numerous occasions as being a ‘fool’, saying that she was ‘dumb’ and ‘stupid’ for doing certain things over the years.

The final expectation was that there would have been some differences between the experiences of the Māori and non-Māori participants. The health disparities between these two population groups are considered to be partly due to the fact that existing mental health services are based on a biomedical model that is very different from the Māori perception of health and illness (Durie, 1994). There is an increasing awareness that for Māori, health and well-being is a much broader and far more holistic concept that has spiritual, emotional, physical and family dimensions. The recovery model does however go a long way to meet Māori health needs through its congruence with the holistic nature of Māori perceptions of health.

However, differences in people’s experience of recovery were found in the bicultural study of Lapsley et al. (2002). They found that, while there were some similarities in people’s stories, there were also aspects of recovery that were unique to Māori. It was therefore surprising that there were no distinguishable differences between the stories of the two Māori women in the present study and those of the three Pākehā participants. This also takes into account that, while one woman appeared to have been raised with non-Māori families, the other woman was brought up by her whānau in a traditional Māori environment. This lack of differences may in part have been due to the unstructured interview format used and the fact that a second

interview could not be carried out on either of the Māori women (see page 66). There was therefore no opportunity to further explore and clarify these issues. This was also the case for ethnicity differences in experiences of stigma and discrimination.

Sayce (1998) pointed out that ethnicity potentially compounds the stigma and discrimination experienced by people with mental health problems. This being the case, it was expected that the Māori participants would report more experiences of discrimination against them, or at least some differences in their perception of how they had been treated. Once again, this expectation was not borne out by the data. This was particularly surprising in light of the additional difficulties that reportedly arise from exposure to multiple categories of discrimination (MHC, 1997; Van Den Tillaart et al., 2009). Having a mental health problem, plus being Māori, plus being a woman, created the potential for three-layered discrimination experiences. However, Peterson et al. (2006) reported similar findings, with few differences between the discrimination experiences of Māori and non-Māori, men and women.

6.3 Summary

This chapter discussed the themes that emerged from the life stories of the five participants and presented my interpretation of the meanings embedded in their stories. The themes were explored to show how the social and political developments in New Zealand had impacted on people's lives and illness experiences. The issues identified in the literature search relating to social inclusion that did not emerge from the data were discussed and reasons for their absence suggested.

The next chapter addresses the final two aims of the thesis: to explore how mental health nurses can support individuals to make a positive contribution to their community as citizens, employees, family members and neighbours; and to develop a position from which mental health nurses can explore initiatives and strategies for social inclusion. The limitations of the study and implications for nursing education

and practice are discussed. Finally the conclusions reached about the study are presented.

Chapter seven: Conclusion

7.0 Introduction

This chapter answers the question ‘what does social inclusion mean to people with an enduring mental health problem?’ In doing so, it addresses the final two aims of the thesis, which were to suggest how mental health nurses can support individuals to make positive contributions to their communities and to help develop strategies and initiatives for social inclusion. The limitations of the study, a summary of the findings and the implications that they have for mental health nursing practice are presented. Finally, the suggestions for future research and concluding comments indicate how the findings of this study validate and add to previous research on social inclusion for people with enduring mental health problems.

7.1 Limitations

As an exploratory, qualitative study, there are some limitations in terms of the study’s rigour. It could be argued that the pattern of social inclusion experiences of the very small number of people interviewed might not show the complete picture of the social exclusion associated with an enduring mental health problem. Transferability of the findings is limited by the fact that the average age of the participants is 62.8 years. It is expected that people of a younger age group would have socio-historic experiences that are quite different to those interviewed, resulting in even greater differences between the life stories of mental health service users. In addition, the site of the study was supported housing based in one local area. This may have created further limitations in that the issues concerning people living in supported housing in a small rural town would likely be markedly different from those experienced by people in more independent living situations in large cities.

Another limitation became evident when I could not follow through with the chosen method. Only one participant had a second interview and only one of the transcripts was returned for verification. Furthermore, I have no experience of living with an

enduring mental health problem. Lester and Tritter (2005) suggested that non-disabled researchers may have limited understanding of issues raised by service users, and this in fact may add to their disempowerment. Although I made every attempt to represent the voices of the participants fairly and transparently, my interpretation of their words may not be the same as that written by people who have experienced mental health problems.

7.2 Summary of findings

In order to ensure that I had answered the four research questions listed in Chapter one, each question is answered in terms of the key findings of the study.

