Narratives of People's Everyday Occupational Lives

Following Long Term Psychiatric Hospitalisation

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements.

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Ethical Approval

Ethical Approval to undertake this study was granted by the Auckland Ethics Committee on 5 February 2003, Application number: AKX/03/00/012 (See Appendix A).

Language Use

There is no universally applicable guide to grammar, spelling and style in the English speaking world. Conventions for grammar and spelling differ across America, Australia, Britain and New Zealand, as well as changing over time. Because of this, the decision about which conventions to use has been beset with difficulties. Neither has it been easy to determine the most important audience to satisfy – potential examiners and professional colleagues internationally, or my fellow New Zealanders, be they participants, students or colleagues. Accordingly, because there seems to be no ideal solution, this thesis has been prepared to be true to its context in Aotearoa, New Zealand.

This has meant the inclusion of Maori terms (with English translations in brackets); the application of English grammar as outlined in *English at Work* (Snodgrass, 1985), the adoption of New Zealand English spelling as programmed into Microsoft Word 2000, backed up by *Chambers English Dictionary* (Schwarz, Davidson, Seaton & Tebbit, 1992) and *A Dictionary of the Maori Language* (Williams, 1975). In addition, the guidelines of the Auckland University of Technology for the presentation of theses have been followed, as well as the style requirements of the American Psychological Association (2001). Even so, inconsistencies appear in the text, some of which are due to retaining the original spelling and grammar in all quoted extracts of others' work. Sincere apologies are given in advance to readers whose editorial eye will be jarred by the use of conventions different from those they have adopted.

Abstract

This narrative study examines the stories of the everyday occupational lives of eight people with a serious mental illness who had been subject to the policies of psychiatric institutionalisation and deinstitutionalisation in New Zealand. The participants, who ranged in age from 35 to 66 years at the time of the interview, had spent at least five years living in psychiatric hospitals. Seven were now living either on their own, with spouses, or sharing a flat. One person was living in a mental health group home in which non-clinical staff were available to provide minimal supervision. A semi-structured interview format facilitated responses to the question: What, from the participants' perspectives, had influenced their everyday occupational lives in the community since leaving hospital?

A review of the literature highlighted the need for people to have a balance and variety of occupations in their lives. There does not appear to have been any research undertaken into the longer term effects of the institutionalisation and deinstitutionalisation polices on people's everyday lives. In this study, a narrative methodology was selected to enable some of this group of people to tell their stories of living in the community since their deinstitutionalisation in the 1980s and early 1990s. The interviews were audiotaped and all participants were given the opportunity to comment on their own transcripts. A thematic analysis was undertaken, and the major influences which emerged were the effects which illness, lengthy hospitalisation and psychiatric medications had had on the participants' everyday lives. The consequences of these influences were that the participants continued to pursue a limited range of roles and occupations. In particular, five of the participants did not appear to participate in the roles of family member, friend, or

paid worker, despite these roles being highly valued by them. In addition, an exploration of the narrative typologies revealed that a number of the participants framed their stories in a restitution narrative. Their past experience, shaped by the health system, has given them the understanding that it is the role of health workers to restore them to positive health and well-being.

There is a need to undertake research into how and where people in New Zealand find friends, to enable this knowledge to inform the support which is provided to people with a mental illness who have been socially isolated. Recommendations have also been made for further research into people who have been subject to deinstitutionalisation policies. It is argued that some people will require long term support from health workers, perhaps for the rest of their lives.

Chapter One: Introduction

In this study, I have gathered the narratives of eight adults, who have spent at least five years in New Zealand psychiatric hospitals because of a diagnosed serious mental illness, and who are now living in unsupervised accommodation in the community. My research question has been: from their perspective, what has influenced the everyday occupations of people with mental illness since their discharge from their long term stay in a psychiatric hospital? Before interviewing the participants, I explored the background literature with respect to the role of everyday occupation in people's lives, as well as what was already known about the everyday life for people with a mental illness in New Zealand. A narrative inquiry approach was used to gather and explore the stories of the participants, and the findings were placed within the social context of the meaning of everyday occupation to the New Zealand population throughout the relevant time period. As Leibrich (1999) wrote in the introduction to her book of people's recovery experiences, I hope that this study of the everyday lives of people with mental illness will open "doors on mental illness, and [let] some light in for *all* of us" (p. 7, emphasis original).

Why this Study?

I have had a life-long interest in what people do, how they do it, and why. Since an early age, I have also been involved in trying to assist people. These tendencies were undoubtedly reinforced by the traditional values of small village life, where everyone knew each other, and helping neighbours was commonplace and expected. This interest led me to

working as a social worker in the 1970s and early 1980s. At that time few people in my workplace had obtained formal qualifications although we attended many courses and workshops. During this period, I became aware of the links between paid employment or lives full of activities and the progress of the young people I visited. It was not until the mid 1990s that I discovered the existence of occupational therapy, a profession which has the value of meaningful occupation at its core. I embraced the undergraduate course with great enthusiasm, relishing the opportunity to explore ideas and values which at times reflected, and at other times challenged, my own. Following this, I worked in a physical health hospital setting, before transferring to working with people with mental illness who were living in the community.

During my home visits I became aware of a small number of people who had previously been placed for a number of years in psychiatric hospitals. I wondered what it had been like for them to find themselves returning to the community. The people I knew appeared to be living quiet, almost invisible lives. Stretched resources in the New Zealand mental health system had understandably often resulted in services being concentrated on those people who were most acutely at risk to themselves or others, rather than on those with chronic conditions whose health or behaviour was considered to be of no immediate concern (Haynes & Abbott, 1986; Mason, 1988). This was a medically and politically driven perspective of mental health and illness. My own personal and professional perspective, however, is more consistent with the World Health Organisation definition that health and well-being is more than the absence of illness (World Health Organisation, 1946). Mental health is also about actively participating in one's own life and engaging in meaningful occupations and relationships in the community (Hasselkus, 2002; Wilcock, 1998a). I wondered how those people who had returned to the community after a number of

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years in a psychiatric hospital viewed *their* participation in everyday occupations, and *their* sense of well-being. I wondered how their occupational lives had changed over the ten or twenty years since they had left hospital, and what had influenced these changes, or lack of them. I wondered, too, how they viewed their past and present situation, and what dreams they had about their future everyday occupational lives.

Pre-Suppositions

It is generally accepted that the data gathered during an interview in qualitative research will be influenced not only by the participant's previous life experience and his or her thoughts and feelings on the interview day, but also by his or her interaction with the interviewer. The interviewer's interaction with each participant will have been influenced in turn by the professional and personal life experience and judgements which he or she has brought to each interview. These judgements will also have influenced the researcher's selection of the thesis topic and interview questions. It is therefore important to make explicit the researcher's pre-suppositions, to enable readers to gain a fuller understanding of the context of the subsequent analysis and findings (Ellis & Berger, 2002; Wengraf, 2001).

I participated in a 'pre-suppositions' interview two weeks prior to interviewing the first participant. This interview clarified my thinking about why I had chosen the study, as well as my choice of methodology and methods. It also helped me to uncover some of my underlying beliefs. These included a belief in the uniqueness of individuals, and the extraordinariness of ordinary life. I believe that despite our uniqueness as individuals, there are commonalities in the human experience which enable us to be inspired by the stories of others, and in turn, we inspire others with our stories. The first eleven years of my own life

were spent in a small village in which we all knew each other, and in which activities often involved people of all ages and backgrounds. This close community life had provided me with insight into the richness and positive qualities which each individual had to offer, as well as the stigma and prejudice which was attached to those who were judged to act beyond the norms of acceptability.

I believe passionately in the strength of the human spirit, no matter what the situation in which we find ourselves. I also believe that every one of us has an important story to tell. I noted in my interview that it seemed to me that the struggles of everyday life were often overlooked in the news media, and undervalued in favour of the unusual and notorious. Yet the activities involved in maintaining everyday life were central to most individuals, and to the fabric of many communities. This had led to my interest in exploring the occupations of people whose everyday lives had been disrupted by lengthy periods of institutionalisation.

In my interview, I acknowledged that twenty years ago my prejudices were such that I would have predicted that people's institutional experiences could have had only a negative effect on their daily lives. However, my own life experience and reading over the years had tempered this opinion. At the time of the interview, I believed that people would have both positive and negative views of the effect of institutionalisation on their lives. I also expressed the opinion that people have a need to have a positive ending to their stories. I therefore expected the participants would either describe how they had overcome the difficulties they had faced, or would redefine them as a positive learning experience. I think this had always been one of my core beliefs, but it had been reinforced in my reading over the last two years in the fields of narrative methodology (Kleinman, 1988; Ricoeur, 1988; White, 1981) and recovery from mental illness (Lapsley, Nikora & Black, 2002). The

example I particularly remembered were the words of Kim, a participant quoted in the Lapsley, Nikora and Black (2002) study: "My mental breakdown was a breakthrough to a better way of life" (p. 98). I had an expectation that the participants in my study would validate their potentially negative experiences in a similar way.

Overall, I expected to find that the participants in my study would have hopes and fears, daily routines and occupations similar to other people living in New Zealand in the same time period (since the 1980s). If there was a difference for the participants, I predicted it may lie in the timeline of people's journeys. For example, many people learn the occupations of maintaining themselves and their household, and forming friendships and relationships in their late teens and twenties (Papalia & Olds, 1992). I anticipated that this stage of life would be the time when the participants in my study had been experiencing the most acute periods of their mental illness (Kaplan, Sadock & Grebb, 1994). They may therefore have learned these tasks at a later age. I was aware from my reading that studies had shown that in the first year or two after leaving psychiatric institutions, people were involved in very few activities (Ng & McKinlay, 1986; Sheerin & Gale, 1984). I hoped that my study would show that ten years further on people had developed a greater range of occupations and a greater involvement with other people.

Despite undertaking this pre-suppositions interview, more specific pre-judgements became apparent as the interviewing progressed. For example, I had not realised beforehand that I expected people to answer a demographic question with a direct answer. When I asked Jure how long he had spent in which hospitals, he stated that he was in [Hospital A] from 1983 to 1992. In fact, he was the only person to respond in this way. Frank knew he had spent four years in [Hospital F], but was unclear about the length of stay or the years of his other shorter term admissions. I had not been prepared for the first

interviewee, Anthony, to answer this question by starting with a story about his early teens, progressing to his late teens, getting into trouble, and then ending up in a mental hospital. It was only after telling this part of his narrative that he started to mention the years in the manner which I had initially expected. I reflected on this in my journal, noting that his response was a really good example of the storytelling which I had been hoping to elicit from the participants. Consequently, I was much more prepared for the responses of subsequent participants.

Definitions

In any study, defining the terminology used is important to provide clarity and avoid misunderstandings. In defining the terms which follow, I am also setting some boundaries for the study. For example, it will be seen that mental illness does not include everyone who has ever taken an anti-depressant tablet, and institutionalisation does not refer to people who have spent only a few days in a hospital. The major terms in this study which require discussion and definition are: naming the people with mental illness; mental illness; institutionalisation and deinstitutionalisation; everyday occupations; and living in the community. I also explain the terms I have used in place of the real names of the participants and the hospitals in which they were resident.

Naming the People with Mental Illness

The first term to consider is what to call the people who are the focus of this study. Few authors in the mental health literature explored in Chapter Two have explained the reason for the terms they used, the most common of which were: ex-hospital patients;

mental health patients; psychiatric patients; people with mental illness, mental health issues, or mental health problems; people with a psychiatric diagnosis, disorder, or disability; consumers (of mental health or psychiatric services); psychiatric survivors; and people recovering from mental or psychiatric illness.

From my personal experience as a health professional, I have observed that in current New Zealand practice it has been common to call people: 'patients' if they were temporarily in hospital; 'residents' if they were living in group homes in the community; 'clients' when discussing named individuals living in the community; and 'consumers' if groups were being referred to. The terms 'psychiatric', and people with 'mental illness/ health problems/health issues' were used interchangeably. In addition, some people have defined themselves in terms of their diagnosis, and refer to themselves as 'I am a schizophrenic' or 'I am a bipolar'.

In order to make a decision, I limited my attention to terms used in recent New Zealand literature. However, this did not result in any clarity. In the end, I have decided to use the term 'people with mental illness', which was used by the editor of "A Gift of Stories", a collection of autobiographical stories of New Zealanders who had experienced a mental illness (Leibrich, 1999). As Leibrich collaborated fully with the people whose stories she presented, there is some reason to believe that this term is acceptable to those most affected by the mental illness experience.

Mental Illness

It is estimated that in New Zealand approximately twenty per cent of the population experience some degree of mental illness within their lifetime. However, I am defining mental illness according to the criteria required for the three per cent of people with the

most severe disorders to access the government funded psychiatric services (Ministry of Health, 1997a). These criteria required people to have been diagnosed with an Axis I or Axis II disorder according to the Diagnostic and Statistical Manual of Mental Disorders IV. Axis I includes illnesses such as schizophrenia, bipolar disorder, anxiety, major depressive episode, and substance disorders. Axis II includes personality disorders (Kaplan, Sadock & Grebb, 1994). Most of the authors cited in Chapter Two defined their populations using these criteria.

Axis I also includes people with an intellectual disability. Although this group of people were often institutionalised in psychiatric hospitals in New Zealand (Dowland & McKinlay, 1985; Haynes & Abbott, 1986), I have excluded them from this study. At the point of deinstitutionalisation in New Zealand, the needs of this group were provided for separately from those with mental illness (Brunton, 1986; Jack, 1986). They ceased to be included in the funding for psychiatric services, unless their primary health issue was an Axis I or Axis II psychiatric diagnosis (Ministry of Health, 1997a).

Institutionalisation/Deinstitutionalisation

The Chambers English Dictionary defined 'institutionalise' as "to confine to an institution: … as a result of such confinement, to cause to become apathetic and dependent on routine" (Schwarz, Davidson, Seaton & Tebbit, 1992, p. 740). For the purposes of this study, I am using 'institutionalisation' to mean the policy of confining people with mental illness for lengthy periods in psychiatric hospitals. In New Zealand, long term placement resulted in people experiencing everyday life differently from people in the community. For example, many hospital residents were expected to wear hospital clothes, conform to hospital routines with respect to personal hygiene, mealtimes and outings, and were not

expected (and at times, not permitted) to take responsibility for management of their own finances, cooking or household tasks (Dowland & McKinlay, 1985).

Deinstitutionalisation refers to the systematic government driven policies undertaken to reduce the populations of large psychiatric hospitals. It will be seen that in the western world this trend began in the 1960s, and continued throughout the next forty years. People were placed from hospitals into a variety of community based settings, ranging from staffed group homes which are sometimes described as mini institutions, to living alone with minimal supports (Brunton, 1986; Coppock & Hopton, 2000).

Everyday Occupations

I am defining everyday occupations as those purposeful activities which an individual considers to be part of their usual way of living (Christiansen, 1991). Examples of everyday occupations include showering and personal grooming, household chores, various leisure activities, spending time with people socialising, attending church, and undertaking paid employment or educational courses. The Canadian Model of Occupational Performance (Canadian Association of Occupational Therapists, 1997) grouped these activities into the general categories of self care, productivity and leisure, and acknowledged that what we do is influenced by our own values, as well as the social, cultural and physical environment in which we live. In addition, in his Model of Human Occupation, Kielhofner (1995, 2002) pointed out that what we do may be influenced by the roles we hold, and by the impact which habits and routines have on our choice of occupations and how we do them. For example, part of the role of being a worker may involve a weekday routine of showering, dressing and walking to the bus stop at the same time each morning. In referring to everyday occupations, I believe it is useful to take into

account both of these models. As human beings it is not only the choice of occupations we undertake (self care, productivity and leisure), but also how often we do them (habits, routines) and why we do them (roles) which makes up the fabric of our everyday lives. The term 'everyday' does not necessarily mean that an occupation is undertaken every single day. Rather, everyday occupations are those which an individual considers to be part of ordinary living, as opposed to occupations which are extraordinary or unusual in a person's life (Christiansen, 1991).

Living in the Community

In her Auckland study of family members caring for people with mental illness, Warren (1997) carried out an extensive literature review in order to define the word 'community'. Her decision was to accept a general definition provided by Hillery that was cited in another study. Hillery had combined elements common to 94 different definitions to conclude that a community was a group of people who shared: a geographical area; economic, social and political activities; some common values; and a sense of belonging to each other.

In the literature, three major forms of accommodation in the community are described for people with a mental illness: hospital, group homes, and unsupervised accommodation. Although all of these forms of accommodation may be found within the same geographical area and operate within a similar socio-political context, these commonalities may not result in people feeling that they belong in the community which surrounds them. From an occupational perspective, it is likely that living in a hospital setting is a very different experience from living in a small, staffed group home in a residential street. The occupational experience of people living in unsupervised

accommodation, such as one's own home or flat, is different again (Ng & McKinlay, 1986; Sheerin & Gale, 1984). I have chosen to use the term 'living in the community' to describe people living in unsupervised accommodation, which is a criterion for this study. The extent to which these participants are actively involved in the community is discussed as it arises throughout Chapters Four to Eight.

Names of People and Hospitals

To assist with anonymity, each participant was invited to nominate a pseudonym by which he or she wished to be known in the study. Each selected a first name which had meaning for him or her, and these are the names used throughout the study. In addition, I have allocated a letter to denote each hospital that participants mentioned. For example, both Anthony and Brett spent time in [Hospital A], and Anthony and Martyn both spent time in [Hospital B]. Only Jean was admitted to [Hospital G], although she also spent time in [Hospitals A and B].

Background

In the first half of the twentieth century in New Zealand and other English speaking western countries, it was thought that the best way to assist people with serious, chronic mental illness was to place them in specialised psychiatric institutions. This enabled people to be physically cared for in a safe haven, and enabled clinicians to adjust and monitor medication and other treatment in a more controlled environment than people's homes (Coppock & Hopton, 2000; Haynes & Abbott, 1986; Mason, 1988; Newton, Rosen, Tennant & Hobbs, 2001). However, by the 1960s and 1970s there was a growing

realisation throughout the western world that long term institutionalisation in psychiatric hospitals may not be the best solution for most people with psychiatric problems. The advent of new drugs, the rise of the mental health consumer movement, an understanding that people recover better in their familiar natural environment, and a belief that caring for people in the community was a cheaper alternative, all contributed to the development of policies to transfer people from hospitals to community settings (Haynes & Abbott, 1986; Mason, 1988).

The occupational therapy profession tended to follow the trends of the health sector, with emphasis in the 1950s and 1960s on treating a person's dysfunctions (Wilcock, 1998a), and the development of more encompassing occupational models in the 1980s and 1990s (Canadian Association of Occupational Therapists, 1997; Kielhofner, 1984). However, throughout the twentieth century there was an understanding that it was beneficial to health and well-being for every individual to be engaged in meaningful occupations, which provided a level of challenge and which was stimulating but not overly stressful for that individual (Csikszentmihalyi, 1993; Goldstein, 1996; Hasselkus, 2002; Kielhofner, 1995; Wilcock, 1998a). In addition, it has become increasingly accepted in occupational therapy literature that health and well-being is enhanced by having some habits and routines in one's life. These tasks, which can be performed almost without thinking, enable people to concentrate their energy on other challenges (Clark, 2000; Dunn, 2000; Kielhofner, 1995). It is also believed that each person's occupational needs will depend on his or her physical, emotional, social, cultural and spiritual way of knowing the world (Canadian Association of Occupational Therapists, 1997; Kielhofner, 1995; Primeau, 1996). As individual circumstances and needs change over time, so does the choice of

occupations, and the meaning they hold for each person (Canadian Occupational Therapy Association, 1997; Hasselkus, 2002).

With this occupational focus in mind, I undertook a review of the literature with respect to people with mental illness living in the community. Research studies undertaken in New Zealand in the early 1980s revealed that those people with mental illness who had been deinstitutionalised preferred living in the community where they experienced a greater sense of freedom. People in both hospital and community settings, however, expressed concern about having insufficient to do, little choice, and few social contacts. Those who had moved home to live with family members had not acquired responsibility for household tasks or financial decision making. Many had little contact with old friends, and believed they lacked the skills to make new friends. The most frequently cited occupations in both settings were watching television, reading and walking (Dowland & McKinlay, 1985; Ng & McKinlay, 1986; Sheerin & Gale, 1984), all of which tend to be low stimulus, solitary occupations.

Despite an extensive search for literature, I was unable to uncover any studies since 1986 which have examined the occupations of people over the years since their deinstitutionalisation. As will be seen in Chapter Two, some studies with respect to mental health recovery have examined people's journey from being unwell to feeling in charge of their lives (Deegan, 1993; Lapsley, Nikora & Black, 2002; Leibrich, 1999; Ralph, 2000). There were also many studies which concentrated on the design and effectiveness of skill building programmes (Anthony, Cohen & Farkas, 1990; Farkas, Cohen & Nemec, 1988). In both cases, the populations described appeared to consist of people with serious, chronic mental illness who had spent only weeks or months in psychiatric hospitals. For them, hospitalisation was likely to have only temporarily disrupted their everyday lives. For the

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group who were the focus of my study, the hospital environment was their home for years, and may therefore have significantly influenced their everyday occupational choices and performance on their return to the community. Although I believe the stories of recovery and the studies of skill building programmes reflect the experiences of many people with mental illness, they may not be an accurate reflection of the experiences of this long term institutionalised group. In addition, my interest was in the stories of peoples' experience of everyday living. The occupations associated with recovering from mental illness and learning new skills in formal programmes may or may not have been significant influences in their everyday lives.

Overview of Methodology

The methodology used in this study is described here in broad outline only; detail is provided in Chapter Three. Given the paucity of research about the long term effects of institutionalisation on people with serious, chronic mental illness in New Zealand, I wanted this study to be a voice for the participants as much as possible. I also wanted the study to reflect any changes and developments in the participants' experience of everyday life in the community over a period of time. I selected a narrative methodological approach because it is concerned with people telling the stories of their lives over time (Mattingly & Lawlor, 2000). Narratives of mental illness may serve to provide a vehicle for listening, an opportunity for insight by both the storyteller and the listener, an opportunity to break down stigma, and a means to dispel myths and misunderstandings (Freckelton, 2002).

Stories do not make sense unless they are situated within the contexts in which they occurred and in which they were told. According to Guba and Lincoln (cited in Schwandt,

1994) truth is "a matter of the best-informed and most sophisticated construction on which there is a consensus at a given time" (p. 128). Using this definition, both institutionalisation and deinstitutionalisation were truths about how to assist people with mental illness in particular eras. They were socially constructed policies which had a major influence on the lives of this cohort of people with mental illness. I have therefore examined briefly these and other aspects of the New Zealand social context which may have influenced the participants' lives in order to add to our understanding of the participants' stories.

Overview of Thesis

In this chapter, I have set out the focus of this study. I have briefly explained the personal journey that led me to undertake it, and some of my underlying beliefs about people. I have introduced the policies of institutionalisation and deinstitutionalisation which set the scene for the study, and indicated that it is important for both the participants and health policy makers to understand the effects of these policies on people with mental illness. I have also provided a very brief overview of the methodology and methods used for the study.

In Chapter Two, I review the existing literature relevant to the research question. This includes the link between everyday occupation and health; the policies of institutionalisation and deinstitutionalisation; and what is currently known about the occupational lives of people who were subject to these policies.

In Chapter Three, I set out in more detail the philosophy and elements of narrative methodology, before detailing the methods undertaken to select and recruit participants, interview them, and ensure that ethical issues were carefully considered. I describe the

methods used to analyse the data, and include measures undertaken to maximise the trustworthiness of the study.

In keeping with the narrative methodology, the headings used in Chapters Four to Seven are those one may see when reading a play. In Chapter Four I have introduced the Heroes of the play – the participants. Chapter Five contains descriptions of the Supporting Cast, that is, those people or issues which emerged as significant players in the plots of the participants' everyday lives. Chapter Six describes these everyday Occupational Plots. Chapter Seven brings the play to a close with the Moral of the Stories, that is, the participants' views of their lives so far, and their thoughts about the future.

In the final chapter, Chapter Eight, I have linked the stories told by the participants to the narrative typologies explored in Chapter Three, and answered the research question by discussing the issues which have emerged from the participants' stories as being the major influences on their everyday occupational lives. I have concluded the discussion with recommendations for the future support of those people with mental illness who have been the subject of the policies of institutionalisation and deinstitutionalisation in New Zealand.

Why it Matters

It has been suggested that the four functions of the researcher are: to assist personal transformation; to improve professional practice; to generate knowledge; and to appreciate the complexity and beauty of reality (Bentz & Shapiro, 1998). It is hoped that this study may help to provide a voice for a group of people who have been largely invisible in society, and whose background or illness may have left them feeling misunderstood or unheard (Frank, 2000). Using a narrative inquiry approach may help participants to

understand themselves and their situation more fully. This group has been caught up in a societal experiment. They were subject to society's best intentions when they were placed long term in institutions; and they were subject to society's best intentions again when they were transferred to live in the community. This appears to be one of the first studies to examine their experiences over the many years since their initial transfer from hospital to community living. I believe we owe it to them, and to New Zealand's policy makers and health practitioners, to evaluate the long term effects of the institutionalisation and deinstitutionalisation policies on the everyday lives of the people concerned. By using a narrative inquiry approach, I am hoping to increase the understanding of researchers and health professionals "in ways that nothing else quite does" (Mattingly & Lawlor, 2000, p. 12).

Chapter Two: Literature Review

This study has set out to explore the influences on people's everyday occupations following their discharge from New Zealand psychiatric hospitals. As stated previously, my focus is on people living in unsupervised accommodation in the community. In this chapter I have reviewed the relevant literature from New Zealand and other English speaking countries which arguably share a predominantly Anglo Saxon lifestyle, namely, Britain, Canada, U.S.A., and Australia. The review begins with exploring the link between occupation and a sense of health and well-being. This includes: the concepts of occupational choice and performance; the importance of habits and routines in people's lives; and the impact of the social/cultural and physical environment, and the concept of time, on occupational choice and performance.

This is followed by a review of the literature describing everyday occupational life for people with mental illness in New Zealand in the 1970s and 1980s in the hospital setting, as well as their initial experiences of living in the community following deinstitutionalisation. I have explored what has been written since the mid 1980s with respect to people with mental illness which, although it has not focused specifically on the target group of this study, does provide general insights into some aspects of living in the community. Finally, I have examined the occupations valued by the general New Zealand population in the last twenty years, and the attitudes of New Zealanders towards people with mental illness. This will enable the stories of the participants to be considered within the context of their wider community.

Occupation and Mental Health and Well-Being

In this section I explore why it is important to consider people's everyday occupations when discussing issues of mental health. Although the domain of meaningful occupation is central to the profession of occupational therapy, other mental health professionals have implicitly acknowledged occupation as an indicator of people's health and well-being. As will be seen in later sections, occupations undertaken by people with mental illness featured strongly both in the study of people living in New Zealand mental hospitals (Dowland & McKinlay, 1985), and also in the studies of people who had recently been transferred to the community (Ng & McKinlay, 1986; Sheerin & Gale, 1984). In all three studies the researchers, who were not occupational therapists, examined what people did, their level of satisfaction with what they did, and their aspirations for the future.