7.21 What does social inclusion mean to people with an enduring mental health problem?

In Chapter one, I suggested a simple definition of social inclusion put forward by Bonner et al. (2002): social inclusion refers to somewhere to live, something to do and someone to love. The findings of this study indicated that this is what social inclusion means to people with an enduring mental health problem.

All the participants spoke about their general satisfaction with the home, indicating that their current living situation was better than it had been in the past. Some spoke about previous difficulties they had in keeping suitable housing and everyone suggested that their current home was much better than staying in hospital. The participants talked at length about keeping occupied and the importance of being engaged in meaningful activities. Their narratives had numerous comments about a variety of activities, ranging from paid employment and voluntary work, to daily chores and leisure activities. Finally, all the participants reinforced the need to feel connected to significant others. These included family and whānau, friends, mental health professionals and carers, and fellow residents of the home.

7.22 What facilitates social inclusion?

It was evident from the narratives of the participants that there were numerous factors that facilitated inclusion. Of paramount importance was supporting people in their personal recovery journeys. The participants indicated that they valued honest and open communication that was informative, respectful and allowed them to make decisions and have choices. They wanted to have intimate relationships and social networks that provided understanding and support and that enabled them to establish a meaningful position in society. This indicated that mental health professionals should foster hope and optimism within service users, by letting them know that they have confidence in their capacity and ability to recovery. Moving beyond the restrictions caused by mental health problems is assisted by establishing inclusive communities (Lloyd et al., 2006). An inclusive society gives all people equal opportunities to obtain employment, to access housing of their choice and to share in the resources of the community.

A fundamental requirement for the creation of inclusive communities involves the establishment of partnerships between mental health services, supported accommodation services and community services (Russell & Lloyd, 2004). These have the potential to address negative attitudes and help dispel the stereotypical misconceptions about people with mental health problems. Partnerships can promote access to community clubs and groups and provide housing and educational opportunities for service users. An integrated approach should also be taken in developing programmes such as supported employment (McLaren, 2004). Some participants indicated that they valued opportunities to learn new skills and to gain employment. Had they had access to supported employment programmes, they would have had assistance in planning their careers and accessing employment. There is the possibility that this would have enabled people to retain jobs, even through periods of being unwell and being in hospital.

7.23 What are the barriers to social inclusion?

Although the participants did not explicitly discuss this issue, their narratives indicated that stigma and discrimination had significantly impacted on their lives. It was likely that the negative attitudes held by the public, the media and some mental health professionals had contributed to the participants' unemployment, poor income and limited access to community resources. In addition, the findings suggested that some of the participants may have believed in the negative stereotypes about themselves. This self-stigma has the potential to create further barriers to social inclusion through service users becoming isolative due to low self-esteem and loss of confidence (Link et al., 2001).

Additional contributory factors for social exclusion included the length of time that the participants had spent away from their families and communities. Their long-term hospitalisation would most likely have resulted in restricted access to educational and training opportunities, diminished social networks, opportunities to establish intimate and friendship relationships and unemployment. Additional consequences of unemployment include limited opportunities to develop and maintain social contacts and a loss of a sense of purpose and social status (Evans & Repper, 2000). It also contributes to lack of financial resources, a situation experienced by several participants. Dependence on a WINZ benefit may have led to their reluctance to risk this financial security by getting a job and facing benefit disincentives (Sayce, 1998).

Finally, the side-effects of treatment, in particular medication, can create barriers to social inclusion (Stickley, 2005). The participants reported unpleasant treatments that they had received over the years which may have contributed to their inability to do certain things and participate in community activities. Stickley pointed out that the public may exclude service users because of the judgements they make about people based on physical appearance. Side-effects of medication, such as involuntary movements, weight gain and tiredness may result in labelling people as deviant and strange (Kelly & McKenna, 2004; Lester & Tritter, 2005).

7.24 How do life stories reflect the social and political developments regarding mental health in New Zealand?

The major reforms and paradigm shifts that have dominated New Zealand's mental health services over the past three decades have had a profound impact on the experiences of the participants. They have lived through long-term institutionalisation, with the coercive, oppressive and restrictive treatment that this entailed. The subsequent closing of the psychiatric hospitals and the move to community care signalled further changes for the participants, changes which on the most part they considered to be for the better. For example, a recent admission to a psychiatric unit was reported by Priscilla to be a great deal more pleasant than the old hospitals, with people being listened to and treated with respect. This reflected the adoption of a recovery approach as the guiding principle for New Zealand's mental health services. All the participants reported being satisfied with their current lives, having hope and optimism for the future and being supported and assisted by service providers.

7.3 Implications for mental health nursing practice

The findings of this study have important implications for all mental health professionals and in particular for nurses. These implications are discussed by way of addressing the final two research aims. The first of these aims was to explore how mental health nurses can support individuals to make a positive contribution to their community as citizens, employees, family members, and neighbours. In order to provide this support, it is of paramount importance that nurses learn what service users feel, think and want, so that they can be responsive to service users' needs (Crowe, 2000; Repper, 2000). Stickley (2005) suggested that these should relate to the social needs of individuals as opposed to their illness and treatment needs.

However, before mental health nurses can actively promote strategies and initiatives for social inclusion, they need to identify and examine any prejudices and negative attitudes they might hold towards people with mental health problems (Repper, 2000). It is essential that nurses believe in people's capacity to recover, in their

ability to make choices and in their capacity to achieve goals that they set themselves (Bertram & Stickley, 2005). These may be as simple as buying a pair of shoes or as complicated as organising an overseas trip.

The findings of this study indicated that the participants valued practical assistance with everyday tasks and activities and the centrality of the nurse-service user relationship places nurses in an ideal position to provide this assistance (Kirkpatrick & Byrne, 2009). Service users often need help to explore what options are available, to be given information about these options and then support to make decisions and achieve what they have set out to do. Nurses are also able to support people in establishing and maintaining valued family and friendship relationships and roles such as being a mother, a brother or an advocate for other service users. Further strategies to create socially inclusive environments for service users involve facilitating connections with the local community (Repper, 2000).

Mental health nurses need to go out into the community in order to gain intimate knowledge about available resources and to network with community groups that can facilitate education, employment and leisure activities (Repper, 2000; Stickley & Shaw, 2006). Repper also suggested that in order to promote service users' inclusion, nurses need to work towards changing communities and challenging negative public attitudes. This may involve accompanying people to leisure and sports clubs, to churches and to shops, and assisting in organising education and employment experiences. Practical assistance, information regarding rights and options, the promotion of valued relationships and connecting with the local community need to be the focus of service users' recovery plans, not medication, problems and risks (Stickley, 2005). This can only be achieved when nurses work in partnership with service users, listening to their concerns and responding to their needs.

The final aim of the study was to develop a position from which mental health nurses can explore initiatives and strategies for social inclusion. I propose that this is

best achieved through the adoption of a social model of disability. Lester and Tritter (2005) suggested that such a model may provide a framework for understanding the experiences of service users which would empower them to adopt a citizenship role as opposed to that of a 'mental patient'. In addition, a greater understanding of the reasons for society's responses to service users may help guide policy and practice. Sayce (1998) and Repper (2000) supported this view, pointing out that the disability movement challenges structural notions of discrimination by identifying and changing the social expectations that disable people, as opposed to changing the individual to fit those expectations. If nurses were to think in terms of people with impairments and society with disabilities, they would be better able to explore ways in which they could reduce stigma and discrimination and thus help promote social inclusion.

7.4 Suggestions for future research

The reviewed literature identified research gaps regarding people's first-person accounts of experiencing enduring mental health problems, particularly as they related to social inclusion and exclusion. Given the limitations of the very small number of people interviewed for this study, it is appropriate to recommend further research that explores the experiences of people who have different types of mental health problems, who are from different ethnic backgrounds and who live in a variety of different housing situations.

Other issues that posed limitations could also form the basis of further investigations. For example, service users from a younger age group and those living in larger city centres would likely have had different social inclusion experiences than the current participants. Finally, because social inclusion and exclusion are not terms commonly used in New Zealand's mental health services, it would be helpful to explore what they mean to support workers, nurses and other health professionals. This has the potential to further people's understanding of and become more familiar with the concept, thus enabling them to support service users to live inclusive lives.

7.5 Concluding comments

This study demonstrated the value of narratives in understanding the context and complexity of experience. It provided the opportunity to listen to and learn from the participants in order to gain new understanding of the impact that enduring mental health problems have had on their life experiences. As Gawith and Abrams (2006) pointed out, people's personal experiences must be the focus of all mental health knowledge, with the voices of service users at the centre of service planning and delivery. Despite this, health professionals do not always understand what service users need or want. For example, the service users who participated in this study were no different from other service users in that they wanted to engage in meaningful activity, to have financial security, friendships, family contact and access to community clubs and services. In contrast, health professionals consider that professional support, treatment and monitoring should be prioritised (Repper, 2000). In order for mental health nurses to support and foster social inclusion, they need to understand what it means to people with an enduring mental illness.