Before exploring the relationship between mental health and occupation, I will first examine the link between occupation and health in general. It is more than fifty years since the World Health Organisation first defined health as encompassing physical, social and mental well-being (World Health Organisation, 1946). All three components influence our choice of occupations and how we undertake them. We choose occupations to meet our physical needs, and our physical capacities influence how we perform these occupations. Our interaction with others in the social environment creates the social norms and economic reality which guides our priorities for occupations, and limits or enhances our ability to undertake them. Our mental and emotional well-being also directly impact on, and are in turn influenced by, our occupational choice and performance (Kielhofner, 2002; Wilcock, 1998a). Thus it is understandable that occupational indicators are often used to measure the physical, social and mental health of people.

Wilcock has taken the role of occupation further. She believed that "health and well-being result from being in tune with our 'occupational' species' nature" (1998a, p. 123). From this perspective, health is directly related to our biological needs, and to engaging in occupations which address these needs. Apart from the physical benefits which may result, engagement in occupations which meet our needs is likely to result in feelings of happiness, contentment, and energy (Wilcock, 1998a; Yerxa, 1998). The opposite may lead to ill-health. For example, the lack of opportunity for physical exertion in much of our paid employment often leads to obesity, cardio-vascular problems, and the illnesses which result. The lack of balance in our lives between mental, physical, and social activities, often results in boredom or burnout depending on our occupational opportunities and choices (Hasselkus, 2002; Wilcock, 1998a; Yerxa, 1998).

Although these principles were describing society in general, Wilcock (1998a) argued that they were also applicable to people with mental illness, whether living in institutions or in the community. This was particularly apparent from the history of the treatment of people with mental illness in the western world. The value of occupation in psychiatric asylums first appeared in accounts of residents' activities written in the early nineteenth century, where occupations ranged from manual labour to crafts, reading and drama. There was a prevalent belief at this time that, by encouraging people to engage in everyday tasks, they would develop self discipline and internal controls which would enable them to function successfully both within the institutional setting and on their return to the community. Records from the Worcester State Hospital (Massachusetts, United States) between 1833 and 1852 showed that between 65% and 78% of patients were discharged within a year of admission, having been deemed to have improved or recovered. This hospital was one of a number in the period which offered a variety of physical,

creative and educational activities to its residents. Unfortunately, the success of these programmes in the United States caused their downfall. Increasing numbers of people were referred for what was seen as effective treatment. Eventually admissions increased to levels which stretched staff patient ratios and physical resources. This led to staff needing to concentrate their efforts on providing basic care and resolving incidents between patients caused by overcrowding. Opportunities for activity became more limited (Wilcock, 1998a).

By the end of the nineteenth century, the world view had changed from this humanistic stance to a more reductionist paradigm, which arose from new discoveries in the industrial revolution as well as in medicine. Consequently, the emphasis on the occupational aspect of rehabilitation in asylums was gradually replaced by emphasis on physiological treatment. As will be seen, the number of people in psychiatric hospitals increased, reaching its peak in the middle of the twentieth century (Wilcock, 1998a).

In New Zealand, a similar pattern occurred. In a presentation to the Mental Health Foundation of New Zealand's 1985 Conference, Brunton (1986) traced the history of psychiatric institutions in New Zealand. He pointed out that a network of asylums was established between 1854 and 1872. They were often built in rural areas, which enabled people to be held in a safe haven with a minimal need for restraint, and enabled the establishment of hospital farms. In addition to farming activities, hospital patients were involved in "ordered routine and programmes … intended to permeate cumulatively to the patient's real self and to restore mental order" (p. 46). The asylums operated with a sense of community, for example, patients were encouraged to take part in social activities such as dancing.

In the 1870s these policies changed in New Zealand. Increasing emphasis was placed on a person's prognosis. Those who were considered incurable after six months

were deemed to require hospitalisation for life. Brunton (1986) stated that in the late nineteenth century this included many men who were suffering from the effects of alcohol abuse and syphilis and who had no relatives in the colony to care for them. The large number of people with mental illness diagnosed as incurable led to a constantly increasing asylum population. The total number of registered patients rose from 595 in 1873, to 2672 in 1900, 5199 in 1922, and 8829 in 1945. Very little effective treatment was available before the advent of the new medications in the 1950s. The increase in asylum populations corresponded with an increasingly negative view expressed by New Zealanders regarding mental illness. Brunton argued that this was because the new institutions were bigger, more overcrowded, and there were more incidents of violence reported. Also, people suspected of being mentally ill were often publicly paraded through the streets to the court house, held in locked cells, and (apart from not being asked to plead) were treated exactly the same as those arrested for criminal acts. Life in institutions became depersonalised, drab, and alienated from the community.

It was not until the re-emergence of the humanist movement in the 1950s and 1960s, that there was a general resurgence in the value of meaningful occupation. Since that time scientific inquiry into the role and nature of occupation has developed significantly. Occupational models such as the Model of Human Occupation (Kielhofner, 1984, 1995, 2002) and the Canadian Model of Occupational Performance (Canadian Association of Occupational Therapists, 1991, 1997; McColl & Pranger, 1994) were developed in the 1980s and 1990s. These two models reflected the humanistic world view of client centredness espoused by Carl Rogers (1973), whereby the individual was perceived to be the expert on his or her health and well-being. Viewing each individual as the only one to really know what was in his or her mind, supported the view that who we were, and how

we perceived ourselves, was a result of our interaction with our environment. Accordingly, we alone could judge what was best for us as individuals. Rogers also emphasised the importance of congruence between our inner selves and our environment.

The occupational therapy models expanded on Rogers' client centred theory by placing occupation as an integral cornerstone of health. Both the Canadian Model of Occupational Performance and the Model of Human Occupation were based on assumptions that humans had a basic need to engage in occupations, and that this engagement exerted an influence on all aspects of our being (Bruce & Borg, 1993; McColl & Pranger, 1994). Our occupational performance, what we did and how we did it, was both an indicator of our health and an agent in promoting or hindering good health. In both models, the link was made between our innermost values or spirituality; our physical, mental and emotional attributes; and our interaction with the social and physical environment in which we lived. Engaging in meaningful occupations therefore enabled us to express our inner self in our physical and social environment (Hasselkus, 2002).

Another concept that emerged as important in the literature was the concept of balance. As previously stated, health is related to balancing our needs for physical, mental and social activities (Wilcock, 1998a; Yerxa, 1998). Choosing occupations which promoted balance was therefore a significant factor in attaining overall health and well-being. Our needs change in a constantly dynamic state throughout our lifetime, hence the difficulty we have maintaining balance each time we achieve it. When any aspect of our health is undermined, so is our occupational performance. When our occupational performance is out of balance or out of tune with our environment, with our sense of meaning, purpose or connectedness, then ill health may result (Canadian Association of Occupational Therapists, 1997; Hasselkus, 2002; Kielhofner, 1995).

Occupation is consequently more than just 'doing'. It is also about 'being' and 'becoming' (Wilcock, 1998b). It is the impact of doing that gives meaning to our lives in the spheres of 'being' and 'becoming'. 'Being' describes the act of expressing ourselves and experiencing the moment, for example, the pleasure, frustration or satisfaction at any given moment of writing a thesis. 'Becoming' describes the potential we unfold by our 'doing 'and 'being'. For example, by completing the thesis successfully my 'doing' will provide me with a qualification, but it will have also transformed my knowledge base and expanded my experience and skills in interviewing people and writing an academic paper. I will have 'become' a different person. Both Hasselkus (2002) and Primeau (1996) have expanded on this concept to suggest that occupational therapy should aim to go beyond helping people to undertake their everyday occupations. It should also be concerned with assisting people to discover and develop the meaning in their lives. By encouraging people to participate in occupations of their choice, therapists are helping people in their 'doing' to express their 'being' and unlock their potential for 'becoming'.

Occupational Choice

In the previous discussion about the significance of occupations in our everyday lives, I have commented that what we do and how we do it are both key elements for successful occupational performance and, therefore, for healthy living. Choosing what to do is equally important and is influenced by many factors. Wilcock (1998a) identified four major functions of occupation: to provide for our immediate needs for food, shelter and self care; to maintain our health; to develop both social structures and technological aids to ensure our survival in the fight against others and the environment; and to enable each person and society to flourish. We therefore make choices according to the unique and

complex mesh of relationships and influences which we experience (Goldstein, 1996). This may even include the influence of the international context in which we live. For example, which car we purchase may depend on our patriotism (for example, buy New Zealand made), or perhaps our international politics (buy a car which is the most environmentally friendly). However, the same choice will also take into account family issues (buy the cheapest as long as it is safe), or community pressures (buy a make which fits socially with the neighbourhood). Personal preferences based on one's previous experience and taste will also feature (for example, I'm buying 'x' brand because I have always found them reliable, and I like red cars because they stand out and I will be safer).

As can be seen from the above example, even making a choice about the purchase of one item requires the consideration of a diversity of options, and is influenced by many factors. The nature of major mental illnesses is that they often negatively impact on either the ability to think clearly, or on emotions and moods (Kaplan, Sadock & Grebb, 1994; Kielhofner, 1995). This may result in people not being able to see a future for themselves (so why make choices), or seeing their capabilities through a distorted lens (thoughts of uselessness or superhuman ability) and therefore making poor choices (Kielhofner, 1995). In addition, choices for people with mental illness are often compromised further when people are placed in a hospital environment. It is frequently the health workers who choose the time of day the patients will get up, what they will eat, and how they will spend their day. They are often protected from the many competing influences of the outside world: family, community, society, world events (Dowland & McKinlay, 1985).

It could be argued that it may be totally appropriate to remove some choice from people who are acutely unwell for a period of time, provided that choice is gradually reintroduced. The difficulty with this viewpoint is deciding when a person is ready to

resume the opportunities and responsibilities which are inherent in making choices. Rogers (1973) acknowledged that some people lacked the ability to evaluate their situations for themselves. He believed that, given an appropriate therapeutic environment, they would nevertheless develop their internal resources over time. He did not consider it appropriate to impose decisions or solutions on people, no matter how benevolent the intention (Thorne, 1992). Although Rogers' hypotheses of client centredness have been criticised because his theories have not been subjected to rigorous testing (Thorne, 1992), they remain the cornerstone for the humanistic thinking of those working with people with mental illness.

The current thinking expressed in literature both in New Zealand and overseas is that, unless there is evidence that harm to self and others is imminent, people should be given all relevant information and be encouraged to make their own choices (Advocates Inc. & Deegan, no date; Blain & Townsend, 1993; Law, Baptiste & Mills, 1995; Sumsion, 1993). Advocates Inc. and Deegan believed that preventing people from making choices in their everyday institutional life resulted in many acquiring a learned helplessness. This in turn led to apathy and loss of belief in their ability to make choices. The authors developed eight performance standards for mental health workers to enable client choice. These included the concept that it was normal for all of us to have opportunities to take risks and to fail; this was how we learned. The worker's role was to be supportive, to advocate and to help people put their choices into action. They conceded that some people were not capable of processing information in order to make a choice, and on these occasions it may be appropriate to seek the appointment of a guardian to act on their behalf. But they emphasised that this would be needed by only a very small number of people.

The studies described later in this chapter give details of occupational choices made in both institutional and community settings, but do not tend to explore the reasons for the

choice. It is not known whether a choice was made because it was what the people really

wanted, because it was the best option from the poor selection available, or because it was

the choice of more powerful or assertive people around them.

Occupational Habits and Routines

Just as choice and variety in occupations is important for our health and well-being,

so is repetition and predictability. In fact some people assess their return to health following

an illness or accident by the degree to which they have returned to their familiar routines, or

by their ability to develop new routines (Hasselkus, 2002). Csikszentmihalyi (1993) argued

that:

> … the natural state of our minds is chaos, not order. When we have nothing specific
> to do, when we are deprived of ordered stimulation … the mind begins to drift in
> random patterns, and usually ends up bringing up depressing thoughts, whether we
> like it or not. (p. 38)

He believed that a person's sense of well-being was significantly related to the stimulation

and challenge of the activities they undertook. One could argue from this quotation that if a

degree of order enhances health, then it follows that habits and routines may play an

important part in everyday well-being. Habits are occupations which are "performed

repeatedly, relatively automatically, and with little variation" (Clark, 2000, p. 126). Some

habits are too small to be considered an occupation, for example, chewing gum. However,

others are occupational, for example, the particular way an individual washes the dishes.

Once established, habits are characteristically difficult to give up or change (Clark, 2000;

Kielhofner, 2002). This is because habits are not neutral. They "serve to preserve patterns

of actions, so they are naturally resistant to change" (Kielhofner, 2002, p. 69). Charmaz

(2002) interviewed 140 people with serious chronic illness, and came to the conclusion that

habits were embedded in context, and in our perceptions about ourselves. Before we can discard an existing habit or develop a new one, we therefore need to understand the meaning that the habit holds for us, and be prepared to change our view of ourselves and our contextual relationships.

Whereas habits are occupations or activities which are performed repeatedly, routines are often described in terms of processes or procedures which order our occupations (Clark, 2000), and are linked to regular patterns of use of time (Kielhofner, 2002). When we get out of bed in the morning, we often have a set routine of which occupations we do in which order. On work days a limited time frame may dictate the speed of the performance. For example, some people will shower, get dressed and then have breakfast, all within half an hour to ensure they leave for their workplace by a set time. This is their weekday routine. At weekends this routine may change to having a leisurely breakfast before showering and dressing, with no concern about time. Rowles (2000) believed people developed routines to respond to a particular situation, and that we may continue these routines even though the original situation may have changed. He believed people would adapt to a new situation, provided the need to change was compelling enough. For example, when a worker goes on holiday, he or she may continue to wake up at the usual time for the first two or three days. However, as the holiday progresses, the worker is likely to adapt to a later, less regulated time to fit with the more relaxed circumstances of the holiday.

Both habits and routines are essential to our health and well-being. By having some tasks in our everyday lives which are almost automatic, we free our mind and energy for more creative occupations (Clark, 2000; Hasselkus, 2002; Kielhofner, 2002). However, our response to routines and habits is very individual. Each of us needs more or fewer routines

in our lives than other people, and our health can be adversely affected if we do not achieve the balance which we as individuals require. Indeed, the lack of habits at one extreme and the domination of habits at the other extreme can interfere with our ability to live happily, and may even place our existence at risk. In mental health terms, these extremes may reflect diagnosed illnesses such as severe depression or obsessive compulsive disorder and substance abuse addictions (Dunn, 2000).

Our propensity to regulate our habits may be influenced not only by our mental and emotional state, but also by the operation of our sensorimotor system. Each person has his or her own unique neural stimulation threshold, and our response to this threshold affects our behaviour. People with a low registration to high thresholds may appear flat and exhausted. They require increased contrast in stimuli and more variety in order to arouse their level of interest (Dunn, 2000). Unfortunately, it would appear that some people who feel flat may believe they are providing themselves with plenty of stimulation, when the reality is that they are not. A study of 59 women with major depression showed that people were likely to overestimate both what they did and what they thought they were capable of doing (Rogers & Holm, 2000). This has implications for researchers studying people's accounts of their occupational habits and routines. It will be seen later in this chapter that many people with mental illness reported they had insufficient to do on a daily basis. Yet, according to the Rogers and Holm's (2000) study, even the occupations they did report doing may be an exaggeration of reality. However a lack of routines is not necessarily bad for one's health. As Williams (2000) discovered in his comprehensive five year longitudinal study, people who were the least set in routines did not experience psychological distress unless they were experiencing serious unexpected negative stressors in their lives.

In contrast, people who were high responders to stimuli required stability and fewer interruptions in order to concentrate (Dunn, 2000). Despite their reliance on predictable daily routines, such people may experience high levels of psychological distress at all times, not just when unexpected stressors occur (Williams, 2000). However, if people have too many routines and habits and not enough variety, they may experience the same feelings as those with a lack of routines: boredom, apathy and depression (Rogers, 2000). These studies support the view that, in order to maintain health and well-being, each individual must find a balance of routines and stimuli which meet his or her unique set of personal needs.

The Quality of Occupational Performance

Just as choice in what we do is important to our health and well-being, so is our occupational performance, that is, how well we do things. Good physical and mental health enables us to successfully perform occupations which have meaning for us, and the quality of this performance is one source of our feelings of well-being (Christiansen, 1999). Although he was describing how occupation was linked to personal identity, Christiansen (1999) also pointed out the influence of social relationships and societal expectations on what we choose to do and how we do it. He believed that our feelings of competence were directly related to our ability to conform to our roles and responsibilities in society.

People with mental illness often find it difficult to perform everyday occupations. They may experience decreased motivation, feel overwhelmed by what were previously simple tasks, and lack the ability to concentrate on their occupational performance (Kaplan, Sadock & Grebb, 1994; Kielhofner, 1995). This lack of concentration may result not only in fewer opportunities to experience competence, but also in an inability to experience

flow, the state of being totally absorbed in an occupation. Csikszentmihalyi (1993) has

undertaken a number of studies which explored the concept of flow. He argued that when

people had sufficient complexity and stimulation in an occupation, they were unaware of

time passing, and experienced pleasure from being totally involved in the activity. He

believed that "a fully meaningful life depends on the ability to find occupations that are

challenging, yet within the scope of our abilities" (p. 41). In one study, in which

participants logged what they were doing and how they were feeling, it became apparent

that people experienced far more flow in their working life than in their leisure pursuits

(Csikszentmihalyi & LeFevre, 1989). Apart from the skills and challenges of paid

employment, other occupations which seemed to be a common source of flow for people

included driving a car, and conversations with family members and friends. It will be seen

that in the period of institutionalisation and deinstitutionalisation in New Zealand, few

people with mental illness were in paid employment, and while it is not known how many

drove a car, it is known that many lacked regular contact with friends and family.

Occupation and the Cultural and Social Environment

As has been discussed, there are many factors which affect people's choice of

occupations, development of routines, and satisfaction with their performance. In addition

to their physical, emotional and mental attributes, their participation in occupations is

influenced by the complex mix of social and cultural conventions unique to each person

(Canadian Association of Occupational Therapists, 1997; Hasselkus, 2002; Kielhofner,

2002). Relationships with other people can both provide opportunities and present

limitations in occupational choice and performance (Kielhofner, 1995; Rebeiro & Cook,

1999). For example, in a recent conversation to me, a friend described both the joy and

frustration she experienced in cooking a meal for a vegetarian friend. This occupation provided her with the opportunity to explore new ways of preparing food, but also limited her selection of ingredients and recipes.

The influence and expectations of friends, family members, and other people from our culture, society or local community on our occupations is profound. We oscillate on a continuum between experiencing our uniqueness and our commonality with those around us (Hasselkus, 2002). Creativity and individuality may provide people with both positive and negative feedback from others, depending how difference is viewed. Similarly, the desire to belong within a group, to be accepted by others whose opinion or relationships we value, will provide opportunities or limitations in our choice of daily occupations and how we perform them (Hasselkus, 2002; Kielhofner, 1995). In a qualitative study of people with mental illness living in a Canadian community, it emerged that the participants spent considerable time and effort negotiating the complex relationships with mental health and welfare systems, managing their social interaction with employers and the power hierarchies in work and leisure activities (Rebeiro, 1999). The occupations involved in maintaining these relationships had an enormous influence on their sense of well-being.

Kielhofner (2002) pointed out that people with a mental or physical disability were often constrained in their social relationships. This was partly because of society's "deep ambivalence towards persons with disabilities" (p. 109). Friends tended to drift away when people were no longer able to participate in activities the way they used to. This resulted in a reduction in both social relationships and social occupations.

One factor which sometimes added to the difficulties faced by people with mental illness was the cultural attitudes and beliefs of the health professionals, who were products of, and influenced by, the communities in which they lived. It became apparent in the 1980s

that health professionals sometimes treated people with mental illness according to the values of the dominant culture rather than the individual's culture. For example, in Britain there was evidence to suggest that Asian people were more likely to be diagnosed with depression, and African and Caribbean people were more likely to be diagnosed with schizophrenia, than their white counterparts (Coppock & Hopton, 2000). The authors posed the question as to whether the values and beliefs of psychiatrists impinged on their diagnosis of people of races other than their own. They believed the issue had also become more complex given the "post modern notion of multiple and conflicting interpretations of reality" (p. 119) compared with the modernist training of many psychiatrists. An increasing number of writers have emphasised the need for orthodox medical treatment to no longer be considered the sole remedy, but to be provided in conjunction with culturally appropriate services, in plans which are tailored to meet the specific cultural, social and personal needs of the individual (Castillo, 1997; Coppock & Hopton, 2000; Jacob, 1999; Lothian, 1998; Okasha, 1999; Ritchie, 1992).

In New Zealand, Maori have historically been over-represented as consumers in all health services, including mental health (Durie, 1994; Pomare et al., 1995). Just as community attitudes to mental illness had begun to change during the 1980s, so did the attitudes of health workers. By the early 1990s, government reports and documents were recommending that mental health initiatives needed to be linked with the development of Maori culture, and improvements in general health, education and employment initiatives. Maori had already begun to address some of these issues, and in more recent years had received increasing government support to do so. These steps included: schemes to re-establish the place of Maori language and culture in both Maori and the wider New Zealand society (Smith, 1999); renewing spiritual and cultural ties within family networks (The

Mental Health Foundation of New Zealand, 1997); the inclusion of the Treaty of Waitangi as a principle underlying new legislation (Ministry of Health, 2000); and the settling of some of the historical land losses by the return of some government owned land, together with compensation for the loss of other land (Durie, 1994). Some government departments acknowledged the existence of institutional racism (Department of Social Welfare, 1986; Irwin, 1988), leading to the recruitment of more Maori staff, and consultation with local tribes regarding policies and practices (The Mental Health Foundation of New Zealand, 1997; Ratima et al., 1995).

In the mental health arena, these changes resulted in Maori people with mental illness being given greater opportunities to be involved in service planning and development and to access rehabilitation and community resources which matched their cultural values and culturally relevant occupations (Mental Health Commission, 1998). It was also acknowledged that no single solution would suit all Maori people, and that people's values or views of their culture were not static (Patterson, 1992). For example, one person may wish to participate in the traditional occupation of gathering sea food; a second may want to gain the skills and confidence to speak te reo (Maori language) in formal hui (gatherings); whereas a third may not wish any involvement with his or her cultural traditions whatsoever.

Occupation and the Physical Environment

Just as our social and cultural environment impacts on our occupations, so does the physical environment. This environment includes both the place where the occupation occurs and the objects in that environment. As with the social environment, the physical environment can provide both opportunities and limitations to our occupational lives

(Hasselkus, 2002; Kielhofner, 1995). Using a previous example, cooking a meal becomes a very different task when it involves cooking over an open fire on a windy day at the beach, compared with cooking in a fully equipped kitchen. As with the social environment, no two people placed in the same physical environment will respond to it physically, mentally, or emotionally in exactly the same way. A person who values the precision, routine, and benefits of the most advanced technology in a modern kitchen, may find the need to adapt to the less controlled beach environment very demanding. On the other hand, another person may find the limited number of ingredients and equipment taken to the beach an enjoyable opportunity to relax and be creative. Once again the continuum between commonality in occupation, in this case cooking a meal in a kitchen or at the beach, and the uniqueness of each individual's experience of the occupation, comes into play (Hasselkus, 2002; Kielhofner, 1995).

Occupation and the Concept of Time

A further dimension which influences our choice and performance of everyday occupations is the context of time (Zemke & Clark, 1996). As previously pointed out, many of our daily routines exist within timeframes set by others, especially with respect to paid employment. Indeed, formal group activities such as attending a church service or rugby practice depend on having pre-arranged timeframes to ensure people meet as a group. This in turn is likely to influence the times people set aside for dressing in appropriate clothes and travelling to the agreed venue, and often the time of the next meal.

In addition to set appointments and daily routines, our choice and performance of occupations may be influenced by seasonal and annual timeframes, for example, planting vegetables or celebrating birthdays (Zemke & Clark, 1996). The era (and country) in which

we live also influences our understanding of time. When I was very young, it was accepted that the normal way of communicating with someone in another town was by letter, and that a reply would take at least two days to arrive from when the original letter was posted. Telephones soon became common in most homes, so instant communication was possible. It was accepted that if a person was not at home, one needed to keep trying until the person returned. Now many people have a mobile phone and can be contacted almost twenty-four hours a day.

These and many other advances in communication technology have created their own opportunities and expectations about how we spend our time, and how much time we spend on various occupations. If you are arranging something exciting, having a mobile phone so you can be contacted immediately may be a positive experience. If however you are "on call" from your workplace after a very busy day, the convenience of the mobile phone may be viewed less enthusiastically. Clark (1997) pointed out that this increased speed of communication has resulted in changes in our lifestyle pace. For example, a wider range of products is now available in shops because goods can be flown around the world within hours. More shops are within our reach because of the improvements in roads and transport. The immediacy of advertising media ensures we are kept up-to-date with the products available, and the dates when they can be purchased at a special low price. As a consequence, there is pressure to go out and buy goods today, causing some people to become trapped in a cycle of working and spending (Clark, 1997).

It will be seen in Chapter Three, when discussing features of narrative methodology, that each individual also experiences time in the context of the meaning accrued from past and present experiences (Clark, 1997). For example, a person who in the past spent twenty years in a psychiatric hospital, may consider a more recent two weeks' stay to adjust

medication to be of little consequence. However, for a person who has spent only two weeks in a psychiatric hospital in his entire life, each of the fourteen days may have been experienced as an eternity, to be endured minute by minute. Lifespan is another aspect of time which influences what we do and how we do it.

A number of studies have explored how we spend our time during the week, and the effect of perceived time pressures on people's sense of well-being. In general, adults in the USA spend about eight hours sleeping; approximately two hours maintaining the household; two hours in personal self care (which includes such activities as showering, dressing and eating); and a further eight or nine hours in paid employment (Christiansen & Baum, 1991). These could be considered obligatory occupations to maintain oneself and one's environment. This leaves three or four hours per person for discretionary occupations. In a separate study, Zuzanek (1998) used results from Canada's National Population Health Survey to examine the relationships between time use, feelings of pressure, personal stress, and life satisfaction. He analysed the survey responses of more than 17,000 individuals, representing a range of ages, marital, family and employment statuses. He concluded that those who reported the highest levels of life satisfaction and emotional well-being were employed married people between the ages of 25 and 64 years, despite the fact that some of these groups considered they were pressed for time. Those with the lowest levels of life satisfaction were unemployed people, who had insufficient to do, and divorcees, who often experienced time pressures. This appears to reinforce the ideas expressed in the occupational therapy literature already reviewed, that we do best when we have a balance of meaningful occupations in our lives, including some routines, as well as having valued relationships with other people. However, it is important to note that Zuzanek concluded that the issue is a complex one, and that more research needed to be carried out in this area.