This study explored individuals' experiences in areas such as employment and finances, leisure activities, becoming and being unwell, relationships with friends, family and service providers, and how their lives had improved. The exploration of these factors highlighted the social barriers created by stigma and discrimination and helped explain the continued marginalisation of this group of people. This development of knowledge about what service users need and want has the potential to impact on their lives, both at an individual level and by providing a broader framework that puts more responsibility for inclusion on societal and political structures.

As evident in the examination of key documents and research presented in Chapters two and three, New Zealand's mental health services have not embraced a social inclusion philosophy. This means that, while mental health nurses may display recovery-oriented attitudes and practices, they may not view facilitating social inclusion as part of their role (Lloyd et al., 2006). As Repper (2000) pointed out,

nurses may see social inclusive practices as being the responsibility of the social worker, the occupational therapist, or the multi-disciplinary team as a whole. In order to help and support service users to contribute to society as citizens, employees and neighbours, 'social inclusion' must be included in the vocabulary of mental health nurses, just as 'recovery' is part of everyday language within mental health services in New Zealand.

Appendix A

An exploration of what social inclusion means to people with an enduring mental illness

Information Sheet

Principal Researcher:

Jenny Cheer

You are invited to take part in a study that explores the experience of social inclusion for people who have had mental health problems for many years.

What is the study about?

Put simply, social inclusion refers to somewhere to live, something to do and someone to love. For many people, long periods of time in hospital, stigma and discrimination have resulted in being excluded from leisure and family activities as well as education and employment opportunities. In order to fully understand these issues, it is important to talk to people who have experienced them.

Who is the researcher?

My name is Jenny Cheer and I am a Master of Arts in Nursing student at the School of Health and Social Services, Massey University and this study is part of the requirements for my degree. I have worked in mental health for many years and am interested in what social inclusion means to people who have lived with mental health problems. I believe that by understanding what it has been like to live with mental health problems and experience social inclusion, nurses and other people working in mental health would be more able to support and help people on their recovery journeys.

What would I have to do?

This study will involve talking to you about your life and your experiences of having mental health problems. If you agree to take part in the study you would need to:

- Tell me about your experiences: what it has been like living with mental health problems; what things have been helpful; and what things have not been helpful.
- Have at least two meetings with me at a time and place that is convenient for you. At the first meeting I will simply listen to your story. At the second meeting, I will ask you some questions to make sure that I have the details of your story correct and more fully explore your experiences. I expect that each interview will take approximately one hour, but this will depend on how much time you have and how long it takes to tell me your story. You may refuse to answer any particular question and may have a support person present at the interview if you wish.

- Agree to have the interview tape recorded. You may ask for the tape to be turned off at any time during the interview. You can have a copy of the tape if you wish, as well as a copy of the typed transcript of each interview.

Then what happens to the information?

If you agree to take part in the study:

- Anything you say will be kept confidential and I will only use what you have told me with your permission.
- No material which could personally identify you or your home will be used in any transcripts or reports. I will ask you to choose another name to be known by in the report and will refer to ... House as 'the home'.
- All information about this study will be kept in a locked filing cabinet. The tape recordings will be either returned to you or erased when the study has been completed.
- A summary of the completed study will be made available to you either in written form or as a presentation, which ever you wish. I will also be presenting summaries to various groups of care givers, nurses and other health professionals who are interested in helping to improve the care to people who have experienced mental health problems.

What are the risks and benefits of my taking part?

- There is a risk that telling your story may be upsetting for you or it may bring back unpleasant memories. The interview can be paused or stopped at any time, as can the tape recording. You will be given the choice of whether the meeting carries on after having a break or is put off for another time. Alternatively, you may decide that you want to withdraw from the study completely. If you decide to do this, you will not have to give me a reason. I will be happy to discuss any issues that arise for you and options for further support if you feel you need it.
- There may be no direct benefits to you in taking part in this study. However, it will give you the opportunity to talk about your experiences and add to our understanding about the needs of people in your situation. It will help improve mental health care and services by understanding what social inclusion means to those people who have ongoing mental health problems.

Do I have to take part in this study?

You are under absolutely no obligation to participate in this study. Deciding not to participate or withdrawing from the study will not affect your treatment or your rights in any way.