In this first section of this chapter, I have explored the close relationship between the performance of everyday occupations and our mental health and well-being. With respect to people with mental illness, it has been noted that occupation was deemed to be beneficial in rehabilitation as early as the nineteenth century. However, this concept was replaced in the late nineteenth and early twentieth centuries with an emphasis on physiological treatments. It was not until after the resurgence of the humanist movement in the 1950s and 1960s with its notions of client-centredness, that the occupational models which form the theoretical basis of current occupational therapy practice were developed. The literature reviewed appears to be in agreement that what we choose to do and how we do it is influenced by factors such as our physical, social and cultural environment, as well as our individual physical, emotional and mental attributes. These factors combine to form a unique context for each person, providing both opportunities and limitations in occupational choice and performance. We need to develop some habits and routines to establish a degree of order in our lives, but these too should be in balance with our unique physiological responses and personal circumstances. It is also considered to be important to have a balance of stimulation and challenge in our occupations, so that we are neither too stressed nor too bored, but can experience the satisfaction of flow. This sense of well-being appears to be experienced most often when people are involved in the occupations of paid employment and conversing with friends and family. In the section which follows, I review the literature pertaining to everyday life for people with a mental illness, both in hospital and community settings, including the prevalence of these particular occupations.

Deinstitutionalisation

As has been discussed, in the hundred years between 1850 and 1950 it was thought that it was most beneficial for people with serious mental illness (and intellectual disability) to be placed in institutions built specifically for them. These asylums were intended to provide safety and security for both patients and the community, and to enable people to be cared for and receive treatment. In the 1960s and 1970s, attitudes to the treatment of people with mental illness began to change. New medications and treatments made it possible for people to be supported more easily in their own homes. People with mental illness and their families began to voice their preference for community based options, and health providers could see the economic advantages of disestablishing expensive buildings in favour of outpatients' services (Bean & Mounser, 1993; Coppock & Hopton, 2000; Haynes & Abbott, 1986; Mason, 1988; Newton, Rosen, Tennant & Hobbs, 2001; North Health, 1996).

People were systematically discharged to group homes, boarding houses, or unsupervised accommodation. Coppock and Hopton (2000) pointed out that, in Britain in 1986, the majority of those discharged from psychiatric hospitals were living an institutional life in small group homes, where many decisions about daily life and routines were being made for the residents. However, this was still a major change from living long term in a large institution alongside people who were acutely unwell. In the hospital setting, the top priority of staff was to manage those with acute problems. This meant that attempts to support other patients by providing recreational opportunities were often restricted by hospital routines or interrupted by acute incidents. In group homes, whether in Britain, Australia or New Zealand, routines were still shaped to suit staff rosters, but there were more opportunities for workers to support people in discretionary occupations (Coppock & Hopton, 2000; Dowland & McKinlay, 1985; Newton, Rosen, Tennant & Hobbs, 2001).

In New Zealand, the number of residents in psychiatric hospitals reached a peak in 1944, and then decreased significantly during the 1970s and 1980s. By the end of 1993 there were only 2331 people in hospital because of a mental illness, nearly half of whom (1126) had been resident for less than six months. Only 368 had spent more than five years in hospital (Ministry of Health, 1996). The majority of long term hospital residents were initially discharged to boarding houses or unsupervised accommodation, and a smaller number to group homes (Ng & McKinlay, 1986; Sheerin & Gale, 1984).

Occupational Life in Psychiatric Hospitals

The two largest hospitals in the Auckland area, Carrington and Kingseat, closed their last wards in 1992 and 1997 respectively (Regional Coordination Service, 2003). As previously stated, however, the most significant reduction of numbers in these hospitals and throughout New Zealand took place between 1970 and 1974 (Brunton, 1986; Haynes & Abbott, 1986; Sheerin & Gale, 1984). It is not surprising therefore that the literature examining the transition from hospital to community care appears to have been written a few years later in the early 1980s.

In 1985, Dowland and McKinlay reported on their ethnographic study of nine New Zealand psychiatric hospitals which explored how both staff and patients spent their day. As this study appears to be the only one exploring everyday life in New Zealand's psychiatric hospitals, its reliability is a particularly significant issue. The authors visited the nine hospitals during 1983 and 1984, using interviews and participant observation techniques to gain their data. They participated in a wide range of activities and outings, and described the process of becoming accepted by residents and staff. Their descriptions of each institution and each part of institutional life were minutely detailed, and they drew

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out themes which covered the major aspects of institutional life. The length of time they spent as participant observers, and the depth of the descriptions of their observations, are indicators that their study is an accurate reflection of the data gathered. Although the authors also discussed aspects of hospital life for specific groups such as those with an intellectual handicap, and conditions for staff, I will concentrate on their findings with respect to the occupational life of long stay residents with mental illness.

Self Care Occupations and Routines

The daily routine of getting up, showering, eating and going to bed was similar from hospital to hospital. Unless people needed help, they were left to get themselves out of bed. Bathrooms were generally supervised even for those who did not need assistance, and were often locked outside specific times of the day. Although residents could ask to use the bathrooms at other times, the fact that they had to ask staff to unlock the rooms limited their freedom of choice. Residents were permitted to wear their own clothes, and some were taken on supervised shopping expeditions to buy clothing out of their welfare benefit. For those who lacked the finances, pooled clothing was issued by the hospital. These clothes were often practical rather than fashionable, and at times were ill-fitting. Night clothes issued were generally identical throughout the hospital. Dowland and McKinlay (1985) expressed concern about this lack of choice, pointing to the importance of clothing in assisting people to express their individuality. Once dressed, many residents were expected to make their own beds, but sometimes the need to keep the wards tidy overruled the residents' attempts, and staff would feel obliged to remake beds to nursing standards (Dowland & McKinlay, 1985).

Meals were a major part of everyday life in the hospital setting, but residents were rarely involved in the occupations of selecting menus, preparing, cooking, serving the meals, or washing up. In the early 1980s, meals were usually prepared in a centralized kitchen and transported to the individual wards and villas. Mealtimes in each institution were arranged to fit in with organisational logistics and staff rosters. Consequently, if residents arrived late at breakfast time they usually missed out on that meal. In all cases, there was a very long break between the evening meal (usually served at 4.30pm or 5pm) and breakfast the following day. Some wards provided supper in the form of a biscuit or cake. Dowland and McKinlay (1985) pointed out that both the timing of the meals, and having the main meal in the middle of the day to accommodate staffing levels, were inconsistent with life outside institutions. Although the food was nutritious, residents had no choice about the menu, except in Kingseat Hospital in south Auckland, which was just beginning to experiment with giving people some choices. Given that this study was undertaken when the process of deinstitutionalisation was under way, the inflexibility of hospital routines was not helpful to those making the transition into the community, where people would need to structure their own day and make their own choices, often without support. Another consequence of timing meals to suit staff duties was that residents were often rushed, with some residents complaining that their plates were cleared before they had finished eating. In addition, residents were expected to move out of the eating area promptly, which limited the opportunity for meals to be a social experience.

At the end of the day, bed times were flexible unless people needed assistance. Staff had the final say, however, and would insist that some people stay up longer or go to bed earlier depending on their behaviour. If residents needed assistance or close supervision, they had even less choice, as they were dependent on staff fitting them into their workload

for the day. It was common for those needing help to be prepared for bed in the early evening, even though others did not get undressed until 10pm or 11pm (Dowland & McKinlay, 1985).

Leisure and Recreational Occupations

As has been discussed previously, it is important for our health and well-being to take part in occupations which have meaning and value for us. Interacting with family is an important ingredient in giving meaning to occupations for many people. In the hospital setting, interaction with family often consisted of the occupation of letter writing. Although in most wards there were good systems in place to enable residents to send and receive mail, Dowland and McKinlay (1985) found that some mail was not sent because the staff believed the content was incoherent. All hospitals had telephones for patients to use for local calls, but sometimes they were situated in buildings which were accessible only at specified times. This proved to be a major disincentive for people to keep in touch. In addition, over the years many residents had lost contact with friends and relatives and had no-one to call. In some cases, people who had been in hospital for longer periods did not know how to use a phone.

The most frequently performed recreational occupations were reading and watching television. Other leisure pursuits provided at the time of this study were often related to the particular hospital's treatment goals, as well as the training and background of the recreational staff. Many activities took place in the hospital recreation hall, and included occupations such as bingo, watching films or attending concerts. Participating in sports was also popular, as were ward outings. Many of these activities were available during the day only, so those involved in occupational therapy or work programmes during the day often

missed out on these recreational opportunities. Evenings and weekends were unstructured free times, when residents were usually left to initiate their own activities. However, Dowland and McKinlay (1985) commented that without considerable prompting, many people spent this time smoking and watching television.

Work Occupations

Most hospitals offered work programmes organised by their occupational therapy departments. This included work contracts undertaken by the more able, such as light assembly. Sheltered workshop tasks were provided for the less able, but people were still expected to produce goods which could be sold to defray costs. Carrington Hospital in Auckland had a particularly strong focus on work assessment and retraining in their industrial workshop, sewing and woodwork rooms. Cherry Farm hospital near Dunedin organized scrub cutting and gardening gangs to work in the community. In all cases, residents who worked generally received a small amount of money as an incentive. Their work hours were organized to fit in with hospital meal times, and people were often given lengthy breaks. The emphasis was on people participating rather than on the work ethics of punctuality, consistency and efficiency expected in the general population (Dowland & McKinlay, 1985).

Transition: Occupational Life in the Community

One of the major services available to people with long term mental illness is the provision of accommodation. As has just been described, in the past this used to be in the form of hospitals. When the large long term institutions gradually closed, however, they were replaced with supported accommodation in the form of small group homes, situated in

residential areas throughout New Zealand (Sheerin & Gale, 1984). As some of the

participants in my study talk about their experiences in group homes, I will briefly describe

this form of community based accommodation.

The intention in providing a variety of group homes in the community was to enable

people to be placed in a level of care which corresponded to their needs. One of the key

factors in deciding where people were to live, provided their risk to themselves or others

was small, appeared to be where the individual chose to live. Also important was the

existence or lack of legal options open to staff who may disagree with their choice

(Regional Coordination Service, 2003). Group homes are funded according to the level of

care which they provide. There are five levels of care which range from in-patient

rehabilitation to homes in which there is only brief daily supervision from non-clinical

staff. This latter level is offered to people who need some assistance with budgeting and

working towards their goals, but are able to take care of most of their household and

rehabilitation needs either on their own or with the support of the other residents in the

group home. It should be noted that although government documents and health workers

often describe group homes as accommodation in the community, this view is not always

shared by people with mental illness. It will be seen that some of the participants in this

study regarded their time in group homes as part of their hospital experience.

Given the small number of studies carried out in New Zealand, I also searched for

literature about the experience of deinstitutionalisation in Australia. A substantial and fully

documented ethnographic study undertaken by Newton et al. (2001) in the 1990s was

particularly informative. The deinstitutionalisation process in Australia had started in the

1960s, but only reached its peak in the 1990s, much later than in New Zealand. The

researchers were participant observers from 1993 to 1996 of a group of 47 people. They

observed the group during the last six months they spent in their long term hospital placement, and for the first two years they spent in four group homes in the Sydney community.

Newton et al. (2001) described the process of change which the residents experienced as they progressed through the transitional phases of leaving a large institution. This included initial delight and shock at the freedom they had in everyday occupational choices, such as making hot drinks whenever they wanted to, and being able to return to their rooms at any time of the day. A settling in period followed, with one residence experiencing a number of incidents which led to two residents being readmitted to hospital. However, most people made the adjustment and celebrated the first year with parties. Staff were able to be less directly involved in people's daily care, although group outings rather than individuals acting independently were still the norm. The number of staff required had reduced, and Newton et al. described the change in the staff role from initially being one of providing close supervision, to later becoming more rehabilitative in nature.

Community Living in New Zealand

Although the Newton et al. (2001) study concerned itself with people in group homes, it nevertheless confirmed the issues experienced in the first years following deinstitutionalisation in New Zealand. At the same time that Dowland and McKinlay's (1985) study of hospital life was being undertaken, two other New Zealand studies explored the everyday experiences of people who had been recently deinstitutionalised. I will briefly describe the methods used in these studies by Sheerin and Gale (1984) and Ng and McKinlay (1986), and then compare their findings with those of the Dowland and McKinlay (1985) hospital based study.

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Sheerin and Gale (1984) explored the transition of a randomised sample of 111 people from Christchurch's Sunnyside Hospital to the community. A third of the group had been living in the hospital for at least five years. A pre-tested interview schedule was administered by trained interviewers to 34 people living in group homes, 20 in boarding houses, and 39 living in private accommodation. With the permission of the participants, 59 friends and family members were also interviewed. A structured questionnaire was completed by 93 of the health professionals supporting this group of people. The detailed documentation of this study leaves an audit trail which suggests its findings are credible. It presented a valuable description of life for people who had been recently deinstitutionalised.

In 1986, Ng and McKinlay reported on a comparative study they had undertaken of 98 people who had been discharged from Cherry Farm hospital between December 1982 and December 1983. They used a convenience sample of adults who were discharged to live in Dunedin. All 98 people were interviewed by a social worker not known to them. In addition, 34 hospital staff returned case study questionnaires about 40 of these participants, who were also assisted to complete a case study questionnaire. It is this exercise which formed the basis of their comparative study.

In contrast to the Sheerin and Gale study (1984), a greater number of the people in Ng and McKinlay's (1986) study (45%) lived in flats or homes owned by themselves or their family, 28% lived in rental or boarding houses, and only 21% lived in group homes. The researchers did not make it clear why they chose to classify rental and boarding houses together. Although both rental and boarding accommodation have lack of ownership in common, there are obvious differences in the living situation with respect to household

responsibilities, and possibly in terms of leisure occupations. This study's findings are nevertheless similar to those of Sheerin and Gale (1984).

Self Care Occupations and Routines

In both of these studies, few people with mental illness considered they had problems with household occupations such as cooking, cleaning and doing the laundry. However, Sheerin and Gale (1984) pointed out that many did not participate in these occupations any more than they had in hospital. These responsibilities were undertaken by staff in group homes and boarding houses, or by other family members at home. Most health professionals believed that the majority of the consumers performed their personal self care occupations adequately. One difference from hospital life expressed by some people was that they now had greater freedom to choose when and how they carried out these occupations.

Leisure and Recreational Occupations

People in both studies listed their main leisure occupations as watching television, reading, going for walks, and going to the shops. Knitting and sewing also featured strongly in the Sheerin and Gale (1984) study. It is interesting to note that these occupations were the same as the main activities observed in the hospital setting (Dowland & McKinlay, 1985). They were also activities which did not require the input of other people, involved little physical activity, and were cheap, which was important as lack of money was a concern for people in both community based studies.

Although they were able to choose their leisure occupations, 46% of people in the Ng and McKinlay (1986) study and 30% of those in the Sheerin and Gale (1984) study

indicated that they did not have enough to do, and were not receiving enough help with filling in their spare time. This opinion was echoed by family members and friends, but health professionals in the Christchurch study appeared to be out of touch with this aspect of their patients' lives. They believed that the majority of people (73%) did have enough to do. This was in contrast to the health professionals in the Dunedin study, whose opinions were almost identical to their clients, and who expressed views that there was a need for the creation of social activities training programmes.

As has been discussed, lack of contact with friends and family had been an issue for people in Dowland and McKinlay's (1985) hospital study. At the point of deinstitutionalisation, approximately 73% of people in the Dunedin study, and 40% of those in the Christchurch study, had moved in with family or flatmates. Despite this, 27% of the Christchurch group saw family members less than once a month, and 34% never had contact with friends. The Dunedin study's findings were similar. Hence it is not surprising that everyday social occupations such as going to the pictures, spending time with friends, attending parties and going to the pub, were listed as rare occurrences (Sheerin & Gale, 1984). Belonging to recreational and sports clubs was also uncommon. This too is not surprising. These occupations were not experienced in the hospital setting, and people in these studies indicated they lacked the confidence and skills to initiate new leisure occupations.

Work Occupations

Health professionals believed only 14% of the people in the Christchurch study would benefit from paid employment. At this stage, 15% were in full time employment, and a further 34% wanted part or full time employment (Sheerin and Gale, 1984). This

discrepancy between the perceptions of health professionals and people with mental illness about work were consistent with a large, longitudinal study undertaken by the Ohio Department of Mental Health. Over an eight year period in the 1990s, this study explored similarities and differences between the views of health professionals, family and 457 clients about clients' aspirations. It found that the most valued unmet need expressed in every year of the study was in the area of employment (Ohio Department of Mental Health, 1999; Watts, Lutz & Dunbar, 1998).

In comparison to the Christchurch study, 48% of those in the Dunedin study (Ng & McKinlay, 1986) were already in paid work. Given that both groups had similar backgrounds in terms of mental illness and length of hospitalisation, this difference is surprising. Neither study explained what assistance, if any, was available to help people to obtain employment. However, Sheerin and Gale reported that the Christchurch health professionals they surveyed did not believe many of their people were capable of holding down a job, and it was unnecessary for them to do so. It is reasonable to conclude that they therefore did not actively assist them to achieve their employment goals.

Occupations of People with Mental Illness Since the Mid 1980s

Having established the everyday occupations of people in psychiatric hospitals, and during the initial period following deinstitutionalisation, I intended to review what the literature revealed about the development of occupational choices and performance for people with mental illness in New Zealand since that time. However, once the initial deinstitutionalisation had taken place, no subsequent studies about this particular group of people appear to have been undertaken. Despite this, concern was expressed that insufficient resources were devolved into the community (Haynes & Abbott, 1986), and

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that insufficient services were being offered to people who lived in their own homes. For example, the Mental Health Commission (1998) recommended that more support and educational services be provided to people to assist them "to live well independently, including skills for self management and participation in, and integration with, the person's community" (p. 37).

Prior to the deinstitutionalisation policies, people with a mental illness were likely to experience lengthy hospital stays, sometime of more than ten years duration. Since the mid 1980s, however, hospitalisation periods have been much shorter, with most people staying less than three months, just long enough to alleviate their most acute symptoms (Ministry of Health, 1996). Consequently, much of the mental health literature in the last twenty years has focussed on people with serious chronic mental illness who have spent the majority of their time living in the community. It could be reasonably assumed that the dominant occupational habits and routines for this group were therefore those which they had learned in their own homes. Fitting into institutional routines will have required them to make only a temporary adjustment until returning home to their own familiar occupational routines once more.

In many cases, recent literature has not differentiated between those who were institutionalised long term, and those who were not. Occasionally a study has provided the average length of stay in hospital, but more commonly reference has been made either to the number of readmissions to hospital in the previous year, or to the length of time since a person had been diagnosed. This may or may not be an indicator that a person had been hospitalised for a lengthy period.

The focus of the literature has also changed. Studies since the 1980s appear to have concentrated on three areas: programmes to teach daily living skills, work skills, or

personal social skills; narratives of recovery; and an exploration of the best way to organise

mental health services to meet the needs of particular groups. With respect to mental health

services, deinstitutionalisation changed both government and public perceptions about the

type of services which would best meet the needs of people with serious mental illness.

There seems to have been some agreement that people needed a variety of services to assist

them with their medical, social and welfare issues with living in the community (Anthony,

Cohen & Farkas, 1990; Mental Health Commission, 1998; Rebeiro, 1999). Negotiating the

labyrinth of services and the bureaucratic procedures to access these has sometimes been a

cause of stress and frustration for people (Rebeiro, 1999). However, the proliferation of

non-government organisations which provide support services in the community, together

with case management services, in which each person is allocated a primary case worker,

have both contributed to a reduction in hospital readmission rates to hospital. In some

cases, these improved community services appear to have resulted in increased employment

or social activity rates (Anthony, Cohen & Farkas, 1990). For example, one controlled

study of a case management model carried out by Goering, Wayslenki, Farkas, Lancee and

Ballantyne in 1988, demonstrated that when a specific case management intervention

process was used, people showed improvements in their self care, leisure and work

occupations compared with a control group (Anthony, Cohen & Farkas, 1990).

This understanding of the benefits in structuring services to meet the unique needs

of individuals arose at the same time as the emergence of recovery issues and the

development of skills training programmes. These will now be discussed in more detail

with a view to uncovering an understanding about the everyday occupations of people with

serious, chronic mental illness. However, it is important to note that it is not clear whether

those who were institutionalised long term were among the populations being described.

Occupational Skills Programmes

Although health workers acknowledged the importance of occupation for people with mental illness in the 1850s, it has only been since the 1980s that there has been a concerted attempt to measure the effectiveness, especially cost effectiveness, of specific rehabilitation programmes. In this section, I will not be discussing the individual merits of these programmes, but will concentrate on the type of occupational skills being taught, and how it was known that these were occupations which were valued by people with mental illness. In all cases, the studies under consideration were those targeted at people with serious chronic mental illness, that is, those with the Axis I or Axis II diagnosis from the DSMIV described in Chapter 1 of this study.

In 1990, Anthony, Cohen and Farkas undertook a major review of psychiatric literature to complement previous research by them (Anthony, 1979; Anthony, Cohen & Cohen, 1984). They concluded that people with serious, chronic mental illness could benefit from skills training, provided this was in conjunction with other supports. They also concluded that the development of consumer and family movements since the 1970s had played a large part in empowering individuals and families to make changes in their personal and family lives. The authors emphasised the importance of developing measurable and accountable programmes, with clearly defined goals agreed to by the individual receiving the assistance, and with each person's responsibilities in giving or receiving skills and supports equally well defined (Farkas, Cohen & Nemec, 1988). They recommended the adoption of the psychiatric rehabilitation approach which they had developed at Boston University. This approach concentrated on giving people the skills and supports they needed in four areas: living (accommodation and daily living skills), working, learning and socialising. Given that Anthony, Cohen and Farkas (1990) worked in

close conjunction with self help groups, had constantly reviewed contemporary literature, and had tested out their theories in practical programmes, their conclusions are likely to be an accurate reflection of the needs and desires of people with mental illness.

Whether programmes are well measured or not, it does appear that many people with chronic mental illness want help in the areas of accommodation, social skills, and training or work described by Anthony, Cohen and Farkas (1990). These categories fit well with the occupational therapy literature classifications of occupations of self care (accommodation), leisure (social skills) and work (training or employment) (Canadian Association of Occupational Therapists, 1997). My own anecdotal experience in New Zealand has reinforced the significance of these issues in people's lives. In 2002, I was employed by a non-government organisation which offered support to 125 people with mental illness living in the community. An informal survey of their files revealed that of the four categories created by Anthony, Cohen and Farkas (1990), living skills were of the least concern. In some cases this was not because the individual was confident or competent in their personal grooming or household chores. Some people did not acknowledge their lack of skill, whereas others did not value improving their level of skill. In many cases, other members of the household were responsible for occupations such as meal planning and preparation. Social occupations, however, were valued by 28% of people, who wanted help to participate in a range of leisure activities. A key goal was to make friends with whom they could share leisure pursuits, and 8% wanted to participate in occupations which would help them to find and form relationships with a life time partner. Training was important to 11% of people, who wanted to improve their skills in personal communication and self esteem to enable them to participate more confidently in their chosen social occupations. A further 8% expressed a desire to undertake formal education. As with the studies carried out

in New Zealand in the 1980s (Ng & McKinlay, 1986; Sheerin & Gale, 1984), and in the United States in the 1990s (Ohio Department of Mental Health, 1999), the most important issue for which people wanted help was in the area of paid employment. Forty-five per cent wanted to obtain part or full time work, or to increase their hours or change the type of work they were currently doing. As a consequence of this survey, the non-government organisation has developed strategies which will either involve people in their chosen occupations, or give them the requested training and skill development to work toward their occupational goals.

Recovery Related Occupations

Patricia Deegan, a leading writer about the personal experiences of recovering from mental illness, described the term 'recovery' as the process of "recovering a new sense of self and of purpose within and beyond the limits of the disability" (1988, p. 150). According to Ralph (2000) in her extensive review of recovery literature, there has been debate among people with mental illness regarding the suitability of the word 'recovery' to describe their experiences. She noted that it was nevertheless the word in common usage at this point. The literature reviewed by Ralph included descriptions of recovery as a complex journey with many struggles, as an attitude and belief that bad times would pass, and as a spiritual reconnection with oneself as a human being. Ridgway (2001) used grounded theory methods within a narrative framework to explore the recovery processes which people experienced over time. Her findings mirrored those of Ralph.

In New Zealand, a recent publication by Leibrich (1999) typified this literature. "A Gift of Stories" contained the personal accounts of twenty-one New Zealanders diagnosed with mental illness who had learned to be active in their lives and their communities.

Although some people described their experience of frequent hospitalisation, none of them appeared to have been part of the institutionalisation/deinstitutionalisation era. For those who contributed their stories, recovery did not necessarily mean an absence of symptoms or illness. However, each described a journey from when the illness dominated his or her life to a point where they were able to participate in occupations of their choice once more. Feelings of hope, and plans for the future, had overcome feelings of despair. For example, after describing in detail his traumatic experience of being locked in a hospital room when he was acutely unwell, Toby Adams stated:

> I did eventually get out of the room, and it was a start of a life that has been challenging and exciting. It is a life that I did not plan to have, but adversity has made me stronger … I am now working closer with the consumer movement and have taken on board Christianity.
> (Leibrich, 1999, p. 73).

In the past, many health professionals, family members and people with mental illness did not believe that recovery from chronic mental illness was possible. Recently, however, some researchers have argued that complete recovery from mental illness is possible. Harding et al. (1987) reported the results of a 32 year longitudinal study carried out in Vermont. Patients from the Vermont State Psychiatric Hospital who were selected for the study in the mid-1950s had been mentally unwell for an average of 16 years, and hospitalised continuously for six years. Thirty-two years later, 34% were reported to have recovered fully both in psychiatric terms and in social functioning, with a further 34% having made considerable improvements in both areas. The researchers defined recovery as having no remaining symptoms of illness, receiving no medication, being in paid employment, socialising with friends, and not behaving in any way which would enable others to detect they had been hospitalised for mental illness.

When asked to identify the factors which had assisted in people's recovery, some people mentioned occupations such as: eating nutritiously, socialising with close friends, participating in spiritual occupations, and occupations which they personally found relaxed them or developed their creativity (Ralph, 2000). These occupations were similar to those described in an extensive narrative study of forty New Zealanders who self identified as having recovered from a disabling mental illness (Lapsley, Nikora & Black, 2002). A key element to people's recovery was their understanding of the importance of personal agency, that is, a belief "that one can control, or at least influence, the circumstances of one's life" (p. 72). Most of the participants no longer used psychiatric medication, and had not used mental health services for the previous two years. Beneficial occupations which participants identified as assisting them on their journey to recovery included: reading and learning about illness and alternative remedies; talking with other people about their experiences; exercising; and eating in a more balanced way. They acknowledged the importance of developing more healthy occupational habits and routines, and the helpfulness of repeating strategies which worked.

Attention to the social environment was also an important factor in the recovery of people in the Lapsley, Nikora and Black (2002) study. As part of the process of taking charge of their lives, many appear to have either maintained and built on existing relationships, or developed new ones. Some people moved to be geographically closer to their families. Others found support and friends by increasing their networks, changing their attitudes with respect to relationships, and joining consumer organisations, or groups which supported their cultural or sexual identities. At the time of being interviewed, two-thirds of the participants had a partner, and a similar number had children.