Please take some time to think about whether or not you wish to take part. Do not hesitate to ask any questions you may have and talk to family or friends before making your decision. A Māori elder (Kuia) will also be available to discuss the study with you and answer any questions. If you decide that you want to take part, I will then arrange a suitable time for us to talk.

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

If you would like to contact the researcher, Jenny Cheer, please phone: 07 8837394

If you have any queries or concerns about your rights as a participant in this research study you can contact the Health and Disability Advocacy Service.

Telephone: 0800 555 050 Fax: 0800 2787 7678 Email: advocacy@hdc.org.nz

Supervisors of this study are:

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Appendix B

Participant Consent Form

Title of Project: An exploration of what social inclusion means to people with enduring mental health problems.

Principle Researcher: Jenny Cheer

I have read and understood the information sheet about this study. I have had an opportunity to discuss this study and ask questions about it. I am satisfied with the answers that I have been given and know whom I can contact if I want further information or wish to make a complaint.

I understand that:

- It is my choice to take part in the study and that I may withdraw from participating at any time without having to give reasons. I also have the right to refuse to answer particular questions.
- Withdrawing from the study will not affect my treatment or care in any way.
- Any information I provide will be kept confidential to the researcher Jenny Cheer, her supervisors, the person who transcribes the interview tapes and Māori elder (Kuia) if she has been involved in the interviews and their analysis.
- No material which could identify me will be used in any reports on this study.
- I may ask further questions at any time during the study.
- I may ask for the tape recorder to be turned off or paused at any time during the interview.

I _____ (full name), agree to participate in this study.

Participant Signature:

Date:

Name of Researcher: Jenny Cheer

Contact phone number: (07) 883 7394

Researcher Signature:

Date:

Appendix C

Authority for the Release of Transcripts and Audio-taped Interview Consent Form

This form will be held for a period of ten (10) years

Title of Project: An exploration of what social inclusion means to people with enduring mental health problems

Principle Researcher: Jenny Cheer

- I understand that I will have the opportunity to read and amend the transcript of the interviews conducted with me
- I agree that the edited transcript and extracts from this may be used by the researcher Jenny Cheer in reports and publications arising from the research
- I agree to the interview being audio taped
- I wish to have the tapes of my interviews returned to me Yes / No

Participant Signature:

Full Name (printed):

Date:

Appendix D

Transcribers Confidentiality Agreement

Title of Project: An exploration of what social inclusion means to people with enduring mental health problems

I.....(Full Name – printed) agree to transcribe the tapes provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature:

Date:

Appendix E
Confidentiality Agreement

Title of Project: An exploration of what social inclusion means to people with enduring mental health problems

I(Full name – printed) agree to keep confidential all information concerning the project.

I will not retain or copy any information involving the project

Signature:

Date:

Appendix F
**An exploration of what social inclusion means to people with an enduring
mental illness**

Family/Whānau Information Sheet

Principal Researcher:

Jenny Cheer

Your family/whānau member has been invited to take part in a study that explores the experience of social inclusion for people who have had mental health problems for many years.

My name is Jenny Cheer and I am a Master of Arts in Nursing student at the School of Health and Social Services, Massey University and this study is part of the requirements for my degree. I have worked in mental health for many years and am interested in what social inclusion means to people who have lived with mental health problems. I believe that by understanding what it has been like to live with mental health problems and experience social inclusion, nurses and other people working in mental health would be more able to support and help people on their recovery journeys.

This study will involve talking to your family/whānau member about their life and experiences of having mental health problems. They would need to have at least two meetings with me in order to tell me about their experiences. Anything they tell me will be kept confidential and I will only use the information they have given me with their permission. No material which could personally identify the person or the home will be used in any transcripts or reports.

There is a risk that telling their story may be upsetting for your family/whānau member or it may bring back unpleasant memories. If this occurs, the interview may be paused or stopped at any time and the person will be given the choice of whether the meeting carries on after a break or is put off for another time. Alternatively, they may decide to withdraw from the study completely. They will not have to give me a reason and I will be happy to discuss any issues that arise for them and options for further support will be offered.

While there may be no direct benefits in taking part in the study, it will give your family/whānau member the opportunity to talk about their experiences and add to our understanding about the needs of people in their situation.

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

If you would like to contact the researcher, Jenny Cheer, please phone: 07 8837394.

If you have any queries or concerns about participants' rights you can contact Health and Disability Advocacy Service on (Ph) 0800 555 050, (Fax) 0800 2287 7678

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