From these studies, it would appear that people recovering from mental illness acknowledged the effect of their occupational choices on their health and well-being. It also became apparent that, while each person found his or her uniquely individual path to recovery, there were commonalities in their experiences, in line with the continuum described earlier in this chapter (Hasselkus, 2002).

Everyday New Zealand Life and Attitudes from 1980s to Present

The literature reviewed in the last section examined what was known about the everyday lives of people with a mental illness, particularly those living in New Zealand. However, both the people whose experiences were described in this literature, and the participants of this study, were members of a wider New Zealand society. In this section I intend to provide some background information about the typical everyday life and expectations of the general New Zealand population since the 1980s. Obviously, a treatise on life in New Zealand (or any other country) could fill several volumes. The particular topic areas I have selected to consider are the two which appear to relate most directly to the participants of the study. I will start with what is known about New Zealanders' occupational lives. This will be followed by discussing attitudes to mental illness.

Everyday Occupations in New Zealand

Earlier in this chapter, it became apparent that the major occupations for many people with mental illness, both in hospital and soon after their discharge, consisted of watching television, reading and walking, with some in paid employment (Dowland & McKinlay, 1985; Ng & McKinlay, 1986; Sheerin & Gale, 1984). To compare these

occupations with the general New Zealand population, I referred to government publications for the relevant national statistics.

Paid Employment

Employment and unemployment rates have been measured both as part of the five yearly population census, and by the three monthly Household Labour Force Survey. These documents show that the percentage of the working population who were unemployed and actively seeking paid work in 1986 was 4.7%. This rose to 9.8% in 1991, remained at that rate in 1996, but has fallen back to 4.7% in 2003 (Department of Statistics Te Tari Tatau, 1992; Statistics New Zealand Te Tari Tatau, 1997; Statistics New Zealand, 2003).

According to the 1989 New Zealand Values Survey (Gold & Webster, 1990), nearly half of those surveyed stated that they worked because work was interesting. One in three stated that they worked for the money, and one in five considered work to be central to their lives. In 1989, those surveyed valued job security, good pay, interesting work and pleasant work colleagues, more than achieving worthwhile things, or increasing their skills.

Leisure and Recreational Occupations

In contrast to employment issues, there do not appear to have been regular surveys carried out among the general New Zealand population with respect to the leisure occupations in which they engaged. The one survey which I was able to locate was the 1989 New Zealand Study of Values (Gold & Webster, 1990), which included a survey of a wide variety of social issues in addition to values about employment. Respondents were asked to name their three most enjoyed activities out of a list of eleven. The most highly valued occupations were as follows:

- Family activities 48%

- Visiting friends 46%

- Entertainment (TV, radio, music) 34%

- Sport (watching and participating) 32%

- Home and individual activities(gardening) 21%

- Reading 20%

- Hobbies and crafts 19%

- Home improvements 15%

- Individual outdoors (walking, hiking, rambling) 14%

- Cultural (theatre, films, restaurants) 13%

- Church activities 8%

It should be noted that this is what people valued most highly. It is unclear whether this is what people actually participated in, and does not analyse how actively they pursued their favourite occupations, or how much time was spent in each area of interest. It is also important to take into account the fact that this survey was undertaken in 1989, and people's valued occupations may well have changed in the intervening years. Since 1989, the New Zealand population has increased significantly, objects such as personal computers, video recorders and cellphones have become commonplace, and the number and variety of special leisure events has increased significantly in the Auckland area, which is where the participants in my study currently reside. Despite this, I believe the survey is a useful indicator.

The survey pointed out that there were some differences in valued occupations over a person's lifespan. For example, visiting friends was valued by more people in the 18-24

age group (70%), and this became a less valued occupation by the time people were in their fifties and sixties (approximately 30%). Family activities were valued equally highly by those in the 25-39, 40-49, and 50-59 age groups (54%), but by a smaller percentage in the 18-24 (38%) and 60+ (35%) age groups. Thus it can be seen that interaction with family and friends is reduced for the general New Zealand population once people are in their sixties. The value of sport and entertainment did not vary a great deal over the lifespan, but gardening was an occupation valued more and more as people increased in age (Gold & Webster, 1990).

The 1989 New Zealand Study of Values also examined concepts such as life satisfaction and happiness. Over 90% of those surveyed stated that they were happy with life, and over 80% believed they had freedom of control over their lives. The respondents were asked to rate on a 1-10 scale how satisfied they were with various aspects of their life: children, marriage, friendships, standard of living, health, sex life, leisure activities, housework, financial situation, and their life as a whole. They were very satisfied with the first five items, rating them at 7.5 or higher, and rated their life as a whole at 8.3. The items with the lowest rates of satisfaction were housework and people's financial situation (Gold & Webster, 1990).

Overall, the statistics indicated that many New Zealanders valued highly their paid employment and their relationships with family and friends. It is interesting to note that in the literature described previously, these were the areas of unmet needs among people with mental illness.

Attitudes to Mental Illness

People with a mental illness do not exist in a vacuum. They live in a society in which their actions may affect how others perceive and treat them. Similarly, society's actions and reactions impact on the people with mental illness. The results of this interaction may be positive or negative for the parties involved. It is therefore important to explore what is known about societal attitudes towards mental illness in New Zealand since the 1980s. One of the difficulties in doing this is that discrimination often takes place in private. A personal interchange between a person with a mental illness and an employer, landlord or shopkeeper may not be witnessed by others. There appears to be continuing anecdotal evidence that discrimination in these areas of everyday life persists, but very few instances have been publicly recorded.

As has been stated, there is evidence to suggest that, in the past, health workers believed that people with chronic severe mental illness were unlikely to recover to the extent that they could enter mainstream employment and participate fully in the everyday activities enjoyed by the general population (Ralph, 2000). Furthermore, some health workers have told me that it was previously considered advisable for people with mental illness to remove stresses from their lives. This underscored the need to avoid stressful situations such as joining social groups and paid employment. This may have been based on the treatment model philosophy in which the aim of workers was to reduce a person's symptoms, and removing stress was one method of doing this (Anthony, Cohen & Farkas, 1990). The prognosis for schizophrenia was described as recently as 1994 as being poor for at least 50% of people, with medication still being regarded as the "mainstay" of treatment, and other psychosocial initiatives being regarded as merely augmenting the benefits of medication (Kaplan, Sadock & Grebb, 1994, p. 481). Even the major proponents of the

psychiatric rehabilitation approach described as "new knowledge" ideas such as people with mental illness being able to identify realistic goals for themselves; and the role of health services being to improve and not just maintain client functioning (Anthony, Cohen and Kennard, 1990, p. 1249).

Discrimination against people with mental illness in the New Zealand workplace was not declared illegal until the advent of the Human Rights Act in 1993. Jobs in the government sector were not included until 2001. As Peterson (2003) pointed out, this did not mean that discrimination no longer occurred. It simply meant that people experiencing discrimination had a right of redress. There has been little research in New Zealand to quantify the amount of discrimination experienced in the workplace. However, the Mental Health Commission (1999) reported that submissions made to them by people with mental illness, and mental health agencies, listed discrimination as the major barrier to people with mental illness obtaining employment. Since the legislation in 1993, there have been few complaints laid under the Human Rights Act. Those that have been registered include: people being offered positions only to have the offer withdrawn once the illness had been disclosed; people already in employment being dismissed after disclosing that they had a psychiatric illness; and people being sidelined into less valued positions because of their illness rather than their work performance (Peterson, 2003). One of these complaints was from a person working as a consumer advisor in a mental health service. The fact that mental health services which are expected to promote acceptance of people with mental illness in the community (Mental Health Commission, 1998), have difficulty putting this into practice in their own workplaces, suggests that prejudice against people with mental illness continues to be a norm within New Zealand society.

The Mental Health Commission (1999) pointed out that some people were discriminated against by being stereotyped, receiving lower pay, and being restricted in the positions for which they were genuinely being considered by employers. They expressed concern that such discrimination may lead to people losing confidence in their own abilities. As Peterson (2003) pointed out, people with mental illness face an unenviable dilemma. If people disclose their mental illness, they may lose their job or experience discrimination. If they do not disclose, they run the risk of being dismissed because of their dishonesty.

Issues of discrimination and stigma are the subject of much discussion and consultation, with both national and local government mental health agencies taking the initiative to consult widely with people with mental illness and the non government agencies which serve them. This has resulted in numerous reports and proposals for improving services, and promoting more acceptance for people with mental illness in the community (Health Funding Authority, 2000; Ministry of Health, 2001; Northern DHB Support Agency, 2002). A national example of this is the anti-discrimination initiative 'Like Minds, Like Mine' which has been actively attempting to counter stigma since 1997, and includes high profile television advertising (Ministry of Health, 2001). Despite all these initiatives, the current reality for the participants is that they are likely to have to cope with discrimination in both the workplace and elsewhere in their communities for a number of years to come.

Summary

In this review of literature, I have explored the everyday occupational lives of people with serious, chronic mental illness. Links have been made between health and occupation. It has been argued that to achieve a sense of well-being, we need to have both enough to do, and choice in what we do. It is also important to have a balance of habits and routines which enable us to manage the regular activities we undertake, and leave us with sufficient energy and motivation to engage in more valued occupations. What we do and how we do it is influenced by our social and physical environment, both of which provide us with opportunities and limitations. We are also influenced by how we and those around us perceive the concept of time and the way time should be spent.

Psychiatric institutions in the middle of the twentieth century provided people with set routines, physical care, and a safe haven. Many of the household tasks and most of the decision making, however, were undertaken by staff members. Hospital residents had limited choices in what they did, and when they did it. Staff attitudes and interests, and hospital rosters and resources, all significantly influenced not only the range of leisure occupations available to residents, but also the opportunities for people to be engaged in work skills training.

Studies undertaken during the early 1980s indicated that people with mental illness were happy to have been discharged from institutional care to the community. Their occupational choice was still limited, however, with predominant occupations being watching television, reading and walking. At this stage, it appeared that others were continuing to take responsibility for household tasks and financial decisions. Also, many people were having difficulty with social skills, which limited not only their ability to make friends, but also to participate in social and employment activities.

Since the 1980s, the literature both in New Zealand and elsewhere has indicated that people with mental illness valued the same occupations as the general population: working, spending time with friends and family, and having a variety of leisure and socialising activities. There were indicators that, despite continuing evidence of discrimination against people with mental illness, it has been possible for some people to recover from their chronic illness to the point where they may live, work and socialise without others realising they have ever experienced a mental illness.

This review has attempted to track a particular group of people: those with serious, chronic mental illness who had been placed in long term psychiatric institutions and had been transferred to the community as a result of the deinstitutionalisation policies of the 1970s and 1980s. However, the trail appeared to run out in the mid 1980s. From this point on, reports of services and programmes have not differentiated consistently between those who were institutionalised long term and those who remained predominantly in the community. In addition, although studies mentioned general classifications of occupations undertaken, for example 'socialising', individual occupations were often not listed separately.

Despite an extensive search, I was unable to discover any recent studies which described the daily occupations of people with mental illness living in the community. Instead, the emphasis has been on people's stories about their individual journey of recovery. These stories described occupations related to achieving recovery, for example, reading about health, or learning yoga for relaxation. They also commented on what the person was doing now in terms of employment, volunteer work, and maintaining family relationships. However, those telling their stories appeared to be people whose experience of mental illness and recovery had taken place since the mid 1980s. We do not know about

the occupations of those who had not experienced recovery, or of the group who were

subject to the policies of institutionalisation and deinstitutionalisation. This gap in the

literature leaves unanswered questions about whether these people's everyday occupational

lives have developed since leaving hospital, what has influenced any changes, and how

their lives and aspirations compare with those of the general New Zealand population.

Exploring these questions is the focus of the chapters which follow.

Chapter Three: Methodology and Methods

All research needs to be described in sufficient detail that the reader can evaluate the reliability of the study and its findings. Given that by definition an interpretative study is a person's interpretation, it is essential that the lens through which the interpretations are made is clearly identified (Krefting, 1990). Part of this lens is formed by the life experience and professional background of the researcher, some of which was referred to in the introduction and presuppositions in Chapter One, and the literature review of occupational and mental health literature in Chapter Two. However, my interpretation is also coloured by the methodological underpinnings I have selected for the study and the methods used. For the reader to have confidence in the findings, it is important that there is a clear audit trail, which shows congruence between the research question, the theoretical perspectives underlying the methodological approaches used, and the application of the research methods (Burns & Grove, 1993; Rice & Ezzy, 1999). In this chapter I describe the methodological approach I have chosen and the reasons for that choice. This is followed by a detailed account of the research methods selected, and how these were applied in practice. I conclude with a discussion of the ethical considerations and Treaty issues which were taken into account throughout the research process, and other measures undertaken with respect to ensuring rigour in the study.

Methodology

As previously stated, I have selected a narrative inquiry approach for this study. This appears to be one of the first studies to examine the long term effects of

institutionalisation on people with serious, chronic mental illness, so I believe it should reflect the stories of the people themselves as much as possible, and the meaning which they attribute to their occupational choices and performance. I am also seeking to understand people's experiences in the community over a period of time. Reflecting stories about real life situations and their meaning over time are features of narrative inquiry (Clark, Carlson & Polkinghorne, 1997; Mattingly & Lawlor, 2000; Robinson & Hawpe, 1986).

The theoretical underpinnings of narrative inquiry are compatible with the position of occupational therapy which, as discussed in Chapter Two, situates the performance of everyday occupations in the context of people's understanding of their world and the socio-cultural environment and times in which they live (Canadian Association of Occupational Therapists, 1997; Christiansen & Baum, 1991; Kielhofner, 2002; Mattingly & Lawlor, 2000; Wilcock, 1998a). The stories we tell ourselves have a strong influence on our occupational lives. What we choose to do and how we choose to do it depends at least partially on our understanding of the sort of person we are, and the type of plots we believe are taking place in our lives (Kielhofner, 2002).

Narrative inquiry is an approach which enables us to gain this understanding of the meaning of events and experiences in the lives of human beings. It is based on the ontological premise that we "actively attempt to understand, to interpret, and to explain our lives" (Kirkman, 1999, p. 2). A narrative is made up of socially constructed words which describe socially constructed experiences. In constructionist theory, objects are neutral, and only develop meaning when we consciously think about them, and attribute meaning to them. This meaning is developed from our past and present experience of the world, which in turn has been influenced by the social environment in which we live (Lawler, 2002). In

the constructionist paradigm truth is not objective. Neither is it merely subjective. Meaning is not created, but is constructed from objects and experiences which already exist. It is therefore a result of the relationship between the person who is narrating and the object or experience which is being described. Another person, or the same person at a later time in his or her life, may construct a different narrative about the same event, because the experiences which can be drawn on will be different, and will change the relationship, and therefore offer a different social construction (Crotty, 1998; Polkinghorne, 1988). It will be seen that time is an important social construct not just because it influences the way in which we later attribute meaning to the narrative, but also because it influences the way in which we initially experienced the event or object (Crossley, 2000; Ricoeur, 1988).

Why People Tell Stories

Human beings tell stories for a number of reasons. It assists people to make meaning of their lives at any given time by expressing past events in ways which make sense to themselves and others. In telling their stories, people are able to position themselves in the social world in which they live (Lawler, 2002), draw meaning from their lives, and make deliberate decisions about how to live now and plan for their future (Frank, 2002a; Kielhofner, 2002). This is particularly relevant for people who have experienced significant periods of illness in their life. In addition to the debilitating nature of the illness, the processes involved in hospitalisation and treatment can often be devaluing and demoralising. Choosing to tell one's story, and having someone listen carefully and empathetically to it, can be an empowering experience for some people, and a helpful part of the healing process (Draucker & Hessmiller, 2002; Frank, 2000, 2002b; Kleinman, 1988). Telling stories is also beneficial for those of us who choose to listen, whether

directly as the interviewer, or indirectly as a reader of the written accounts. Each story either helps us to revisit a form of life we understand from our own experience, or gives us a glimpse into a world which is different to ours (Frank, 2000).

Truth in Stories

People use narratives to express an understanding of their world, and to make sense out of chaos, but this raises the question as to whether their stories are the truth. White (1981) argued that history, that is society's story, is the knowledge of understanding, and cannot be scientifically tested. It is at best a "plausible conjunction of all the available data about the event to be studied" (Wyatt, 1986, p. 197). It gives us insights into human events and the human condition. As with authors of formal history books, an individual's narrative is also a subjective selection and representation of experiences and events (Riessman, 1993). The truth lies in the consistency and context of what is written (White, 1981). For example, a clinician's view of chronic illness and that of the person experiencing it are often very different (Frank, 1995; Kleinman, 1988), but both add to our understanding of how cultures perceive illness, time and transition (Mattingly, 1998). In a comparison study of younger and older adults by Bluck (2001), it was found that both groups were accurate in remembering the core of emotionally charged autobiographical events. This suggests that a narrative study can be considered reliable when it accurately reflects the participants' meaning of events within the context of the person's world (Polkinghorne, 1988; Riessman, 1993).

In this study, some participants have commented extensively about their interaction with mental health workers or aspects of the mental health system. As the participants placed themselves at the centre of their stories, the truth which was being represented was

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their experience of an event. For example, Jean explained how her first hospital admission came about. "I was first in it in 1969, in [Hospital G] because of a beating from my first and probably only boyfriend, which the staff never questioned. Never questioned as to that beating. Never questioned why I had the bruises."

This was Jean's understanding. Her psychiatrist may well have told a story about the issues most relevant to him, for example, her signs and symptoms of mental illness. Her family may have told a story about what was uppermost in their minds, perhaps about Jean's behaviour and not knowing how to respond to it. We do not know these things, because this is Jean's story. She has told us the two themes in this account which were most significant to her, namely, that she had been treated badly by a person she trusted, and that people in authority did not value her opinion. These two themes were true to her view of her life, as they continued to be evident in other anecdotes throughout her interview.

Personal Stories in a Social and Temporal World

Stories are told in a relationship with the listener, that is, the particular person who hears the stories first hand. The participants' stories and the meaning they attribute to them will have been constructed within their range of socially constructed language, according to their experiences, within their social environment. What they say and how they say it will also be influenced by their interaction with the researcher (Bruner, 1990; Riessman, 1993). The story teller is aware of his or her audience, and consciously or unconsciously shapes the story in response to the message he or she wants that particular listener to hear. The telling of the story is also influenced by the listener's verbal and non-verbal relationship with the story teller (Frank, 1995; Frid, Ohlen & Bergbom, 2000; Kielhofner, 2002; Mishler, 1986b). The researcher in turn constructs meaning from these interactions based

on his or her own socially constructed world and use of language (Bruner, 1990; Riessman, 1993).

Every story is also embedded in the wider social, political and historical environment in which it took place, linking the individual with the collective voice (Lawler, 2002). The complex and multiple aspects of our environmental context influence not only what happened to the story teller, but also what significance he or she may give to individual events and experiences (Crossley, 2000; Riessman, 1993; Schwandt, 1994). Even the language used to tell the story provides opportunities and boundaries to the description of the experiences, and reflects the story teller's social positioning (Kenyon & Randall, 2001; Ricoeur, 1980; White, 1981). Consequently, a story told to one person may not make sense to another unless there is a shared understanding of language, and of the wider cultural, social, political and historical context (Bennett & Detzner, 1997; Fitch, 1998). It is therefore important for the reader of studies using a narrative inquiry approach to have an understanding of the social contexts of both the participants and the researcher (Frid, Ohlen & Bergbom, 2000). Accordingly, in addition to presenting the participants' words in numerous excerpts in the chapters which follow, I have also described the values of the general population of New Zealand in Chapter Two, which is the wider social context for myself and the participants.

Although the story teller is generally the central character of a story, the events of the plots are often concerned with their relationships with other people, and with social norms and expectations in the story teller's world (Lawler, 2002). The way of knowing, or ontological perspective, of a narrative approach is therefore one in which reality and truth are relative and contextual (Martin-McDonald, 1999; Mishler, 1986a; Schwandt, 1994). For example, the hospital institutionalisation that the participants in this study experienced

needs to be judged within the positivist, clinical context of the mid to late twentieth century. At this time it was believed that the best way to experiment with drug treatments for people with mental illness was to create as close to a controlled environment as possible. It was from within the boundaries of this 'truth' about their environment that people developed their identities and attributed meaning to their stories (Lawler, 2002). This study is being undertaken within the post modern world context of 2003 in which individuals' experiences and opinions are often valued as much as those of mental health professionals. This 'truth' will undoubtedly have influenced the way people see themselves now, as well as the way they now tell their stories of the past.

The era in which the events and the storytelling take place is just one influence of time on the story telling. Scientifically, time consists of constant chronological intervals calculated from the angle on which the earth turns on its axis (Schwarz, Davidson, Seaton & Tebbit, 1992). However, the passage of time can also be experienced subjectively. It may expand or contract within the storyteller's context of their occupational experience (Crossley, 2000; de Vries, Blando, Southard & Bubeck, 2001; Ricoeur, 1980). For example, a thirty minute dental appointment is likely to be experienced as a much longer period of time for the patient than for the dentist.

Narrative Typologies

Narratives are considered to be a way in which we make order of our lives (Crossley, 2000). Some authors have also made sense of narratives by grouping similar ways of telling stories into narrative typologies. I will briefly describe two such classifications. Firstly, I will describe the narrative categories used by Gergen and Gergen (1986). These categories could be applied to stories told by anyone. They provide a

foundation of understanding of how human beings in general construct meaning in their lives. This foundation is a useful background from which to consider Frank's (1995) more specific narrative categories, which are particularly relevant to this study, because he attempted to classify the stories of people whose lives had been disrupted by serious illness.

For Gergen and Gergen (1986), a person's goal was central to the story he or she told. They described three basic narrative plots which they believed were common to most people's stories of their lives. In the progressive narrative, the story teller progresses successfully through struggles towards his or her goal. In the stability narrative, he or she makes no movement from the beginning to the end of the story in relation to the goal. In the regressive narrative, the story teller moves away from his or her goal, that is, experiences a deterioration in his or her position. Gergen and Gergen argued that one story may involve more than one of these plots. For example, they described the tragic narrative as a story which occurs when a person moves suddenly from a progressive to a regressive plot. The opposite may also occur. A sudden shift from a regressive to a progressive narrative is likely to result in an outpouring of emotional release, which Gergen and Gergen termed a comedic plot. The 'happily ever after' or romantic plot, is the combination of a progressive followed by a stability narrative.

These themes of progression and regression appear to be evident to some extent within Frank's (1995) illness narratives. Illness and trauma are sometimes regarded as interrupting our life narratives (Draucker & Hessmiller, 2002). However, Frank would argue that the narratives continue in a different form. He categorised people's experiences of illness under the headings of restitution, chaos and quest narratives. In the restitution narrative, the story teller responds to societal and medical expectations that health is normal, and is therefore to be recovered. In this story, the person tells a tale similar to

Gergen and Gergen's (1986) regressive/progressive narrative. He or she recounts a journey into temporary unwellness, but has a goal and expectation of restoring good health in the future. The progression to good health will not be a consequence of the person overcoming struggles, however, but of the medical world taking charge and producing treatment or a cure. Frank (2002b) expressed the view that western societies regard being in control as "good manners as well as a moral duty" (p. 58). In this social environment, illness is therefore a sign that a person has lost control of his or her body, and carries with it the stigma of having failed morally. It then becomes the moral duty of physicians to restore the body and regain control on behalf of society.

In contrast, Frank's (1995) chaos narrative recounts a story of illness as a permanent feature in the story teller's life. This story always involves numerous anecdotes of insults to body and soul, of suffering and abuse. This may leave the person in a constant state of chaos and uncertainty, wondering about the timing and nature of the next disaster. This seems to me to be a turbulent form of Gergen and Gergen's (1986) stability narrative. Both Frank and Kleinman (1988), another doctor concerned with the effects of the illness experience on people's lives, argued that the chaos story is challenging and uncomfortable for the listener to hear. This is because it does not fit the optimistic 'happy ever after' scenario we are used to hearing. They believed that for this very reason it is important that this type of narrative be listened to carefully, and be treated with particular respect.

The third type of illness narrative which Frank (1995) described was the quest narrative, which appears to be an elaborate form of a progressive narrative. Unlike the restitution narrative, the story teller is the hero of the quest narrative. No matter what adversities may occur, the hero will win in the end in some form. Frank argued that the quest generally involves three stages. The first stage is a departure on a journey, which is

often signalled by the first symptoms of illness. The second stage is the journey along a road of challenges, and involves significant periods of physical, emotional or spiritual suffering. It is during this stage that the hero is rewarded with treasure from the quest, for example, in the form of increased life experience and personal awareness. The third stage is the end of the illness, at which point the hero is changed forever. It is at this point that a person is most likely to become involved in using the new found understanding of illness and suffering to help others.

Gergen and Gergen's (1986) narrative categories describe the trials and tribulations of everyday people leading everyday lives. Frank (1995) has argued that when people face significant illness, these story plots may change to form somewhat different patterns. It will be interesting to see which, if any, of these narrative types describe the stories of the participants of this study.

Elements of a Story

Central Character and Plot

Traditionally, a story of fiction contains a beginning in which the central characters and settings are introduced, a middle in which the central plot unfolds and often reaches a climax, and an end in which there is a resolution of the plot, and the moral to the story. Narrative inquiry assumes that the story teller is the central character and expert of his or her life story (Turner, 1981). As with fictional accounts, a person's story in a narrative study also contains a beginning point, a middle section and an end, which often contains a moral (Frank, 2002a). However, in narrative studies, people tend to tell their stories in ways which have meaning for them. This may not be as an ordered chronological, or even thematic, account (Frank, 2000; Molineux & Rickard, 2003; Riessman, 1993). In addition,

experiences in life overlap, and yet need to be written in a degree of order for the reader to make sense of them (Frank, 2002b). The plot may therefore need to be compiled, or emplotted, by the researcher. This involves making sense of the scattered parts, identifying patterns and creating expressions of meaning over time (Kirkman, 1999; Polkinghorne, 1988; Ricoeur, 1980).

Beginning and Ending a Story

As previously explained, people do not always tell a story in a chronological order. Each person recounts events in ways which have meaning to them. As a result, they also begin their story where it makes sense to them (Riessman, 1993). In this study, for example, Anthony answered a question about his daily household chores by placing it in the context of what happened both before and after. His story started with waking up, that is, before undertaking his chores, and finished with what he did after his chores. Italics have been used to denote the emphasis he placed on some words.

> Now the other thing is that I have to do my duties every morning. When I wake up, I usually have a cup of tea or cup of coffee and some toast. We like having eggs for breakfast, the ones where you sort of have the egg in the cup? You cut the top off and dip the toast into it. We love that. It's one of our *favourites*. And, um, then, ah, I do my duties and by about 9.30 I'm ready to leave the house and then we either go out to church or we, um, visit the pools.

In contrast to Anthony, Martyn indicated that he wanted to start his story before the time of my question by saying, "Do you want me to go further back than that?" He often ended by stating he would go into more detail later: "And I'll explain that to you later"; "And I'll explain more of that when we get along"; "And I think that was one of the reasons why, *and* some other contributing reasons, which we'll go into later on then". In contrast Anne used words more sparingly. She started her responses at the point of the question, and

indicated she had finished by saying "mmm". In response to being asked how she learned

to do the things she was doing, Anne responded:

> Anne: Well, they taught us to budget at [government mental health agency]. Taught us how to budget and what to do, mmm. I think in life you're brought up with your family, you know, and taught you how to cook and wash and that.
> Researcher: Your family taught you to do these things?
> Anne: Yeah. Nice indeed. If you're a mother you'd have taught your daughter to cook, wouldn't you? And that's quite normal. Mmm. (Pause).

The Moral of the Story

When people tell stories they are making moral judgements, and as we have seen,

often describe a story in terms of good overcoming evil or struggles, or affirming their

beliefs and values as being the source of strength to help them overcome a perceived threat

(Kleinman, 1988; Ricoeur, 1988; White, 1981). This moral or 'point' of the story is as

essential an element to a narrative account as the characters and the plot (Lawler, 2002).

The moral is the reason for telling the overall story. It affirms what matters to the person in

relation to how he or she has lived his or her life (Frank, 2002a). A single anecdote or event

may in itself not appear to have a moral. However, when the researcher places it within the

context of a number of events and anecdotes, each informs the other, and meaning is often

derived from the synthesis of the whole (Bruner, 1990; Lawler, 2002). Key elements of

stories are often repeated in the storytelling. The event or type of anecdote which is

recounted most often and most cogently by the story teller is usually an indicator of what

matters most to the story teller, that is, it reveals the point of the overall story (Draucker &

Hessmiller, 2002). The end thus serves to make a judgement about the story. But it also acts

as the beginning of another story, and forms the basis of the next life goal (Ricoeur, 1980).

A narrator is a person who tells other people's stories. I have had some misgivings about my right as a narrator to interpret the experiences of other people's lives. However, this question is not new to narrative literature. An important role of the narrator is to place the stories in a wider context of which the story teller may not be aware (Frank, 2002a; Frid, Ohlen & Bergbom, 2000). As a researcher, I also have a responsibility to use my academic and professional background to make sense of the stories individually in terms of plot, and collectively in terms of themes (Molineux & Rickard, 2003). By using extensive excerpts from the story tellers' own words, describing the socio-political context in which the stories unfolded, and telling some of my own story, it is hoped that my interpretations will be judged for what they are: a synthesis of all these parts.

Methods

Number of Participants and Selection Criteria

In narrative inquiry, the researcher needs sufficient participants to enable a richness of data, including similarities and differences in people's stories and experiences. However, one also needs to be conscious of the depth of information which each participant's contribution may generate (Rice & Ezzy, 1999). Taking these issues into account, as well as the practical time and resource limitations inherent in a Master's degree thesis, I decided to recruit a purposive sample of between six and ten participants who met the following criteria:

- Currently living in the greater Auckland area (for convenience)

- Had spent at least five years living in a New Zealand psychiatric institution because of a mental illness (not an intellectual disability)

- Currently living in the community, that is, on their own or with family members, sharing a flat, or in private board. Excluded were people living in designated mental health group homes where significant staff support and input was available on site. As previously described, this latter group's experiences of everyday living were likely to be different, and may be the subject of a future study.

- Had sufficient conversational English to tell their stories without being hindered by language difficulties. It was anticipated that most people who had spent five years in a psychiatric hospital in New Zealand would meet this criterion.

- Male and female, Maori and Pakeha (of European descent) participants of any age, to reflect the populations of psychiatric hospitals at the time of deinstitutionalisation in the 1970s, 1980s and 1990s.

This study may be considered to be limited by confining the sample to those living in greater Auckland. The eight participants who volunteered for the study, however, had between them experienced life in six different psychiatric hospitals or units in the greater Auckland area, four units in other parts of the North and South Islands, as well as psychiatric units in Australia and Great Britain. Some had also experienced short periods in community respite homes, and five had lived for periods in supervised group homes. They were aged between 35 and 66 years at the time of the interview. Martyn described himself as part Maori, and Frank as Maori European. Terrie was born in Australia and Jure in Eastern Europe. Brett, Anne, Jean and Anthony were of New Zealand European descent. From their stories it emerged that six of the eight participants had been born outside the

Auckland region. They had been brought up in a variety of rural and urban settings, and came from a range of socio-economic backgrounds. Their current circumstances and the events which had evolved in their lives were also diverse. Hence, despite the limited geographical catchment area, the study reflected a rich diversity of participant experience.

In designing the sampling criteria, I thought I had defined the parameters clearly, but it became apparent that the concept of unsupervised accommodation was not so easy to define. The very first potential participant, Anthony, was living in a Level Two home, that is, a home which received funding for providing support to people with a serious mental illness. On the surface, this would appear to disqualify him from the study. However, Anthony was making many of his own occupational choices and decisions, and was predominantly responsible for his own self care, leisure, and some aspects of daily living. He was able to come and go as he pleased during the day, although I suspect there may have been rules about night time curfews. His interaction and obligations to the other residents of the Level Two home appeared to be similar to those of people who live with flatmates. From his description, the role of the staff who worked there appeared to be similar to that of a visiting health worker, rather than that of a supervisory staff member. In addition, he stated that there were plans for him to move into his own accommodation within a week of the interview. These factors appeared to suggest that Anthony met the criteria of living in community. He was therefore included in the study.

Another criterion which proved to be more problematic than anticipated, was the requirement that people had spent at least five years in a psychiatric hospital. One of the first questions I asked, both at the time of recruitment and at the beginning of the interview, was how many years a participant had spent in which hospital. This was intended to be a simple demographic question. However, six of the eight participants appeared unsure of

when and how long they had been in hospital. Anthony could remember he was in [Hospital A] for five years, but only that he was in [Hospital B] for "several years". Brett was in and out of [Hospital A] "on and off" between the ages of 23 and 47 years. After further discussion, it became apparent that he had spent more time in hospital than out of it, but for him the entire 24 years was when he was in hospital. Anne remembered being in [Hospital A] for four months in total, but her husband was adamant she had been there for eight years in a block. He based this assertion on the fact that he had been in hospital with her for a similar length of time. He was very precise about many dates in their lives, and showed paperwork to back up some of them (for example, obtaining his driver's licence, date of arrival in New Zealand). This gave credibility to his version of their length of stay in hospital. As will be seen later, some of the participants viewed the entire period of contact with mental health services as being in hospital, until asked for further clarification.

Recruitment Strategy

Intended Strategy

As stated, I had limited the sample to people currently living in the greater Auckland area. I initially intended to recruit participants by:

- Inviting people from the more than thirty consumer networks in the area to attend public meetings at consumer-friendly venues.

- Displaying notices in government and non government mental health service centres, and discussing my study with key staff in these services.

- Displaying notices in drop-in centres and other 'non-mental health' community centres.

- Advertising in the local community newspapers.

- Encouraging snowball sampling, that is, where one participant suggests another who may meet the criteria (Rice & Ezzy, 1999).

The use of such multiple methods is sometimes described as triangulation sampling, which is considered more trustworthy than using a single sampling method (Rice & Ezzy, 1999).

Actual Strategy

As I made contact with different community groups, it became apparent that it was more effective to talk to individuals and groups than to call public meetings. This was because each staff or consumer group already had their own meeting times and venues. Communication was assisted by the fact that I was personally known to some groups and individuals. Some people who were not known to me became interested in the study when they realised I had experience of working within the community mental health services in the Auckland area. My initial approach to groups resulted in a predominantly warm reception, with comments made that the topic was important and valuable. However, most of the individuals and groups I approached did not know people who met the criteria: either they or people they knew had not spent longer than three years in a psychiatric hospital, or people were living in supported accommodation such as group homes.

I had stated in the application for ethical approval for the study that I would not make direct contact with participants until they had indicated they wanted to know more about the project. This meant that the intermediary people I approached were placed in a gate keeping role between me and the potential participants. Most people appeared to have embraced this role positively, with many giving the impression that they would pass the

information on to others. A few were excited, and immediately identified potential participants they intended to actively seek out. In one case, however, the response was positive at the time, but a follow up phone call revealed that the person concerned had misunderstood my intentions. She had somehow thought I wanted the workers to divulge personal information about the potential participants, which was not the case. My attempt to reassure her, that I only wanted the staff to pass on a copy of my poster for people to contact me if they were interested in participating, was unsuccessful.

In addition to personal approaches to more than thirty-five community or staff groups in the greater Auckland area, I placed posters (see Appendix B) in a number of community centres which I knew were frequented by people with mental health problems. I also left posters and information with organisations to place in their newsletters, or on boards in their resource centres.

Despite the warm reception to the concept of the study, the response to my initial approaches to recruit participants was poor, so I submitted an article for publication in the free community newspapers. I hoped that by doing this I would reach people who may no longer have contact with mental health services or consumer groups. I also hoped this would reinforce the impact of the posters I had already distributed. Articles based on my 'press release' were published in at least five community papers (see Appendix C). This did not result in any response from potential participants, but did result in some mental health workers making renewed efforts on my behalf.

In the end, I recruited eight participants from throughout the Auckland region. All except one had been informed of the study by my direct approach to individual key workers (four participants), community support workers (two participants), and the facilitator of a mental health 'drop-in' activity centre (one participant). The remaining participant had

responded to a notice placed in a District Health Board (DHB) public area. Five of the

referring health workers were known to me through my previous employment.

I had not anticipated that it would be so difficult to locate the sample group. In

1983, there were 2074 residents in the four Auckland psychiatric hospitals, approximately

40% of whom were people with an intellectual handicap (New Zealand Department of

Health, 1983). It is reasonable to assume that of the remaining 1200, some (particularly

older) people will have died during the intervening years, and that others are now living in

rest homes. In addition, the Regional Coordination Service (2003) estimated that more than

one hundred of the 981 people for whom supported residential services were provided in

2003, were people who had been previously institutionalised long term in psychiatric

hospitals. This appears to leave several hundred people who would meet the community

living criteria for this study. It is interesting to reflect on the fact that even amongst those

mental health workers I approached who were working in the hospitals in the 1980s, neither

government nor non government workers were aware of more than a dozen potential

participants in total. Does this mean that people are managing really well without input

from mental health services, or that they are not managing well, but are not causing other

people any trouble? One can only speculate as to why people did not respond to the

advertising. Perhaps they did not see the notices. Perhaps there were unhappy memories

they did not wish to recall. Perhaps as Hasselkus (2002) pointed out, some people were

ambivalent about identifying with the disabled community. Unfortunately, we may never

know.

I had concerns that the people who volunteered to participate were likely to be the

more articulate and outgoing members of the target group, and that the voice of the less

empowered would not be heard. In the event, four of the participants indicated they had

stories which they wanted health workers and/or others with mental illness to hear, and expressed a strong belief that other people would learn from their experiences. The remaining four participants were less outgoing, did not appear to have explicit messages to tell, but just hoped that perhaps something they said would be helpful to others. It will be seen in the following chapters that the eight participants included both those who were involved in the community and felt a degree of empowerment in their lives, as well as those who were more isolated and looked to others to make the decisions.

Data Gathering

To obtain people's stories, I chose to use a semi-structured interviewing process. This interviewing style uses a number of open questions prepared in advance to introduce the participant to topic areas the researcher wishes to explore. Wengraf (2001) pointed out that the initial questions should be selected with careful consideration of the purpose of the project. Because I wanted to focus on issues of people's everyday occupations throughout the time since they left hospital, including the influences which shaped their choices and occupational performance, some structure was required in the interview. However, the questions were intended to be sufficiently open-ended to encourage people to tell their stories within these broad parameters. The questions were based on the occupational literature described in Chapter Two of this study with respect to the importance of habits, routines and choice in everyday occupations to our health and well-being (see Appendix D). However, follow up questions were not pre-prepared, but were generated by the researcher according to the participants' responses. Wengraf (2001) suggested that in semi-structured interviews, between 50 and 80 per cent of the interviewer's questions should be

generated this way. For example, in my first two interviews, 73% and 65% of the questions were generated during the course of the interview.

In addition, I contributed numerous interactive remarks such as "uh-huh' or "yes", which are considered to be an integral part of turn taking (Silverman, 2001). These interjections are signals to the participant that the interviewer is engaged in the social interaction taking place, but may not always be neutral or encouraging. Following the first interview, I became aware that I had been guilty of using one of the blocks to listening described by both Mishler (1986b) and Wengraf (2001). I had been listening for responses which I considered relevant to the study. I realised I encouraged these with an energetically enunciated 'yes'. But I attempted to filter out responses which appeared at the time to be irrelevant, often by using 'mm' in a much more muted tone. Fortunately, Anthony was very enthusiastic in his story, and did not appear to take any notice of my unintentionally judgemental input. Subsequently I realised that every part of his story was in fact relevant to the research topic. By reflecting on my input after this interview, I was able to be more conscious and careful in my interactions in subsequent interviews.

I attempted to reflect on my input during the course of each interview as well. When interviewing Brett, I became aware that he needed a longer time to collect his thoughts than I had allowed initially. Although I often waited for a four or five second pause before asking a follow up question, this was not always long enough for him. He would continue with the previous topic. For example, he was talking about how his physical health affected his stay in the psychiatric hospital: "I got a bad bout of the flu and asthma, and uh, that wasn't too good. (Seven second pause). Put me back a bit, I think." Later he described making bird huts. I asked whether he enjoyed this. He replied: "I don't mind it. (Twelve second pause). I don't do it any more because people have gone off my type of hut now …"

In my later reading, I discovered that when Lorencz (1988) interviewed people with schizophrenia on their discharge from a psychiatric hospital in Canada, she "often waited for more than a minute for responses to her questions" (p. 141). In my study, most participants had indicated they had completed their thoughts within two or three seconds. Brett proved to be the exception, and generally I needed to allow six or seven seconds before he would indicate he had completed his response to a question. For example, he had been talking about the importance of taking his medication on time. He ended by saying: "… I mean if you missed the Melleril altogether, well you were in trouble. (Six second pause). Any questions?"

Rice and Ezzy (1999) pointed out that in-depth interviews enable the interviewer to encourage dialogue with the participants, and explore the meanings of the issues under discussion. The length of research interviews can vary, but I intended to use a single ninety minute interview, which was apparently common for many researchers (Rice & Ezzy, 1999). In the end, most participants spoke for approximately one hour. With the permission of the participants I audiotaped the interviews, using two recorders simultaneously. I also made notes as soon as possible following each interview to record details of the setting, significant non-verbal reactions and my own reflections, to assist with interpretation of the data (Wengraf, 2001).

I was concerned about the effect of the tape recorders on the participants as described by Warren (2002), because the equipment needed to be placed close to, and within clear view of each person. I noted that every participant in this study told stories prior to, and immediately after, the taping. These stories appeared to be offered in a freer and more colourful way than the data captured on tape. This is not unusual. Riessman (2002) pointed out that narratives can necessarily only represent the way people choose to

present their lives at the point of interview. In fact, when reflecting on my memory and journal entries of the untaped stories, I became aware that the themes of these additional stories were nevertheless represented in the taped transcripts.

All tapes were transcribed by the same typist, who had signed a confidentiality form (see Appendix E). Care was taken to keep both tapes and transcripts securely locked. Electronic data was secured by the use of passwords and keeping the back-up discs in a secure place. The typist returned the transcripts, the tapes, and the computer discs she had used as soon as they were completed.

As explained in Chapter Two, in addition to the information provided by participants, I have accessed some written material to assist in situating the participants' stories within the wider socio-political contexts of the era. I am aware that this process could have included television, films, radio and other media. However, this was unrealistic for a project of this size.

Data Analysis

In narrative analysis, the researcher analyses and organises the transcribed texts in a systematic way to closely reflect the stories of the participants from their perspective (Frank, 2000; Manning & Cullum-Swan, 1994). The essence of narrative analysis is not to establish 'facts' but to understand the meanings of events in people's lives. These meanings are situated in the context of time and their historical and social environment (Riessman, 2002). The analysis can be very formal and structured or loosely formulated and intuitive. For example, Mishler (1984) used structured, conceptual categories to analyse the linguistic meaning of individual words, phrases and non-lexical indicators of speech. Kleinman (1988), on the other hand, was more intuitive and inductive in his search to understand the

meaning of the narratives' plots. I have chosen Kleinman's approach as a guideline for analysis because this was more consistent with the research question, which was to understand the influences the participants believed affected their everyday occupational experience.

It is typical with inductive approaches to commence analysis following the first interview, because this allows for refinements in the interviewing process in an emergent design. I undertook an initial analysis of each transcript as it became available, and did not attempt to analyse across the transcripts until all transcripts had been through this process.

The first step was to replay each tape as often as required to ensure the accuracy of each transcript. The importance of this step was underlined by Poland (2002) and Riessman (1993). Inaccuracies are often not a reflection on the quality of the typist. The person who transcribed for me brought to her work not only her considerable skills as a typist, but also some knowledge of the general subject matter. She was not present during the interviews, however, and so did not have the non-verbal cues or reflective notes which I had in order to clarify parts of the transcripts. Some of the participants in this study did not enunciate words very clearly, and had the usual cadences of speech which caused some words and entire sentences to be particularly difficult to hear. One person walked across the room while still talking; one tended to race in his speech; another tended to mumble with his head bowed.

After checking the transcriptions several times, I removed some of my interactive remarks, provided they had been used solely as encouragers for the person to continue his or her response. For example, Jean indicated by looking up at me every half sentence that she was wanting me to acknowledge what she was saying. The following passage is shown

with all my interactive interjections, and again without them. Jean is talking about her

condition of trichotillomania, hair pulling.

> Jean: "… *They would not put a name to it.*
> Researcher: Hmmm.
> Jean: Yet it had been known. I've got information on it from the Phobic Trust. It's been known as a disorder – usually stress disorder.
> Researcher: Yeah.
> Jean: For about a hundred years
> Researcher: Hmmm.
> Jean: And then, while they were doping me up and making me bloated, see, I suffered an eating disorder when I was a teenager, and *that* was unheard of.
> Researcher: A what disorder? *(Had not heard phrase clearly)*
> Jean: An eating disorder.
> Researcher: An eating disorder *(confirming accuracy).* Yes.
> Jean: I would starve …"

When the encouraging/acknowledging interjectors were removed, this paragraph

looked as follows:

> Jean: "… *They would not put a name to it.* Yet it had been known. I've got information on it from the Phobic Trust. It's been known as a disorder, usually stress disorder, for about a hundred years. And then, while they were doping me up and making me bloated, see, I suffered an eating disorder when I was a teenager, and *that* was unheard of.
> Researcher: A what disorder? *(Had not heard phrase clearly)*
> Jean: An eating disorder.
> Researcher: An eating disorder *(confirming accuracy).*Yes.
> Jean: I would starve …"

Following this process, I sent each participant a copy of his or her transcript as

recommended by writers such as Kirkman (1999) and Poland (2002). In the accompanying

letter (see Appendix F) the participant was invited to check and return the transcript in the

enclosed stamped envelope. Each was assured that a corrected version would be returned to

him or her to keep. Four of the participants returned their transcripts to me. Brett and Frank

did not request any changes. Frank wrote "Thank you, sweet as" on the top of his transcript,

indicating his satisfaction with its accuracy. Both Jean and Martyn wanted small

corrections made, and Jean also requested the addition of a few words to further clarify the

story of her early life. These were inserted. Martyn indicated he did not want a copy returned to him, but the other three were sent a copy (in Jean's case, an amended copy) for them to keep.

The next step was to over-read each transcript to gain an overview of its meaning, as recommended by Poirier and Ayres (1997). This led to the emergence of broad themes of subjects discussed by each participant. I then placed all passages concerning each subject together, so that a fuller view of each subject category could be obtained. For example, Anthony's entire transcript could be divided into six subject areas: his occupations; his relationships; his thoughts about time and ageing; mental illness and the mental health system and its effects on consumers; spiritual beliefs; and material belongings. Some of his comments fitted into more than one category, and were therefore included in each. At this point, I composed a chronological summary of his narrative and themes as recommended by Wengraf (2001).

Once I had completed a broad analysis of each individual interview, I re-examined the categories across all eight transcripts. An over-riding pattern emerged of influences on participants' occupational choice and performance. This pattern accounted for all the various themes in the transcripts, and led to the decision to order the findings under the major headings and sub-headings which follow in Chapters Four to Seven. I then went back to each transcript and pulled out all the relevant data under each of the new sub-headings, and examined again both what was said and what was left out, for example, the paucity of friends and involvement in the community for some participants. At this stage I was immersed in an enormous amount of detail. However, I had been invited to speak about my study at a Colloquium of the Interdisciplinary Trauma Research Unit at the Auckland University of Technology. This opportunity to consider issues of support and

trauma in the participants' lives enabled me to take a step back from the detail, and consider the effect which the major influences in their lives had had on their stories. As part of my presentation, I prepared the two charts represented in Figures 1 to illustrate the impact of these supportive and traumatic influences on the lives of Jean and Frank. I selected Jean's story because my understanding at that point was that she had experienced more trauma than the other participants. I chose Frank's story as a contrast, because I believed he had experienced the most supports in his life. These charts did not reflect the detailed complexities of either of the stories, but did provide a general picture. The combination of preparing for this presentation, and the discussions which were generated from it, greatly assisted me in drawing the major issues from the detail and themes which I had previously uncovered.

Rigour

In qualitative studies, rigour is closely interlinked with ethical considerations (Emden & Sandelowski, 1998), and this section on rigour needs to be read in conjunction with the section which follows on ethical considerations. Rice and Ezzy (1999) categorised rigour in qualitative research under three headings: conceptual rigour, procedural rigour and interpretive rigour. Each of these issues will now be addressed, or links made to other parts of this study.

Conceptual rigour can be defined as establishing consistency between the focus of the inquiry and the methodology (Rice & Ezzy, 1999). In the methodology section described earlier in this chapter, I have already demonstrated that the use of a narrative methodological approach is consistent with the focus of my inquiry into the stories of

people's everyday lives since deinstitutionalisation. I have also explained that it is

consistent with the theoretical concepts about the place of occupation in people's lives.

Procedural rigour involves documenting clearly every step of the research design to

enable the reader to see in detail the consistency, clarity and accountability of the study

(Rice & Ezzy, 1999). As discussed, I used multiple recruitment strategies. I also used data

triangulation by using data from a number of participants, then placing it in the social

context of the times. I also compared it with the existing literature about the experiences of

people with mental illness, which is a further step in enabling the reader to judge the

trustworthiness of the study (Rice & Ezzy, 1999). I have documented each stage of the

research process: recruiting participants, interviewing and analysis procedures, ethical

considerations. From this procedural audit trail, readers will be able to judge the credibility

of my interpretations and findings (Game & Metcalfe, 1996; Krefting, 1990).

Interpretive rigour involves ensuring the reader can see a direct link between the

data gathered and the researcher's interpretation, and can therefore have confidence in the

truth of the findings for the participants and the context of the study (Krefting, 1990). To

be consistent with my methodology, it is important that I represent the complexity and

multiple realities of people's experiences and their understanding of them (Kearney, 2001;

Krefting, 1990; Popay, Rogers & Williams, 1998). To do this, I have included lengthy

excerpts from people's stories as recommended by Rice and Ezzy (1999).

There is an understanding in narrative inquiry and occupational therapy literature

that participants will be selective in their representation of their stories (Martin-McDonald,

1999), and that the researcher brings his or her own context to any interaction with the

people being studied (Crepeau, 1997; Dickie, 1997; Frank, 2000; Mishler, 1984, 1986a).

Care needs to be taken, therefore, to ensure the researcher's influence and social constructs

are explicit in any research undertaken (Kleinman, 1988; Schwandt, 1994). For this reason it is vital that I have been constantly reflexive about my role in the study (Game & Metcalfe, 1996; Krefting, 1990; Rice & Ezzy, 1999). To this end, I have kept a reflective journal and actively reflected on my participation in discussions with my supervisors. As discussed in Chapter One, I participated in a preparatory pre-suppositions interview to clarify and make explicit my values and prejudgements about my study.

In addition, I have used two strategies recommended by Krefting (1990): member checking and peer examination. Member checking involved returning the typed transcripts to the participants to check for accuracy. For peer examination, in addition to having regular sessions with my thesis supervisors, I have participated in a monthly narrative inquiry/discourse analysis group at the Auckland University of Technology. As well, I presented my initial proposal to groups of mental health workers, occupational therapists and mental health consumer services as part of the participant recruitment process. I also presented preliminary findings both to a group of occupational therapists working in the mental health field in the greater Auckland area, and to an audience of peers at a forum convened for post-graduate occupational therapy students to present their research. The feedback I have received throughout this process has been positive and affirming both of the processes I was using and the findings I was uncovering. People in the initial groups supported the intent of the project and provided suggestions of people to contact to assist the recruitment process. A number of people in the later groups approached me following the presentations to talk to me about their experiences of working in the old psychiatric hospitals, or working with people with long term serious mental illness. They commented that the issues raised and the anecdotes which I had related from the participants' stories were similar to the stories which some of their clients had told them.

Ethical Considerations

Key issues related to informed consent are set out in the participant information sheet (see Appendix G) and consent form (see Appendix H). The information sheet included the statement that ethical approval was granted for this study by the Auckland Ethics Committee on 5 February 2003. Each prospective participant was given a copy of the information sheet several days prior to an appointment being made for their interview. At the point of arranging the interview, each person was given the opportunity to ask questions about the study, and was asked whether or not he or she wished to proceed. Each person was asked to read the consent form. Once again, participants were invited to ask questions, and were asked whether they wished to proceed with the interview, before they signed the consent form. I emphasised their right to withdraw from the study at any point, and reiterated what would happen to their personal information and their transcripts.

Beneficence

Research should benefit both the participants and society (Moore, 1995). It is anticipated that this study may have benefited participants by giving them the opportunity to tell their stories. Recovery and other literature records many examples of the benefits to people with mental illness from sharing their experiences with each other, and the benefits to the community in terms of increased understanding and decreased stigma about mental illness (Deegan, 1993; Lapsley, Nikora & Black, 2002; Leibrich, 1999; Ralph, 2000; Sarbin, 1986). Policy makers and health professionals may also benefit from being able to learn about the effects of the institutionalisation and deinstitutionalisation policies on the everyday lives of some of those concerned. To enable these benefits to occur, I intend to share the findings of this study by: providing each participant with a written summary of

the major findings in addition to the copy of their own transcript; talking with groups of mental health workers and consumer groups throughout the Auckland area; applying to speak at occupational therapy and mental health conferences in New Zealand about the study; and preparing articles for submission to appropriate professional journals.

Nonmaleficence

Research should do no mental, emotional or physical harm to anyone, and no disempowerment should take place (Moore, 1995). Two major risks in this study were that participants: (a) may in their enthusiasm have revealed more than they would ordinarily choose to share with a stranger; and (b) may have experienced strong emotions in talking about their life stories. To minimise these risks:

- The risks of participation were pointed out to participants on the information sheet provided prior to consent (see Appendix G), and verbally immediately before the interview started (Seidman, 1998).

- Participants were invited on the information sheet to consider in advance the existing resources and skills which they already had in place to manage stressful experiences.

- I was constantly alert to the need to pause during an interview if the participant appeared emotionally distressed, and to discuss whether the person wished to continue with the subject and/or the interview. As it happened, this situation did not eventuate.

- Prior arrangements were made with counselling services for the provision of one free counselling session and affordable follow up sessions for those who wished to

make use of this option. This was pointed out to participants on the information sheet, but the service was not required.

- As discussed in the section on data gathering, participants were given the opportunity to review their transcripts and withdraw portions of their story as recommended by Seidman (1998). In fact, no-one asked to withdraw any words, but as explained previously, two people asked for minor corrections of details.

Prior to granting ethical approval, the Auckland Ethics Committee indicated that it was important that risks to the researcher's own safety be protected. A consumer group was kind enough to allow their service to be used as a contact point and message service for me. I anticipated that my professional training and experience in working with people with mental illness would enable me to arrange for assistance for any participants who may be unwell at the point of interview, and to manage safety issues for both them and myself. I carried a cellphone which was turned on in case I needed to make an outgoing call. The number was specific to this project so did not result in any unwanted incoming calls. Although no problems were anticipated or eventuated, I ensured a safety plan was in place for visiting people in their homes as requested by the Ethics Committee.

Justice

Everyone is entitled to be treated fairly, and have the researcher's intentions explicitly stated (Moore, 1995). I set out clearly the purpose of the study during the process of recruiting the participants, on the information sheet and immediately prior to each interview. Both the information sheet and the notice advertising the study detailed the criteria for inclusion of people into the study, and I referred to these criteria before accepting people as participants (Seidman, 1998). Everyone received similar preparation

for their participation, and have had their contributions treated with equal respect. The procedures undertaken in recruitment, interviewing and data analysis have served to ensure that all participants and their contributions have been treated justly and professionally.

Fidelity

Research processes should be explicit, confidential, and follow the negotiated processes. Researchers must be accurate and professional in all their actions (Moore, 1995). The information sheet contained details of the formal ethical approval for the study, and contact details for my primary supervisor and the Health and Disability Advocate if people had any queries or concerns. I did not offer remuneration to participants because this may have compromised not only their motivation for entering the study, but also their feelings of freedom to withdraw at any stage (Seidman, 1998). However, in line with the principles of fairness and consistency, following each interview I offered participants a koha (gift) to acknowledge their contribution. Each person was given the choice between a petrol voucher or a voucher of equal value for a large chain store. It was stated in the information sheet (see Appendix G) that travel costs would be reimbursed, but this was not required. Seven of the eight participants chose to be interviewed at their place of residence. At his request, I provided transport for the eighth person who preferred to be interviewed at a mental health service.

In terms of confidentiality, as stated previously, each participant was invited to provide a pseudonym for use throughout the study, and no friends, family members or hospitals were named. The audiotape transcriber was required to sign a declaration of confidentiality. Computer data was passworded, and all computer disks, tapes and written material concerning the participants were stored in a locked place as recommended by

Seidman (1998). Only essential demographic information required to give meaning to the participants' stories was requested from the participants. However, it was also explained to participants both verbally and on the information sheet that because the interviews would reveal so much about people's lives, anonymity could not be guaranteed. It is possible that a reader who knows a participant personally may recognise him or her (Seidman, 1998). Finally, I agreed with Seidman's (1998) opinion that when participants signed their consent, it was a sign of fidelity for the researcher to regard this as a responsibility to report about the participants' world as faithfully as possible. It is hoped that the care taken in interviewing, transcription and data analysis procedures has ensured that this has occurred.

Autonomy

Participants are entitled to be empowered by the research process (Moore, 1995). To assist with this, care was taken to ensure participants were fully informed about the risks and benefits of participation, and especially about their right to make their own choices, including the choice to participate or not, and to withdraw at any stage in the process (Seidman, 1998). Participants were fully involved in the choice of a mutually acceptable venue, and the date and time of the interview. They were also provided with a copy of their own transcript to amend as they wished, and to retain for their own record, as a further process in empowerment (Kirkman, 1999; Seidman, 1998).

Treaty of Waitangi

In addition to the above principles, researchers in New Zealand need to take into account the three principles of the Treaty of Waitangi described by the Royal Commission on Social Policy (1988): partnership, participation, and protection. In honouring the

principles of the Treaty of Waitangi, I believe it was my responsibility to ensure that Maori were consulted and included in good faith at each stage of my research process (partnership and participation), and that all those involved in the study felt that they were respected as human beings within their spiritual, cultural and social contexts (protection) (Durie, 1994). Some parts of this proved to be more problematic than anticipated.

Implicit in the principle of partnership is a commitment to mutual learning and power sharing. It was in this spirit that I attempted to consult with local Maori groups and individuals to ensure I was providing a safe and relevant study for Maori participants, to assist with recruitment of Maori participants, and to report back my findings. In practice, I consulted with the Group Manager of Maori Health at the Counties Manukau District Health Board (DHB). It was his opinion that this study did not contain "significant cultural issues from a Maori perspective" (see Appendix I), when assessed using the tikanga (rules, customs) framework which the DHB's roopu of kaumatua kuia (group of elders) use to consider research initiatives. He recommended I contact the DHB mental health consumer group. This group in turn wished me well in my study, but did not have members in their group who had experienced long term psychiatric hospitalisation. They indicated that these were the people I should approach for consultation. As already discussed when describing recruitment procedures, this group does not appear to be represented in any of the local consumer groups. Instead, as I was speaking to consumers and consumer groups of various ethnic backgrounds in the recruitment process, I listened carefully to their feedback about my processes and intentions. Common feedback was that it was important that the study should reflect the people's view of their stories as much as possible. Suggestions were made about possible people or organisations which may assist with recruitment, and all these suggestions were gratefully received and followed up.

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The principles of participation and protection placed responsibility on me to take account of all the ethical considerations previously stated. In acknowledging the significance of whanaungatanga (familial connections), I intended to invite Maori participants to choose a culturally appropriate venue for their interview, and to have family and kaumatua or kuia (elders) present if they wished. I intended to be guided by them, as well as use my own skills, to create a relationship in which they felt comfortable about using Maori concepts and expressions to describe their experiences, and to use rituals for the interview such as karakia (prayers) if desired. In fact, I did not discover that two participants had Maori heritage until part way through Martyn's interview, and after Frank's taping had finished. However, they had each made the decision with respect to the venue, and had both chosen to be interviewed on their own. Martyn raised topics concerning his heritage and his spirituality, and told a story about a kaumatua (elder) telling him he was a tohunga (he translated this in his situation as a warlock). It is hoped therefore that he felt safe and comfortable to discuss these aspects of his cultural beliefs. Frank did not make any direct comments regarding his heritage. However, it is hoped that his comments indicating he was content with his transcript, and his confident and articulate responses during the interview, are signs that he would have been able to raise cultural or other issues if he had wished.

In this chapter I have explained the reasoning behind selecting a narrative methodology. A core concept is that it allows the participants to tell their stories in ways which have meaning for them. This client-centred theme has been carried through to the research methods used and the ethical considerations which have been taken into account

throughout the research process. The three chapters which follow are the results of this

process, and contain many excerpts of the participants' stories in their own words.

Chapter Four: Introducing the Heroes

The Play of Life: Setting the Scene

> All the world's a stage,
> And all the men and women merely players:
> They have their exits, and their entrances:
> And one man in his time plays many parts.

This much cited quotation from Shakespeare's play "As You Like It" (Tilt, 1838, p. 313) is particularly apposite to this study. In keeping with the narrative theme, I have chosen to set out the next four chapters in the format of a play. In this chapter I will set the scene and introduce the eight participants of the study. They are the major players, the Heroes, and it is their stories which form the plots for Chapter Six. The quotation above continues with Shakespeare detailing seven stages of life, from the players' entrance as infants, through their school days, to adult stages, and finally to their "last scene of all, that ends this strange, eventful history" (p. 314). The introduction of the Heroes of this study which follows will include a summary of those aspects of each person's early life which they have chosen to disclose, including the years they spent in psychiatric hospitals. In the next chapter I will introduce the Supporting Cast, that is, those people or issues which have acted as supporters and/or villains in the heroic struggles of the central characters. This will set the scene for Chapter Six, in which the occupational plots of the participants over the years since they left hospital will be described. In Chapter Seven, the moral of each person's story will be revealed. This will not be the last scene of all, but is the last scene of their current story, and will include their thoughts about the future, which may be an indicator of the scenes to come.

Throughout the four chapters which follow, there will be extensive use of excerpts from each person's narrative to enable the reader to gain a deeper appreciation of each story and the person who tells it. Those words emphasized by the participants have been written in italics. As previously stated, the names used are the pseudonyms chosen by each person, and the hospitals have been assigned a letter, for example, [Hospital A].

Because this study was concerned with people's everyday life since leaving hospital, participants were not asked any direct questions about their life prior to this time. The summaries which follow therefore reflect the varying degrees to which they chose to include details about their early life in their stories.

Introducing the Heroes (in alphabetical order)

Anne

Anne is a woman in her early fifties who lives with her husband Jure in a small house in a residential suburb. She is a person of few words, and answered each question without embellishment. As no questions were asked about her early life, she did not disclose anything about it apart from stating that she was born in a provincial town in New Zealand. Similarly, the only information she gave about hospital life was what she was asked, which was about the dates and length of stay. In fact, like some of the other participants, Anne was unsure of the dates, but thought she was in [Hospital A] "about six weeks, I think about, February to May. Three months, isn't it? … Yeah, it's a long time." The health worker who introduced Anne to my study told me that she had spent a number of years in hospital. Following Anne's interview, her husband, who was very precise about

dates, stated that she had been there the same time as him, from 1983 to 1992, when she would have been between 33 and 42 years of age.

Anthony

In contrast to Anne, Anthony is a very loquacious 39 year old, who took the opportunity of the interview to reflect widely on his thoughts, feelings and actions. At the time of the interview, he lived in a group home run by a non-government agency. Non clinical staff were available on site to support the residents, but as will be seen in Chapter Six he appeared to have a large degree of independence, freedom of choice and movement. He had his own rooms in a large rambling house which he shared with other people with a history of mental illness. When Anthony was asked about the dates when he was in hospital, he chose to start at an earlier point:

> Well, the story goes back really to when I was in [Asia] when I was a boy. I was at school there for 6 years and when I left I got a job in a film company. And when I left the film company I went to England with a few of my friends.

Anthony and his friends formed a band. They also became involved with "drugs and I accidentally broke a window and I was sent to prison and then I was sent to a mental hospital." At some point soon after this he returned to New Zealand. As with some other participants, when asked about the length of stay in hospital Anthony did not initially differentiate between his time in hospital and his contact with the mental health system. He stated that he had been:

> in hospital now for about twenty years … But actually, most of the places I have stayed at have been houses run by the Hospital Board for poor young kids, poor young people or people who are wealthy who are unfortunate …

A little later, he reflected on the question and became more specific:

Looking logically, I was five years in [Hospital A]. And I was also a few years at [Hospital B]. I was a year at [Hospital C] in the South Island. I was a year at [another group home]. So I've really been shopping around.

Altogether, Anthony appeared to have experienced his first hospital stay in his late teens in the early 1980s, and left his last lengthy stay in 1993. He did not go into detail about his daily life in hospital. He did express feeling "hopeful" and "optimistic" when he arrived at [Hospital A] about the help he would receive there. "But it didn't work out. We had too much to do and I think it was a shame because we lost a lot of good people along the way." However, Anthony himself had made changes, and felt able to cope. He described having to continuously move from house to house at the hospital "like taking steps to improve, you know?" Anthony's faith was very important to him, and he kept praying "Jesus help me, Jesus help me." Eventually he "had a word with" the hospital chaplain who "very kindly found me a place to stay." He moved to another group home for a week en route to his current home, where he has now lived for several years.

Brett

Brett is a man in his mid fifties who lives alone in a farmhouse surrounded by a few acres of land. He was brought up there by his parents when the property was a much larger farm. His parents have both since died. He has a brother and sister, both of whom live within an hour's drive of his home, but he appeared to have little contact with them.

Brett described obtaining his driver's licence at age 17 or 18 years, and said that he would often impetuously "jump in the car and off, go around the Coast." He also used to drive into Auckland "a fair bit". As with Anthony, Brett was unsure about the dates of his hospitalisation, but appeared to have spent lengthy times ("three months", "four years") in hospital "on and off since I was 23 'til I was 46." It was unclear whether some of his tales

about driving around occurred before his first hospitalisation, or during his stays at home between admissions. However, there is no doubt that "scooting around and playing" gave him a great deal of pleasure. The car also gave him the opportunity to apply for jobs in Auckland. But despite having "a couple of jobs lined up there in Queen Street" he decided at the last minute not to go, and said, "I'd chicken out right at the last minute."

After Brett's siblings left home, he continued to stay with his parents when not in hospital. His mother died when he was 38 years old. He stated that the years between when he was first admitted to hospital at age 23, and when he was 38 years old "were bad. I didn't have much of a good, good outlook on life. Since then I've sort of come better." He did not say whether there was a link between the death of his mother and his apparent change of attitude occurring in the same year. When he eventually left [Hospital A] for the last time he went home to live with his father. It was about three years later when his father died, and Brett has lived alone for the several years since then. He still misses his parents, and talked nostalgically about listening to their conversations:

> Ah, in the old days I would listen to Mum and Dad talking, if it was a rainy day and we couldn't work. … They would be talking away at the table. I liked listening on. That sort of thing I miss a bit.

The staff at [Hospital A] told Brett that he was "one of the worst patients." He admitted that he used to get into fights sometimes, as did a number of the male patients. In Brett's case it was connected to his voices.

> You know, people start chipping in bits of my voices and they have you on. Sometimes I would hit someone in the old days … Once or twice I did. And that didn't help me at all… nothing serious but, never against children and young people just … we had the odd fight, the boys in there.

However, it appeared that the patients found a way of containing the violence between them as "most of the time it was pull on the collar and walk away." Brett considered this

was a good way of dealing with conflict in the hospital, because the possible consequences of being too violent included being locked up within the hospital. "There's no use going back into jail, is there, in [Hospital A]? Or on to another hospital? No point in it." Fights did not happen all of the time. Some people were "all right".

The only other aspects of life in hospital Brett referred to were having a shower and making his bed every day, and changing the bed linen once a week. This was in response to me asking how his routines had changed since leaving hospital. At the time of the interview he stated he changed his sheets every second week, and showering was something he did because he should rather than because he wanted to: "I don't like them, but oh blimey I suppose, but I don't, but I have a shower now and again." Overall, Brett was pleased to be older and to leave the bad years behind him. "I'm not sure but, I think I'm a bit better these days at coming mentally to the job."

Frank

Frank was the youngest participant in this study. He is a 35 year old "Maori European" man, who rented one of a block of flats with another man with a mental illness. The flats were privately owned, and situated on a busy urban thoroughfare.

Frank was brought up by his grandmother, mother and siblings on a farm in the lower North Island. A cousin used to visit with his parents during the school holidays and Frank said that "we just had so much fun. We had so much good times right back then."

In 1986 when he was about 18 or 19 years of age, Frank was living alone in a little cottage, "and I spent a lot of time smoking drugs, drinking beer, taking magic mushrooms … I absolutely just flipped." He spent a week at [Hospital D]. His grandmother was older and in poor health at this stage, so she contacted Frank's mother and brother, who took him

with them back to Auckland. He was sick for about three months, eventually resulting in an admission to [Hospital B] for a few weeks. Following this he lived with a brother for about a year, "smoking marijuana every day as well. Flipped again and was back in [Hospital B] for about another two weeks."

Frank said he "did pretty well after that for a period of two or three years." He lived for about eight months in a rural commune, where he had fond memories of one particular woman and her daughter, both of whom he hoped to see again sometime. While there, he said "the doctors weaned me off the medication." Frank moved to another urban centre, working in sales, but became unwell and ended up in [Hospital E] for a few days. This time he was placed in a boarding house, but he soon moved out. In the next few months he lived in two cities and a provincial town, where he set up his own lawn-mowing business. Frank considered himself lucky because "I've always been the sort of guy that's been able to get out there and earn a bit of money when it's needed."

The turning point for Frank came seven years ago when he was charged with grievous bodily harm and threatening to kill. "Threatening to kill is a pretty funny one because all you've got to do is just mention it, and you get done for it. So that's why I ended up in the unit, um, the forensic system." He was admitted to [Hospital F] as a Special Patient, and remained there for four years. For the first year he was in an acute unit, but then progressed to units where he had more privileges. He was able to start a car cleaning business, and occupied himself cleaning the cars of people within the hospital grounds for the next two and a half years. This gave him some independence and he gained pride from his work:

> I went out and I started cleaning cars: washing and waxing and grooming the cars. And that just carried on right through until I left. So for a period of about probably two and a half years I was in there, had newsletters like that letter and stuff, handed

them all around the units, and ring them up: "Oh, anyone there want their car washed or groomed or waxed or anything?" I had a number of about, I think it was ten, eight or nine or ten cars that I cleaned regularly. … So it was quite, it wasn't *that* lucrative but, always enough to get by. Like, you know, in there I was basically living on tailor-mades most of the time. Because I could afford them and stuff. And it gave me independence as well, being able to get out on my own, do some work by myself, and get pride in my work and that. Making sure these cars were done. Some of these cars, mate, I washed them and they looked like they had just come off the line. … So after a period of a couple of years I actually felt, I felt that I could do it really good.

After four years in the forensic system, Frank was released, but was still a Special Patient, which meant that he could be recalled at any time. His stay at [Hospital F] had changed his attitudes. On his discharge he did not return to drug taking or drinking alcohol, and he did ensure he took his medication regularly. "I've got no intention of going back there", he said. It will be seen in Chapter Six that in fact he returns there regularly, not because of his own problems, but to help and encourage other residents.

Jean

Jean is a woman in her mid fifties who lives in her own flat in a residential suburb of Auckland. She traced her problems back to when she was at high school in a small provincial town. She was living with her parents and two sisters, but it was not a happy time. Her parents used to drink and fight with each other, and eventually were divorced when Jean was about 20 years old. Jean felt that she was not loved as much as her sisters. She told me:

Who was the most brilliant? My older sister was Head Girl. Who was the most bubbly? Who had the most personality? Which was my younger sister. So she was loved. The family loved her. I went to a separate … school from my sisters because of my bed wetting, and also because of the commercial studies. The [teacher] placed me in an academic class, saying my I.Q. was high. I was only a few months at the school, as my bed wetting was bad and then I returned to the local high school. … My parents then lost interest and focused on my sisters' school becoming

the best … school in New Zealand. … I was the weak one, who wet the bed and called lazy for that, by my mother.

Jean described suffering from both an eating disorder and a "stress disorder", trichotillomania, as a teenager. "Now, it's known more and treated more by counsellors at the Phobic Trust… But that was one of the first things I said to my first psychiatrist in a mental institute in 1969, my hair pulling." As far as her eating disorder was concerned, Jean described being insulted and ridiculed at school, with girls calling her "Fatty Arbuckle" or "Tubby". So she starved herself, eating only one apple a day to try and "become tiny" like her younger sister. Both of these conditions continued to be problems for Jean for many years. The one accomplishment which Jean mentioned about her schooldays was learning to do shorthand, which formed the basis of her future working life.

In 1969, Jean was admitted to [Hospital G], her first experience of a psychiatric hospital. She stated that it was "because of a beating from my first and probably only boyfriend, which the staff never questioned. Never questioned as to that beating. Never questioned why I had the bruises." Her father found out that she had been involved with a married man. He visited her in hospital "and said, 'I think you'd better pack your bags and leave home young lady'. I was only twenty. It was hard. Lost." A few months later Jean was admitted to [Hospital B]. Following this, the dates were a little unclear, but she was in and out of [Hospitals A and B] throughout the next twenty years. She stayed in a hostel for a short time, where she described "picking the fleas in the mattresses", and waking up covered in bites. Soon afterwards, her mother helped her get the flat where she has now been living for many years. In between hospital admissions, Jean worked full time for a large government department. This will be described in more detail when exploring the Supporting Cast in the next chapter.

Jure

Jure is a man in his early sixties, who was brought up with his parents and brothers and sisters in a town in Eastern Europe. He came to New Zealand in 1959 when he was 20 years old. He is married to Anne and, as previously stated, they live together in a small home in a residential suburb.

Jure answered the questions which he was asked, but did not expand on other areas of his life. Consequently nothing was said about his early family life. He did however talk with some pride about having obtained his taxi driver licence in New Zealand, and made a point of retrieving it from a drawer to show me. He had driven taxis for about three years. He told me he did not do this for longer "because I couldn't make a living out of it. … unless I had my own ah, own car and own licence. That should be OK." But he was working for a company that took 60% of the gross takings.

Jure was very precise about dates, giving me the exact date of his birth, of the day he left Europe, of the years he held his taxi licence, and of the day he gave up smoking. It was for this reason that when he stated that he and Anne were in [Hospital A] for the same period of time, from "1983 to, um, 1992", that the dates seemed trustworthy. During his time in hospital, Jure described occasions when he was allowed to cook.

> They let me cook in ah, the kitchen with my missus. … Sometimes about once a
> week, I used to cook like bacon and eggs, bacon and eggs and tomatoes and chips
> for me and the patients there, you know, that sort of thing.

Jure also described with satisfaction a job he was given at the hospital, assembling garden spray bottles:

> That was a big job, actually, which lasted for about a few years you see when I was
> there. Yeah, I was doing that and ah, I've done about thousands of them, you know.
> It's all different parts have to be joined together. Which means when it's finished
> product, it's actually like about six litres of chemical stuff that using for spraying

like vegetables, or fruit or vegetables, you see? Yes, and that kind of thing. Spraying bottles.

Since leaving hospital, Jure had worked briefly in a rehabilitation workshop, but had not rejoined mainstream employment. At the time of the interview, he considered his current life at home with his "missus" was going well for them.

Martyn

Martyn is a man in his late thirties, who described himself as "part Maori". He lives with his wife in a rural town, and works full time as a caregiver in a rest home complex. He was a natural story teller, and illustrated his responses to my few questions with many anecdotes, a total of 41 in a one hour interview. In response to me asking when he was in hospital, Martyn chose to start when he was eight years old, which is when he first heard voices. However, he considered an earlier incident equally crucial in his life:

> At the age of six, two horrible things happened. My dad almost died of [name of illness]. Since he was very old, mum had to lean on me at the age of six. I had to grow up really quick. Secondly, when he got out of hospital and he was convalescing he said, "You're a man now. No more hugs and kisses." Imagine how that felt.

Martyn did well at school, but left at age 14 years despite his headmaster pleading with his father to let him stay at school. However, Martyn said: "Dad knew something was wrong with me. So I worked [at father's workplace] and at the age of 16 I had a massive nervous breakdown." Martyn believed a contributing factor was that at 14 years he had moved downstairs in the family home to a self-contained rumpus room, joining the family only for the evening meal. He explained: "Well, emotionally and mentally I wasn't old enough for that." He was very scared at night and started having some unusual experiences. When the

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breakdown came at 16 years, his mother took six months off work to look after him. He returned to work a couple of times but "was too far gone".

At age 17 years, Martyn was committed to [Hospital B] as "mentally insane". They diagnosed schizophrenia, but Martyn did not believe he had a mental illness, a diagnosis which he considered was made up by atheists. "I would say three quarters, or even more, seven eights, of the psychiatrists were atheists. They don't know what they are bloody talking about. I mean they are guessing, they're guessing." He believed "it's spiritual warfare", and talked about the battling and struggle. Over the years, Martyn had been admitted to five different hospitals in the Auckland region. "I've been to practically all of them. The only one I haven't been to is [Hospital K]. I've been to [Hospitals B, A, H, I, and J]". The largest amount of time spent in hospitals was "at the onset of the problem. I was in [father's workplace] for twelve years and in that time I went to hospital four times, so it's, it's not too bad." He related many anecdotes about his hospital experiences, some of which will be referred to in the next section when discussing the Supporting Cast in the participants' lives.

Terrie

At 66 years, Terrie is the eldest participant in this study. She was born in Australia, where she lived with her parents, two brothers and two sisters. In response to a question about where she learned to do household skills, she talked about being "brought up to clean the house". She and her sisters shared a room. "We had to keep that clean. Polish our furniture once a week, clean our mirror once a week, um, change our sheets once a week, and um, that sort of thing."

Apart from this, the only information which Terrie volunteered about her life in Australia concerned her illness and its aftermath. She was admitted to [Hospital L] for six months when she was approximately 30 years old. Following this admission she returned to the security of her parents' home saying, "And I seemed to get a lot better when I was with them, and that." Terrie did not appear to have a good memory for dates, resulting in some of the time periods she described conflicting with each other. However, at some point after this hospitalisation her father died. Her mother "got very despondent" and would not go out. So Terrie contacted her brothers who at this stage lived in New Zealand. They persuaded their mother to sell up and emigrate to New Zealand with Terrie. "And I was here for two years and then I got sick again. And uh, and um, I was in [Hospital A] for six months." She was in and out of hospital between then and 1993, usually for weeks or several months at a time. When she was sick she would "spend up big", and on one occasion her brother and mother had to sort out thousands of dollars of debt she had accumulated by "signing cheques that I had no money in the bank for." Yet when she was not sick, Terrie managed her finances without difficulty.

At the time of interview, Terrie had been living for more than twenty years on her own in a small Housing NZ rental flat. She attended a work rehabilitation programme five days a week, and as will be seen, was leading a busy life.

The eight participants of the study, the Heroes of the stories to follow, have now been introduced. Although all eight people were living in the greater Auckland area at the time of the interview, only two had been brought up in this region. The others had experienced life in rural and urban areas throughout New Zealand, as well as other parts of the world. Of the five men and three women aged between 35 and 66 years, Martyn and

Frank identified themselves as part Maori, Terrie as Australian, and Jure from his home country in Eastern Europe. Two of the older participants, Jure and Anne, were married to each other. Although three of the older participants first experienced life in a psychiatric hospital in the late 1960s, all eight people were hospitalised in New Zealand on and off throughout the 1980s and early 1990s, and therefore shared some commonalities of experience.

Chapter Five: The Supporting Cast

All participants in this study have identified people or issues which have played a significant role in their stories. Each of these roles will now be described as members of the Supporting Cast, and it will be seen that their characters are often complex. For example, family members are sometimes viewed as supportive and other times as villainous. On occasions, their presence is significant; on other occasions, it is their absence which has an impact.

In a play, the cast members traditionally have their names written with a capitalized first letter, and I am continuing this convention. I have included two non-human members in the Supporting Cast: Illness and Psychiatric Medication. This is also consistent with theatre tradition. In the Fourteenth century, for example, morality plays used actors to personify the concepts of Vices and Virtues of human beings (Cassell & Company, 1968). It is interesting to note that the Virtues were always victorious, a theme which emerges in Chapter Seven of this study. I have decided to list the Supporting Cast by starting with those closest to the private self, namely Illness and Psychiatric Medication. This is followed by Mental Health Workers and Agencies, because they are often seen hand in hand with the other two, and they have only been introduced to the Heroes because of their close relationship with Illness in particular. Once these three characters have been described, I will introduce Family and Friends. I have reserved the nebulous Community for last, as this would often be regarded as the most distant of people's relationships. It will be seen, however, that the interaction with Community can have a significant impact on the lives of these particular Heroes.

Illness

Illness has played a significant role in the lives of all eight Heroes. Without it, they would not have experienced life in a psychiatric hospital, or have been introduced to the persona of Psychiatric Medication. Although health workers were encouraged to define Illness by using an evidence based diagnostic model (Kaplan, Sadock & Grebb, 1994), few of the participants named their Illness in terms of the formal diagnosis which their Mental Health Workers and Agencies had given them. In addition, most described experiences which suggested that problems had developed long before the diagnosis. Martyn first heard voices at age 8 years, and Jean described stressful teenage years in which she was already exhibiting signs of trichotillomania (hair pulling) and an eating disorder. Illness had also established itself as an influential player in the lives of Anthony and Frank during their teenage years. In both cases it appeared to have been introduced to them by its well known associates, Alcohol and Drugs. Neither Terrie nor Brett mentioned what triggered their illness, but both acknowledged Illness as a current companion.

The only people who did not specifically mention Illness at all were the married couple, Jure and Anne. Illness had nevertheless played a significant role in their lives. It was thanks to Illness that they were both admitted to [Hospital A] where they met and were married. Illness introduced Jure to Psychiatric Medication, which pushed Illness to one side, but gave Jure other problems. Illness also introduced Jure and Anne to the Mental Health Workers and Agencies, which Jure acknowledged as being invaluable supports for them in the eleven years since they had left hospital.

Alcohol and Drugs

Both Anthony and Frank described a connection between the onset of their Illness and a time when they were involved with Alcohol and Drugs. As previously stated, Anthony described getting "into trouble with drugs", breaking a window and ending up in prison and psychiatric hospital as a result. Frank talked about "flipping out" after spending a "lot of time smoking drugs, drinking beer, [and] taking magic mushrooms." Later, after at least two hospitalisations, he recalled "smoking marijuana every day" for over a year and "flipping" again. The only other person who talked about taking Drugs was Martyn. He estimated he had only used marijuana "about five times in my whole life". These were bad experiences, involving vomiting, "horrific" hallucinations and paranoia. The community nurse who helped him through it told him not to do it ever again. He said, "No way" and had kept this promise. Frank also eventually rejected Alcohol and Drugs. He did not claim that his association with Drugs had caused his illness. However, he did acknowledge that Illness had flourished in the presence of Drugs, and he associated wellness with the absence of Drugs and Alcohol. "Overall, no, I'm just enjoying life without drugs, without beer", he said, and advised others with mental illness to give them up too.

Hearing Voices

Four of the eight participants mentioned hearing voices as an indicator that Illness had been present in their lives. For Brett this continued to be a current concern, but he had found some strategies which worked. He explained:

> I'm trying to get rid of the voices sometimes … Sometimes if you agree with them, then they keep going and just spin your mind off, and then you can do what you want. … Walking over the back of the farm helps my mental outlook. It does me good. I walk over in the heat a fair way and it nearly kills me (laugh). That scares most of the voices.

The most effective help to keep Illness at bay, however, was Psychiatric Medication. Brett

considered he was doing "fair enough, yeah, as long as I don't miss my pills". If he forgot

them, "I get depressed and the voices start fighting me all the time. Little things crop up all

the time and the voices are just sat, and the next thing they are all fighting me about it." At

the time of the interview, Brett was spending three weeks in a respite home so that he could

be monitored while a new Psychiatric Medication was introduced to him. He had

experienced the voices "getting worse and worse over the years. If I miss [the pills] it

seems to take longer to come out of it. But these new pills might make a difference, I

suppose."

> Not everyone experienced hearing voices so constantly. For Terrie, it was stressful

situations which brought this aspect of Illness closer to her. At the time of the interview,

she had recently visited her 91 year old mother, and expressed her concern:

> I don't know how long we'll have her. She's in terrible pain all the time with
> arthritis. That's a bit of a worry and that keeps bringing out the voices in me. As
> I've got 'em now. … I saw her on Sunday. She wasn't very well. But she seemed a
> lot better yesterday. So I feel a bit better about it.

As with the other participants, Psychiatric Medication had replaced Illness as her constant

companion. Terrie viewed Illness as a troublemaker, and tried to be alert to early warning

signs that Illness was approaching. She stated:

> If I don't catch the warning symptoms then I end up in hospital. But most times,
> since then, I have been able to. Always feared the thought of spending up big again,
> you know? And getting myself into all types of strife, so.

Frank also concentrated on recognizing early warning signs: "Once these warnings start,

having like paranoia or stress or, um, depression or things like that, I can pinpoint them

before they get out of hand."

Jean: Naming the Illness is Important

Naming her Illnesses appeared to be particularly important to Jean. She was very

concerned that I understood the term trichotillomania, and had been frustrated because her

Mental Health Workers and Agencies had not initially acknowledged that she had this

Illness. Jean had undertaken her own research into the disorder, and told me:

> Now, it's known more and treated more by counsellors at the Phobic Trust in Mt.
> Eden. But that was one of the first things I said to my psychiatrist in a mental
> institute in 1969, my hair pulling. … It's in the Bible too … the Bible says "Go,
> wail and tear your hair out" to the Jewish women. Because they suffered stress, the
> Jewish women in the Bible, in the Old Testament. "Go wail and tear your hair out",
> God says. So they tore their hair out 'cos they were stressed. At first I did tell them
> about my hair pulling. I told sort of the psychiatrist in [Hospital A]. *They would not
> put a name to it.* Yet it had been known. I've got information from the Phobic Trust.
> It's been known as a disorder, usually stress disorder, for about a hundred years.

Jean's other Illness companion was an Eating Disorder. Although this started when she was

a teenager at school, it became a closer companion when she was about 19 years old. On

this occasion, Psychiatric Medication injections supported her relationship with Eating

Disorder. She explained this connection by saying, "I started getting bloated up on the

needles again. … it caused me bulimia." In 1974 she found her first "slimming pill", and

three years later she "found my first laxatives". From that point, she became obsessed with

food and dieting, and described having a distorted perception of her body: "I was very thin,

but I still looked in the mirror and thought I was big." It will be seen that Jean's experience

of Illness has had a significant and largely negative impact on her relationship with all the

other members of her Supporting Cast. As with Brett, her situation only started to become

more positive in recent years when her existing Psychiatric Medication was replaced by a

newer, kinder one.

Martyn: Spiritual Warfare, not an Illness

As previously stated when introducing Martyn, although doctors had given him the diagnosis of schizophrenia, he did not believe he had a mental illness. For him, the turmoil he had experienced in his life was "spiritual warfare". The voices he continued to hear were a gift from God. In his opinion, it was his struggles with Satan that had led to his admissions to psychiatric hospitals. Martyn believed he needed the companionship of Psychiatric Medication to help him control the voices, but hoped one day to be able to control them without this help.

The first time Martyn heard voices was when he was eight years old. He recalled: "I had a real horrific nightmare of all these voices calling my name out. I woke up in a real cold sweat, it was horrible." Since that time, he has had many psychic experiences, seeing ghosts, hearing God speaking to him, and accurately predicting what people were going to do before they did it. As he explained:

> So I've got a real gift. The trouble is, I can't control it. That's why I need medication to do it. And, when I tell you about spiritual warfare, the reason why I *have* to have meds: in the spiritual, they don't have to rest because they're immortal, they're spirits. In the physical we *need* to rest to keep/get our bodies in tune.

It will be seen in the next chapter that overcoming spiritual warfare formed the basis for both the choice and performance of Martyn's occupations. Standing up for God against Satan has been his "life history – the ups and downs of spiritual warfare where the enemy has tried to destroy me at any cost."

Psychiatric Medication

Psychiatric Medication has formed relationships with all the Heroes in this play. It has taken on many names. Sometimes it is called by its brand name, for example, Melleril

or Modecate. Sometimes it is known by the form in which it entered the actors' bodies, for example, needles, injections or pills. From the stories it became apparent that over the years Mental Health Workers and Agencies had believed they were the masters of Psychiatric Medication, that it was their servant. They also believed that it was friendly and would support the Heroes in their fight against the evil enemy Illness. The Mental Health Workers and Agencies sometimes acknowledged that some forms of Psychiatric Medication had brought with them annoying companions known as Side Effects, which the Heroes needed to learn to live with. However, it would appear that on occasions Psychiatric Medication had become all powerful and had controlled the Heroes' lives. The consequences were at times very unpleasant, and Psychiatric Medication's ability to deceive its masters had left some of the Heroes in a state of misery for many years. As Martyn pointed out,

> In those days, they don't have the atypical drugs they have these days so they had cocktails of really crappy medicine and the side effects are far worse than, sometimes worse than the illness itself. And a number of times I ditched the medication because I, it made me feel so horrible, and of course I ended up in hospital.

Both Terrie and Jure appeared to have experienced a similar Side Effect from the medication. Terrie was able to express this problem in a matter of fact way: "I'm not interested in men. I think the medication we take, takes our sexual feelings away. Kills them". Jure had more difficulty in discussing this issue. He started by saying that Psychiatric Medication had made him feel good. He said: "I'm quite happy because it gives me a good sleep, you see, good rest, and I don't get sick, you see". He appeared to find it embarrassing to talk about the Side Effect, yet came back to the topic three times, so seemed to want me to understand the nature of the problem. The closest he came to identifying it was to say:

But all I know is I'm not worrying about it, and for the second reason because I'm not young any more, I'm 63, you know. I'm 63 and I don't, you know, so, yes, I wouldn't like to, it's nothing to worry about really, nothing to worry about. So if the side effects things, like ah, in the near future one day some scientists who work with medication if they improve that, that would be a big help, you know.

In Jean's experience, the Mental Health Workers and Agencies colluded with Psychiatric Medication. According to her, the hospital staff in the past would "give you an injection. Wouldn't tell you what it was for, what it was called, or what the side effects. You just had to, say, you know, bend over and take them." She believed that the staff at one hospital colluded more than others. "More high dosages they gave one in [Hospital A], 'cos they were *known* for it." The major Side Effects which Jean experienced were drowsiness, gaining weight, and dribbling. The drowsiness affected her ability to get up in the morning: "I started getting sluggish, walking sluggishly, and no-one told me." It also affected how she was regarded in her workplace:

> Pretty hard on the medication because you try and take shorthand on that medication and you'd be falling asleep and dribbling over your shorthand notebook while someone was dictating to you and they'd get disgusted with you. "Wipe that, Jean", or "You're falling asleep, are you?" You know. "Wake up! Wake up!" They'd go. And you can't get your shorthand down properly and then you come to reading it and pretty hard in the workforce because when you get sick, you're not only insulted and ridiculed, you're not really wanted.

The increase in weight led Jean to getting tighter and tighter in her clothes. Her way of dealing with this was to take laxatives. This then caused its own problems. As she explained:

> You imagine going to work full time, taking laxatives, an overdose of laxatives the night before, and trying to control your bowels. I used to sit down taking shorthand notes and there's messes on the back of your dresses. And you have to walk in the city with those messes on your dresses, and go to stay at work all day.

Jean's distrust of both Psychiatric Medication and Mental Health Workers and Agencies appeared to have been based on numerous negative experiences of them ganging

up against her. She was convinced that both a cervical cyst and boils were due to the actions of Psychiatric Medication, and that the health workers knew this. She said emphatically: "They *knew* it was the injections causing the boils. They *must* have known. They sent me to a gynaecologist because he discovered a cyst." He was "concerned". But after leaving the room to speak to the psychiatric hospital social worker about it, "the gynaecologist was made to cover up, saying there was nothing wrong."

Whether Psychiatric Medication was supportive or problematic, not keeping in touch with it allowed Illness to return very quickly. Martyn found that within two days without medication he was "back, completely insane". When Brett first left hospital, he found that missing a pill would have an immediate effect: "Funny that, about a few minutes makes all the difference really. Even quarter of an hour late. It seemed to make a difference". If he missed them, Illness would show itself in the form of a worsening of the voices and feelings of depression. Jean, however, believed that she was given medication sometimes for non-medical reasons. At times she went off her injections and "was happily losing weight naturally". Then if someone upset her, people would place her back on medication. At one point she was taking so much medication that her skin had turned a blue colour. She stated that she read "in a dictionary on their medications once that if your skin goes blue, they're overdosing you." But the nurse stood up for Psychiatric Medication and suggested the blueness was due to her old age. However, now that Jean's medication has been reduced and changed she no longer has that particular problem.

The arrival of new Psychiatric Medication was often seen as a turning point by the Heroes. Jean pointed out that her new pills "are the best because they've hardly any side effects". She is no longer in bed all day. She can "wake up, straight out of bed", which she described as "lovely".

The Mental Health Workers and Agencies who introduced the new Psychiatric Medication servant tended to be seen as Good People, in whom the Heroes placed great faith, despite their history of unpleasant experiences with both previous Psychiatric Medications and Mental Health Workers and Agencies. For example, it was the psychiatrist and key worker who placed Brett in a respite house so they could monitor him while they changed his medication. However, the reason for the change in medication appeared to have been the Side Effects accompanying the previous Psychiatric Medication. He stated:

> I came in here because of my heart. Got me off the Melleril on to these new pills because of my heart. They say it might help me get better too. Mainly my heart and mental problems. I hope so.

To help ensure they remembered to take their medication, a number of the participants talked about the importance of developing a routine for taking their pills. Brett elaborated on this the most. He keeps his tablets on the kitchen table:

> In the morning I have them all ready on the table from the night before … If they're on the table every morning I always remember them but, once in a while I forget them, and it undoes everything then.

It is therefore evident that the participants acknowledged the benefits they received from their regular daily visits to Psychiatric Medication, and the value they placed on this companion when it met their needs without too many side effects. Despite this, some of the participants were planning to desert this loyal companion. Martyn believed that if he did not have Psychiatric Medication in his life at present he "wouldn't sleep, I wouldn't eat, I'd be dead." In his opinion, medication was what stabilized his spiritual warfare. However, like some of the other participants, he had exchanged strong Psychiatric Medications for weaker ones over the years, and was now taking reduced doses of these. He had faith in his psychiatrist, who "believes one day I will be off the meds."

Mental Health Workers and Agencies

Mental Health Workers and Agencies (MHWA) included people who, in the eyes of the participants, ranged from heroic status at one end of the continuum, to the enemy at the other end. These were people from different health professions who worked in government and non-government agencies. The participants referred to nurses and psychiatrists in the hospital and District Health Board (DHB) community services. They also referred to community support workers (CSWs) in non-government agencies. Because the mental health sector in the Auckland area is comparatively small, I recognized some of the names of workers referred to by participants. Some of these workers were occupational therapists and social workers, but the participants described all visiting workers as either nurses or community support workers, no matter what their professional qualifications.

Hospital Based Health Workers

For some of the participants, their first hospital experience provided their first introduction to mental health workers, and this was not always positive. Jean, in particular, experienced a lot of problems in being heard and understood. She told the doctors at [Hospital A] about her trichotillomania but "they would not put a name to it". She described being "dumped" at [Hospital B] "by somebody who didn't want me living there" and the staff "just listened to people who dumped me there, wouldn't listen to me." On another occasion a nurse "laughed and scoffed" and told Jean that her eating disorder was not one of her symptoms. As previously mentioned when discussing Psychiatric Medication, Jean had numerous problems with being prescribed medication without explanation, and without being told about potential side effects. On one occasion when she

questioned the hospital doctor and nurse about her medication, she recalled the doctor

responding with: "Take it Jean, and don't ask any questions."

Martyn's first hospital experience as a 17 year old was also negative. He was locked

in a side room at [Hospital B], and what little communication he had with the nurses was

unpleasant. He recalled:

> I was in there for two weeks. They treated me worse than an animal. They opened
> up the door. They ordered me to kneel on a mattress. 'Cos when you're in seclusion
> all you get is a mattress and one of those, um, cardboard things you urinate in, or
> pooh in, or whatever. So they ordered me to sit down. One nurse would stand at the
> door. The other one would put my meal down, would stand over me, watch me, and
> tell me to eat. As soon as I finished, they slammed the door in my face.

Subsequently, however, Martyn had many positive interactions with staff, and managed to

persuade them to give him all sorts of privileges. He told stories of how he had charmed

nurses into allowing him to have a bath in their bathroom instead of the patients' communal

baths where people "would waltz in and out, no privacy". He also managed to get

permission to go unescorted to the local shops at night. At another hospital, the evening

meal was provided at 4.30pm. By 8pm he was hungry, so he gained permission to go to a

nearby fast food outlet. He explained his ability to persuade staff by stating that once "the

old [Martyn] charm goes on, basically nobody can say 'No'". It was a calculated charm,

however, as he said: "I knew how to *use* the system. Never *abuse* it. Always on the

threshold of what I was able to get out of it. And it gave me the skills to survive on the

outside."

Frank regarded the hospital health workers as the same as everyone else:

"Everyone's human. Staff have their bad days and they're, you get levels with other people,

with the staff, and that, and that's just normal." He credited the staff at his forensic hospital

with the ability to observe the patients accurately, and make sound decisions about their

future:

> But that's the good thing about them, you know, they understand. They know where
> you're coming from, you know. They monitor you and they're making sure you're
> doing all the right things, you know – how you're reacting with the community and
> with work, with meeting new people or paying your bills, or buying food, or
> anything like that.

According to Frank, this observation enabled them to assess whether people should go to a

halfway house, or whether, like Frank, they were ready to go into private accommodation

and share a flat. Despite his understanding of the staff and the systems in which they

worked, Frank did not agree with all aspects of the system. Although he was now living in

the community, he was still a Special Patient. Under this special legal status, he could be

recalled to hospital at any time. This in itself did not seem to worry him, because he

considered he was living successfully in the community with minimal supervision. But he

was concerned that as a Special Patient he was restricted in his ability to travel. Even within

New Zealand, he needed special permission from "Parliament and Ministry of Health" to

travel out of the Auckland area, even to go to his provincial home town. He was not

permitted to leave New Zealand under any circumstances. Thirty-five year old Frank

wanted to travel overseas in the future, and expressed his intention to seek a review of his

Special Patient status, because, he said:

> I figured that I'm totally within my rights. I've been out for two years. There's been
> no qualms for about four or five years. The fact that I'm going in [to the hospital]
> and doing groups and everything's successful, I've had no hassles for the last two
> years and all that sort of stuff.

Consequently Frank believed his goal for review of his status was realistic and reasonable.

Community District Health Board Workers

Most participants appeared to have had predominantly positive relationships with their community based Mental Health Workers and Agencies. All eight continue to have their mental state monitored by a psychiatrist from the District Health Board, and each participant appeared to value his or her current psychiatrist. For example, Martyn was pleased that his doctor supported his belief that he would one day manage without medication, and Jean was delighted that her current psychiatrist treated her with respect. Each participant also has a visiting key worker, who is a qualified health professional. Brett described this person's role by explaining that she "keeps asking me how I'm getting along and what I'm doing around the place. I think (she) would like to see me well." Key workers were credited with helping people get through bad times, as well as creating new opportunities in their lives. For example, Martyn was grateful to one of his nurses in the past who had helped him through a time when he smoked marijuana. Terrie's key worker arranged for her to get into a rehabilitation work programme, which she had now been attending for about twelve years. In contrast, Anne expressed the wish that nurses had been less involved in her and Jure's life in the past. She felt that as a couple they were capable of being more independent, but did not want the nurses to disappear from their lives altogether. "Well, I don't think we should kick the nurses out … We know there's a nurse in if you do need one. But we can do everything on our own now. Mmm." It will be seen that Jure did not agree. He was very grateful for the continuing help he was receiving from all their health workers.

Until recently, Jean's experience of health workers in the community was as negative as it had been in the hospital setting. She said: "And then, when you're out in the

community they come down harshly to you, and in front of other consumers as well." This included, in Jean's eyes, the visiting workers taking her flatmate's side against Jean:

> They supported her more than me, and if we had one of our fights, you know, and she was really at fault, they'd come again hard down on me. *Here,* in my own home, and in front of her. You know? I mean that was sort of *another* rude part what they did.

A visiting nurse made light of her eating disorder, with the nurse stating that she wished she had an eating disorder, then she "would be slim too". Jean told me emphatically: "*It's rude. It is so rude.*" Additional problems arose when a nurse assured her employers that her Psychiatric Medication and Illness would not affect her work. This trapped Jean into feeling that she should try to hide her extreme tiredness caused by the medication. But some days she was so tired that she had to ring in sick. She felt angry that the nurse had placed her in a position in which she felt she needed to lie to keep her job.

In contrast, Jean spoke highly of a previous doctor and nurse who helped her remain off the injections despite a temporary setback in her health. She also praised her current "lovely" psychiatrist and nurse, "because when they do something wrong with me, I go nuts at them and they listen." She was particularly impressed by a recent incident in which her psychiatrist apologized to her. It will be seen that one of Jean's recent occupations was writing a book about her experiences with Mental Health Workers and Agencies, about "the way they've treated me, what they've said … But there've been good ones, very good ones. I must admit. But a lot have been rude."

Non Government Health Workers and Agencies

In addition to their psychiatrists and key workers, all the participants except Frank had received assistance from a non-government agency at some stage since their

hospitalisation. At the time of the interview, four people were visited regularly by community support workers (CSWs). These workers, employed by three different agencies, supported the participants in whatever ways the participants wished. For Terrie and Jean this entailed taking them grocery shopping. In Terrie's case, this was a social event because her CSW takes Terrie's girlfriend from work at the same time. Martyn's CSW appeared to provide moral support, and had encouraged him in his goal of becoming a pastor "when it's the right time". Brett explained that his CSW visited to "help with my house cleaning and gardening and that." Over the years, Brett has had a number of workers visiting him. All have worked alongside him on the house and property, but each has had their own way of doing things. Brett stated that the first CSW would

> come every week and, work for, ah I'd work for about three hours constant, and ah, she wouldn't let me sit down at all. And in the end I said, "Well look I'm having a smoke [CSW's name]. And now I'll come and finish that job.

The worker apparently replied grudgingly, "All right." They had built up a good relationship, to the extent that the CSW co-opted her husband on one occasion to help her paint the inside of Brett's house outside of work hours. Brett enjoyed an equally positive relationship with his current worker, who would arrive at his home and start work. He said that she "didn't ask me to help her but, I *had* to work with her. I couldn't sit back and let her do all the work."

Although Jean has had predominantly positive experiences with the CSWs who visited her, her experience of being employed by non-government agencies had been negative. She stated that the agencies who employed "consumers working for mental health– they're the *rudest* to treat on." Jean related a story about working for one agency as a part time secretary. She believed the health workers there were "lazy". She explained:

> But how they help the consumers there, is had them doped up, say they're sick, dope them up, so we can have our meetings and our cakes at our meetings, and plan for the next meeting. That's all that it's about.

Jean believed the consumers liked her working there, but the manager "thought consumers couldn't do anything" and did not treat her with respect. This was reinforced by another voluntary mental health organization Jean worked for, where the "guy who ran it, he never thought, he used to ring me, even on New Year's Day" for Jean to do some work, which turned out to be "his own private work sometimes".

In the past, Martyn, Jure and Anne had all lived for a period in group homes run by non-government agencies. At the time of the interview, Anthony still lived in a group home, although he was planning to leave within a week to live in a home of his own. In addition, since leaving group homes as a resident, Martyn had since worked as a caregiver in a group home so was aware of their value. However, when he was living there he found the restrictions annoying, and described the main difference between then and now as "freedom". He explained:

> Martyn: There's so many damn rules and regulations in those places. Well, they need it to build structure, but when you are well enough as when I am, you don't need that crap.
> Researcher: What sort of rules did they have that you don't have to worry about now?
> Martyn: Well, curfews for a start, and times you have to eat, have to do the dishes, you know, rules and regulations. In a way, it's an institution in an institution. Which I don't like. I mean I like to be able to, if I want to have takeaways, be able to go down the road and grab them, you know?

As with Martyn and Anthony, both Anne and Jure viewed their group home experience as a stepping stone to living on their own. When they were in the group home they had most things done for them, but they filled their day by attending a rehabilitation centre, where they were involved in sorting and packing tasks. Jure was particularly appreciative of the role which the non-government agency had played in his life. After a short period in the

group home, the agency had placed them in one of their flats where they could live together as a married couple. Jure saved some money and they bought their current home, which they moved into within a year of their discharge from hospital. The agency continued to play a major role in supporting them, which Jure valued highly:

> They've done quite a lot for me, and ah, I believe that I won't like to go anywhere else far from them because I like them to be in charge of me, me and my missus, for the rest of our life. For ah, we feel quite secure that they are in charge of us.

Family

I have already described some aspects of each participant's early life with their families in Chapter Four. As previously described in more detail, Brett talked fondly of his parents, and Terrie and Frank both described happy memories of living with their parents and siblings. Jure left his family behind in Eastern Europe. Neither Anthony nor Anne divulged much about their family upbringing. Martyn recalled being told he needed to act like a man from age 6 years, and he started to care for himself in the downstairs rumpus room when he was 14 years. Despite this, he returned to his parents' home following his hospital admissions, and his mother took time off work to care for him. Jean had an unhappy childhood with her parents fighting and, in her eyes, they favoured her two sisters over her. In this section, I will be exploring the role of the family in later years, since each person left hospital.

Family as the Hero and Supporter

Parents and Siblings

Frank, Terrie and Anthony all consider they have family members who continue to be positive and/or supportive in their lives. Frank was the only participant who had talked

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about playing with his siblings as a child. His close relationships and involvement with family members continued after he left hospital. Apart from spending time with his flatmate, in his leisure time he stated he was "basically hanging round with family, with my sisters, my Mum, my brothers, my nephews and nieces – there's just so many of them – nephews and nieces, and their kids." He continues to have a close friendship with the cousin who used to visit them when he was young. He visits this cousin "quite often". Frank is fond of children, and "there's kiddies wherever I go" which Frank finds "pretty cool".

Whereas Frank's relationship with his family appeared to be interdependent, Terrie's relationship with her family appeared to have been a more dependent one. It was Terrie's mother and brother who bailed her out when she was unwell and had spent money she did not have. She also stayed with this brother for a period following a hospital admission before she obtained her current flat. Terrie continues to visit her 91 year old mother weekly, and talked with warmth about her two brothers: one who "looks after Mum", and the other who has "just come back from Australia" and will shortly be sorting out "his affairs" in Australia so he can stay in New Zealand.

Anthony viewed his relationships with the many people in his life very positively. It was unclear how much contact he had with his father, but it was evident that Anthony held him in the highest regard. His father was the person he mentioned most often in his interview, and the descriptions were always superlative. He told me that his father was "a *wonderful* man" who loved him. "He's very, very good, you know, and I love him very much too." Anthony believed his father would take him home from the group home one day "next week". "And I think my father he'll surprise me in the evening. He'll come

round and take me home the next day." After Anthony has moved into his own home, which he said his father had helped him to purchase, Anthony stated he would

> like my father to become … the most important part of my life because of Jesus. After Mater passed away, I realized that Dad was my real, my peace and love. Then when he dies, I'll, I'll take up the reins from him and continue. But that's a long time away and we shouldn't be morbid.

The Love of One's Life

Four of the participants described the importance of one particular person in their life. This person was either their current spouse, or in Anthony's case, the woman he hoped to marry one day. Jure and Anne married in [Hospital A] about eleven years ago. Jure described Anne as his "missus" and considered they enjoyed a good relationship. He said: "She is very kind to me and I'm kind to her and we get on all right together." Anne was a woman of few words, and her only comment about their relationship was that they were "learning now to sort of trust one another, you know? We couldn't trust one another, but we're getting to know each other a lot better." It will be seen that they do many occupations together, including walking every day. Jure stated he did this for his own health, but added that "it's more for my missus because … mostly she stays home during the daytime, you know?" He would prefer Anne to give up smoking like he did a few years ago, but "that's all she's got really, you know?" He therefore did not "want to push her so far to tell her not to smoke any more, you see." With this understanding, according to Jure they "manage to survive anyway, so far we did."

As stated, Anthony was effusive about most people in his life. Apart from his father, the other person with whom he appeared to have a special relationship was 'H'. He "worries a lot" about 'H'. He was concerned that if he married her he would not have enough money to "buy expensive jewellery … a Rolls Royce, a beautiful big castle, you

know, a, a, a whole way of life to suit her reality about her beliefs." He loved her "very much" and believed that she loved him too, stating: "She will always be a part of my life, you know." As with his father, it was not clear how often Anthony had contact with 'H', as he did not mention any occupations which involved her.

In the past Martyn had "had a lot of partners", and had been previously married, but did not go into detail about these relationships. However, he was keen to talk about the nature of his relationship with his current wife. He said,

> She's an equal to me. She's no better, no worse, she's not my slave. She's not my sex slave either, if you know what I mean…. When you're young and you're a blooded young male, you do push it a bit, if you know what I mean, but now I'm older I realize and I never do. And I love my wife very much.

They have been together for three years and had broken up "seven times" before his wife gave him an ultimatum to get help with his anger. Martyn did this and believed that now "we've got a very good marriage". His relationship with his father, who lived nearby, had also improved over the years. He lived with him following the break-up of his first marriage, and continued to visit him regularly and support him. Martyn had always wanted a big family, and although he and his wife did not have children, he explained that his "wife's family, they have got a lot, a big family, so I socialize with them." Apart from Frank and Martyn, none of the other participants appeared to have significant relationships with their extended family, and not one of the participants had children.

Family as the Villain

For Brett and Jean, their relationships with their siblings since their hospital admissions had not been helpful. Brett made little mention of his brother, but when he did, it was always in a negative light. When they were "a wee bit younger" Brett recalled he

used to "go mad and roar at things and kick the cat and, argue with … my brother". One of Brett's hobbies was to do artwork on cars using his own designs. While others admired his work, Brett said his brother commented, "Oh, that looks ugly". His brother lived less than an hour's drive away and owned a business, but Brett said, "I don't see much of him though", and despite a lengthy pause, chose not to pursue this subject further. It was not until after the interview tape recorder had been switched off that Brett mentioned his sister who lived nearby. His comment was that he saw little of her either.

Jean's problematic relationships with her family continued after her hospitalization. At first she stayed with her mother for a while. She was grateful for her mother doing the cooking "because it was all Weight Watchers" as Jean was trying to lose weight. Her mother also helped her buy the flat and "then she helped me get it freehold". However, her mother was less supportive in other ways. Jean stated that she was

> ashamed when she saw me come. You see, it's not only the community, it's family as well. Who don't really want you. And who are ashamed. Who don't believe in their mental illness. They'd say, "Can't you snap out of it?" if one gets depressed.

Jean believed her mother supported other people against her, or if Jean confided in her mother, her mother would say, "Oh, I think you need a doctor." Her mother was not the only family member to upset her. Jean also told stories of an aunt and cousin who had made fun of her. But she felt particularly betrayed by her younger sister, and described one incident in particular:

> She came on the scene and tried to get hold of me. But she only wanted money for her husband to build up his business. And for the first time in her life she was liking me. She always looked down on me as useless and hopeless before that. And I thought I was going to have a beautiful reunion with her, have a chat with her. Never saw her, when I was going through that loan. They got the loan and then they deserted me.

The Absent Family

Following the interviews, I was left with the impression that some participants did not have a role of being a family member as a regular part of their everyday occupational lives. As discussed, Anthony placed great value on his father and 'H', the woman he loved, but never specified any occasions on which he had contact with them in his daily life. Jean also did not mention any current contact with her family. Brett had not had a life partner. He missed his parents who had died, his mother when he was 38 years old, and his father two or three years after his last hospital admission when he was about 48 years old. His siblings were alive but appeared to be largely absent in his life.

Although Anne and Jure had each other, they did not appear to have regular contact with any other family members in their lives. In Jure's case this was for practical reasons. His family were geographically absent because they lived in Eastern Europe. He still thought of them often and hoped one day to return for a visit to "see my brothers and sisters there, where I was born." Anne's relationships with her family, however, were more nebulous. When asked whether she kept in touch with her family, her only reply was vague: "Well, sort of, you know, yeah. I think we will at the moment, you know, most of them newlyweds and things, a few months, a few years. We're settling into new families and things, you know."

When people have few family members to share their life's experiences, they often place greater value on their friendships. These close personal relationships of the participants will now be explored.

Friends

According to Chambers English Dictionary a friend is "one loving or attached to another: an intimate acquaintance: a favourer, wellwisher, supporter" (Schwarz et al. 1990, p. 567). In this section, I will be setting out the nature of the relationship between participants and individually named people whom they regarded at least as favourers, well-wishers and supporters, and who were not family or health workers. Where necessary, I have used initials to differentiate between two or more people. These initials do not correspond to actual names, in order to protect the privacy of those mentioned.

This definition of friend excluded virtually all the people in Jean's life. She did talk about individuals who have figured in her life – her former flatmate, and people in her places of work – however, none of them appeared to fit the definition of being a well-wisher or supporter. The only exception, was a one line comment she made about how she supported her neighbour: "I try and help my neighbour over there, he's got children." Apart from this, the people she saw most regularly were her health workers.

The Friendly Food Sellers

As stated, Brett had little contact with his brother and sister, but like Jean received regular visits from his health workers. When asked about his friends, he named an old "school buddy" who lived about an hour's drive away. He "came over to be with me about, oh, it was about two years ago last time I saw [him] drive in the gate." Apart from these people, Brett named the man at the local store where he bought his milk and cigarettes every couple of days as a friend. He spoke to this person more frequently than anyone else. He also named three other people who visited "once in a while … and that's about all I've got of my friends." When asked to describe the activities he undertook with his friends

Brett responded, "Most of the time I just sit at home. I'm a loner. … Sometimes I like to be alone. Sometimes I like to be with people. I can't quite make that one out."

Brett's circumstances were echoed by other participants. For Anne and Jure, who like Brett had little contact with family, their friends were also the people who sold them food. Jure started telling me about his friends in New Zealand who were from his home country in Europe. When asked how often he saw these friends, he told the story of one friend who

> grows strawberries and he, ah, plants potatoes as well, in the garden. And ah, I went to get some, matter of fact, some potatoes from him, about 20 kilos from him. And another one is in [name of suburb], [Eastern European] friend and his missus. He's, he has got his veggie, fruit and veggie shop there. And I would get some fruit and veggies from him. Not far from here really.

In addition, Jure attended a club where he met up with "New Zealand people". He stated that "they are good friends to me, up at the Club" and this included one man who was a former nurse at the hospital where Jure and Anne were resident, who "must be into his eighties now". Anne did not go to the Club, and so her friends appeared to be only the fruit and vegetable growers. Both Anne and Jure used to attend a consumer drop-in centre but stopped going a few months ago because Anne was the only female attending, and some of the consumers were "ruffians". So now she stayed at home.

Past Friends in Present Thoughts

In contrast to the participants mentioned in the last section, Anthony named over twenty people as his friends. All except three of these were described in glowing terms. For example, 'J' had "been so good to me, you know?" 'L' "was very, very, good", and 'N' was "very, very good, and I like her a lot, you know, and I do love her." Even the three people that Anthony spoke about negatively were regarded as friends, and people who

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needed help. For example, he said: "It wasn't 'P's fault about me. He needed help. He couldn't get it, so he had to pick on someone. He had to." And while Anthony did not like another friend's "behaviour about me", he was nevertheless regarded as "my best friend". When asked whether he managed to keep in touch with all these people, Anthony replied, "very much so". He said he wrote to them: "I do a lot of writing. I must write about 30 or 40 letters, or logically, I would write probably a letter or so every few weeks anyway." However, he did not receive many responses. It became apparent in his discussion of his occupations, that he did spend time with people in his house and at a consumer drop in centre which he attended. He did not appear to have regular contact with the other friends he listed, some of whom were from his teenage days in England.

Friends I Support

If the definition of friends is that they are supporters, then Martyn was a friend to others. He related a number of stories about how he helped people in his life. The stories were told to illustrate his communication skills and psychic gifts. He explained, "I've got this ability to push people's buttons, communication-wise. And oh man, some people have told me their life story" and gave an example of a man who disclosed a particularly personal experience for the first time in his life. He also described incidents in the past when he used his healing skills on a number of people of his acquaintance. In discussing his current life, Martyn stated that he had "a very busy schedule. There's always someone that rings me up and wants to have some advice. Just like friends, any friends, basically." Martyn worked full time, and spent his leisure time in activities with his wife and her family, as well as keeping in touch with his father. He did not specify how much time he

spent with his friends, but he was very involved attending various Christian activities, from which he appeared to have made a number of friends.

Mutually Supportive Friends

Whereas Martyn talked about his friends as the recipients of his God given abilities, 66 year old Terrie talked about her friends as mutually supportive relationships. She often maintained her friendships through good conversation over a hot drink and cigarettes. She mentioned two longstanding friends, both of whom she had met at her rehabilitation workplace, but one had since retired. Terrie explained that she often catches a bus and visits this friend at her home. She said: "We have breakfast together sometimes, on a Saturday: toasted sandwiches and a cup of coffee and a couple of fags and have a yarn (laugh)." Terrie meets her other friend every weekday morning. They catch a bus together to go to work, but arrive early. "And we go to a lunch bar … and have a cup of tea there, and walk down to [work]." She also meets this friend sometimes at the weekend. They would like to go out more but the friend " can't afford to go out either". So Terrie goes to her "place and we have a cup of coffee and a couple of cigarettes and a bit of a chat, you know." Terrie did not mention any friends who were not associated with the mental health system.

Making New Friends

Frank was the participant who was most recently in a hospital long term. His four year stay in the forensic hospital ended only two years ago. He returns there regularly to speak to groups of consumers and encourage them. He talked about these people as "the guys", but did not name any individuals, or describe any of them as his friend. Frank appeared to mix well with people, including his flatmate. However, the flatmate was a

consumer on a limited income who worked in a rehabilitation scheme. Frank had been

working full time in the mainstream workforce and therefore had more discretionary

money. For this reason, Frank hoped to move to another "place" soon where he could share

with "people with steady jobs", who would be able to afford to "go out to a restaurant" with

him, and who had "good work ethics. And um, basically, you know, people, you know, that

don't drink, obviously, no drugs like here in my flat." Frank commented that some of his

friends and some members of his extended family have offered him drugs in recent times,

but that he had not taken any for about six years. Although he talked about doing things

with his flatmate and family, Frank did not describe any occupations involving other

friends.

Community

This thesis is concerned with people living in the community. I have already

introduced the role of Mental Health Workers and Agencies in the lives of the Heroes. In

this section, I am defining Community as those people or groups who do not form part of

the government mental health system, and are not family members or designated as

individually named friends. This section therefore includes other people with mental illness

and other work colleagues whom the participants do not regard as Friends.

Interaction with Community has been experienced by a number of the Heroes of

this play as being stigmatized because of their relationship with Illness. Frank talked about

moving from town to town so that he could start afresh without people knowing about his

mental illness. He was describing someone who had recently "flipped", and said:

I could see it in him how I used to feel like. Sort of ashamed, like I'd, I'd been crazy
… How I used to deal with it was just run away – go to [three regions] where people
don't know you, where you can start, you know, be yourself. And then, when you
get back to people that know you and what you've been through, you go sort of all
ashamed and this.

Jean was the only participant to describe any specific incidents involving members of the

general community. When asked what she found difficult about doing her grocery

shopping, she related a story about the time when she was still receiving injections for her

medication. She explained that the problem with shopping was in fact the walk home:

Walking home, people ridiculing, laughing in their cars going past late at night,
with groceries going, trying to pick up the groceries, and people would be laughing
at you. 'Cos you didn't know how to dress either. You didn't know how to have a
sense of fashion on the needles, as well. You had no sense of fashion.

In the literature review in Chapter Two, it became apparent that many people with

mental illness wanted to obtain and maintain paid employment. However, prejudice made

this very difficult. Martyn had managed to obtain work easily, often as a caregiver, but as

he explained he did not disclose his mental illness:

Martyn: They don't know I've got a mental illness over there or I probably wouldn't have
got the job in the first place. They say there's no discrimination, but that's bullshit.
There is, and always will be.
Researcher: Have you experienced that yourself?
Martyn: Oh, yeah most definitely. That's why when you go for a job interview, you never
write it down. You know that as soon as you write down that you suffer from
schizophrenia, especially schizophrenia, what the media makes of it, they just screw
it up in file 13.

I have already described a number of incidents when Jean felt she was being treated

unfairly by Family and Mental Health Workers and Agencies. She also experienced

problems in non-mental health workplaces. She worked for many years for a government

department as a shorthand typist, and while there she had a number of psychiatric hospital

admissions. At one point she was selected to do the secretarial work for the department's

first lawyer. Soon after this she was admitted to hospital. On her return to work she was no longer wanted for the position. She said:

> When I came out, I was stopped from doing the lawyer's work. And then they started promoting typists there – in the typing pool, people, senior typists - to do the legal work. They wouldn't accept my application because they said my psych. illness. Yet I was the one they had chosen. Before I went into [Hospital B], before I started all those injections, they got me to do the lawyer's work. And yet they started promoting typists to do the legal and medical work.

It was not only the senior staff who gave Jean a hard time. She described her feelings when her colleagues nominated her for a position in the Social Club but not one person voted for her: "And I not only felt belittled, I was holding back tears." She described another incident at the Christmas Social Club party one year, in which colleagues made it clear they did not want her to sit with them at lunchtime. Jean could see everyone else "was grouped together and talking to one another and having fun" so she walked out and caught the bus home. Her conclusion was that it was "pretty hard in the workforce because [if] you got sick, you're not only insulted and ridiculed, you're not really wanted."

Prejudice was not just the prerogative of the general community. It appeared to be a universal trait, which people with mental illness also exercised from time to time. Terrie was concerned about being treated with stigma for a condition she did not have. She was embarrassed when she was living in Australia about having to go for her injection to the same clinic where people were being treated for venereal diseases. She stated: "And I got so ashamed, thinking that people might think I had venereal disease." She refused to go, and it was arranged for her to receive injections from her GP instead. It was important for Anthony to differentiate between himself and some other people with mental illness. He commented that he was happy to move from [Hospital B] "because a lot of patients there weren't quite normal." Jean was the only participant to claim being on the receiving end of

criticism from other people with a mental illness. She described the time when the combination of the side effects of her medication and her weight problems caused her to appear bloated. At this particular time, she stated that her flatmate, a mental health consumer who had some training as a hairdresser, "used to make a wreck of my hair really." Jean was hurt when, as a result, another "consumer rang up and called me, likened me to having Downs Syndrome, calling me a Mongol." Jean also found other people with mental illness were unsympathetic to her. She described how "even some consumers, if I cried to them, even when I've hardly cried before with them, have been happy around, they [would say], Oh what's wrong now?" She was particularly upset when they showed sympathy to someone who had "a beautiful home, swimming pool and that" but not to her. Jean's conclusion was that people with mental illness "don't understand, do they?"

Despite the stigma experienced, five of the eight participants did take part in non-mental health community activities. The exceptions were Brett who had few relationships in his life; Anne whose social life depended on where Jure took her; and Terrie who mixed with friends, but did not appear to have relationships with anyone outside the mental health arena. In contrast, Frank and Martyn worked in mainstream employment; Anthony and Martyn attended church regularly; Jean attended courses run by a private educational establishment, and Jure enjoyed spending time at a Cosmopolitan Club. These activities will be described in more detail in the next chapter, which explores the occupations of the participants.

Chapter Six: Occupational Plots

In the previous chapters, I introduced the Heroes of this story, and those people or issues which have played major or minor supporting roles in their lives. In this chapter I will explore the occupational plots which make up the fabric of the everyday life of the Heroes. After describing their weekday and weekend routines, I will examine the occupations which typically fill their days.

Weekday Routines

The weekday routine for Martyn, Terrie, and Frank is structured by the requirements of their paid employment. They organise their early morning activities to ensure they arrive at work on time, and their other activities can only take place after they return from work. This was typical for some of the other participants in the past when they were also working. For example, although Anne said little about her current daily routine with Jure, she went into detail about her routine when they were living in a group home and attending work rehabilitation. She stated:

> Well, we would get up … about 7 o'clock in the morning sometimes. We would have breakfast, do the dishes, go to work, come home, have cleaning jobs, and um, get money on a Thursday night, go down and buy cigarettes.

There is less need now for Anne, Jure, Brett and Jean to get up at a set time, and they have more flexibility in what they do during the day. Years ago, when Jean was working full time, getting out of bed was always a problem, because of the effects of her medication. Now that her medication has been changed she can jump out of bed feeling refreshed,

which she described as "lovely". Jure, however, preferred to stay in bed a little longer

because he does not sleep well over night. So he declared that "even at ten o'clock in the

morning, if I'm still in bed, I quite happy with that, you know?" Despite this flexibility,

most participants have adopted routines of some description. Brett stated that he does

> most of the housework in the morning, straight after breakfast. I guess I would
> finish that about ten o'clock, or half past ten and I have a bit of a rest. And in the
> afternoon I might go out and do something if it's not too hot. Anything round the
> garden.

Anthony's start to the day is similar. He usually has breakfast and does his "duties", takes

his medication and is ready to undertake his other activities by 9.30am. Taking medication

has formed part of the daily routine of all the participants: after breakfast for Anthony and

Brett, and at night for Jure. The importance of this to the participants was discussed when

introducing the persona of Psychiatric Medication.

For Brett, there is a seasonal difference in his routines. In winter, he finds the time

goes more slowly as he is unable to get into the garden. He then uses smoking to help mark

the passage of time. He said:

> Ah, if I haven't got something on TV I just sit in the chair, space my cigarettes out
> to about one an hour. And if I run out I just stare at the wall and wait for the next
> time around to smoke. That's when it gets boring, when it's wet and that. I'm just
> there, pacing about. I mightn't be doing much but at least it's better than getting all
> het up over voices and, smoking too much. I don't drink at all."

It is Anthony, however, who has the most elaborate weekday routine. This is likely

to be because he lives in a group home, where staff have either introduced him to activities,

or organized some for all the residents. It is also likely to be because he lives in the city

where he is closer to some activities than the other participants who do not work during the

day. Staff may have introduced Anthony to activities, but he appears to have made his own

choice about which activities he continues to participate in, as he and the other residents do

not all do the same things. He said: "Most of the things we chose ourselves … We did most of the things on our own, you know … getting up in the morning and trying to make choices about the sort of things we want to do." Anthony described his typical week as follows:

> You know, I just, I mean, I go to the Club on Wednesday and Friday, and on Monday we don't have anything to do. Ah, we don't have anything to do on Saturday, and Sunday is a very big day cooking, and then I shop once a fortnight on Tuesday. And then on Wednesdays and Fridays I'm at the Club. So it's not really very much.

'Club' is the word Anthony used to describe the mental health drop in centre he attended, which was "a lot of fun". In addition to the activities mentioned above, elsewhere during the interview Anthony stated he attended a recreation group on Thursdays.

Weekend Routines

For Martyn and Anthony, Sundays are the day they attend church. Sunday is also the day when Anthony helps with the cooking in the house. But for Anne, Jure and Brett, the weekends are little different from weekdays. Brett described how when he was younger, at work, he used to "take it easier" at weekends. But now he does the same chores and gardening as he does during the week. As working people, both Terrie and Frank use the weekend to catch up with household tasks, such as laundry washing and cleaning. This is also the time when they visit their friends and do most of their leisure activities.

Paid Employment

Each participant described his or her work experience in great detail, whether it was Jure assembling spray bottles or Frank cleaning cars when they were in hospital, Terrie and Anne working at their rehabilitation centres, or Frank and Martyn describing their mainstream jobs. Anthony was very keen to obtain a "proper job" one day, but did not appear to have done so yet in his life. Jean had not been working for the last two years since she left her unhappy experience with the non-government agency (described in the previous chapter under the heading Mental Health Workers and Agencies). However, she had been undertaking courses. She explained that she was currently "trying to finish" a Business and Computing Certificate and an Employment Certificate. She hoped she may then get "into a business of my own here." She had also registered with an employment agency. In contrast to Jean's continuing efforts to obtain employment, Jure, Anne and Brett considered they were too old now to work in paid employment.

Martyn had held a number of different types of job. He started working with his father in a shop for twelve years. Following that he was a storeman, and at one stage he did some gardening for a non-government mental health agency. However, in recent years he had been a caregiver. He worked initially in residential group homes for non-government mental health agencies, but was now employed in a rest home as a caregiver for people with dementia. He described caregiving as his "forte" and his "passion". He stated: "It's a responsible job, a very responsible job. But I love that type of work, always have done." He believed his own experiences helped him to be patient and understanding with the people he cared for, saying:

> Well, most of the people there are, have dementia, which is Alzheimers. It is a horrible word but they're demented. One minute they can think one thing. The next minute, totally gone. I mean I can say to someone, because toileting is a very

important thing, say to someone: "Stay there for five minutes and I'll be back." You leave them for two seconds, they're up and wandering around. They have no idea. I've got the patience there to give those people. I mean, I've *been* there. I know what it's like.

In stark contrast to Martyn's work with people, Terrie works with nails. She has been working at a rehabilitation centre for the last twelve years. She used to work full time, but "it became too much for me because I was getting too tired of a weekend and I couldn't do anything." So her hours have been reduced. She now works six hours each on Mondays and Wednesdays, and mornings only on the other days. As stated previously, work is a social experience for Terrie. She meets her friend and they catch the bus together. Once they arrive at work everyone starts the day by sitting and having "a cup of coffee and a smoke". She then works hard packing nails:

> I'm on the nails. They weigh 500 grams of nails. There's people on the table and they're putting nails in little cups. The cups weigh ten grams. And um, we weigh them to 500. Put minus ten on the scale and that accounts for the weight of the cup? And then we put them from the cups. We put them into bags and seal them. And put 50 in a box, that's in the lumburlocks. And then we have the boxes. There are all different kinds of nails: spiral, bright, clouts, panel pins, annular grooved. All that kind of thing, you know, big nails like this. And we pack them in boxes, in wooden boxes. They go in wooden boxes. And ah, there's 50 to a box. It all depends on what they are. Some of them you can only get 30. Some of them you can only get 40. The bigger the nails, the less you can get in the box. So ah, and then when the pallet's full, a layer on the bottom, that's five – four fives are twenty – that's twenty on one layer. We do three layers and then they're sent back to where they come from to be sold. That's what I do.

When I asked Terrie what she does or does not enjoy about her work, she replied: "There's nothing I don't like about work. You get to meet all the people. And you're in contact with friends all the time."

Whereas Terrie has worked in the same place for twelve years, Frank has had many different jobs. In his earlier days he set up his own lawn mowing business, and did sales work. At hospital, he cleaned cars for extra money. He currently does carpentry work. He

started out as a labourer, but has now progressed to being a hammer hand, which he preferred. He explained that the money was better, although still "not that much, but it's enough to get by on." Frank described what he liked about his hammer hand job:

> We have a great, um, you know, working relationship, me and these two chippies … We have so much fun, you know, just sitting around and joke at lunch times and joke with you on the side and laugh and carry on. Keep doing our work, you know?

He also preferred the greater variety as a hammer hand compared to labouring, commenting that the greater range of tasks is "just so cool."

Managing the Household

All the participants have taken responsibility for some of the everyday tasks in their households. Those who lived alone have had little choice but to do everything themselves. Anthony was responsible for his own rooms, and appeared to have been allocated some of the communal tasks in the group home. Jure and Anne shared their household management tasks, as did Martyn and his wife.

When asked where they learned these skills, Terrie, Anne, and Jean talked about learning from their family when they were young. As Anne said, "I think in life you're brought up with your family, you know, and [they] taught you how to cook and wash and that." In addition, Terrie took over "all the chores" when she lived at home when her parents were getting older. This was after her first hospital admission, and she initially found the experience "a bit frightening", as she was handling "the most money I had ever had." But she did all that her mother asked of her without any problems, so "after that I was OK," she said.

Martyn taught himself household tasks as a young man. As he explained, "When you're a bachelor if you don't do it yourself you'll just starve, your clothes will never get washed. So I had to do it myself." Jure believed that repetition helped him and Anne to learn to do what was required. He said that when he first left hospital he did not find it easy, but "by doing the same thing every day, we got used to it all." Brett, however, believed there was little skill involved. With respect to housework, he explained that "Ah, well, they're not all that hard to do – cooking the meals and vacuuming the house out." His view of maintaining the property was very similar. He said: "There's no real skill to it, it's just work."

Cleaning

It appeared to be Anthony's job to clean out the dining area in the group home. He swept and mopped the floor every day. Jure and Anne both stated that Anne made the bed, did the dishes, and washed the clothes. Jure did the vacuuming "sometimes". When Anne was asked what things in her life she enjoyed doing, she replied: "At the moment a bit of housekeeping's quite good." This opinion was not shared by Terrie, who found housework a "struggle", especially when she worked all week. "Now I find it a chore doing my housework because I'm 66 now. And I'm beginning to feel my age." She stated that it took her the whole weekend to "clean out the kitchen, vacuum out and mop the floors. And, um, clean the outside of the cupboards because they get dirty." The daily tasks which Brett enjoyed doing the most were "washing the dishes and cleaning the table." He also used to vacuum the carpet every day, but his community support worker advised him to only do it "two times a week instead."

Living with other people did not always result in a mutually acceptable

arrangement with household tasks. Jean was pleased with the way she kept her flat now, but

previously, she had had a flatmate, whom she described as "rather messy".

> And she took over the housework because, she was another one that was calling me
> useless. But when she did the housework, she did everything in five minutes. And
> then after five minutes, it was dirty again. And she thought it was spotless. And she
> stored like her clothes and that in the bedroom. The wardrobe was *chokka*. You
> couldn't shut it.

Jean was pleased when this flatmate left, and she could keep the flat tidy the way she

wanted it. In contrast, Frank appeared content with the division of labour with his flatmate,

even though it appeared that Frank always had the job of cleaning the communal areas. He

talked enthusiastically about getting out of bed at 8am on a Saturday and experiencing "a

little buzz when I'm cleaning", and found himself doing one task after another.

Cooking

Martyn stated he enjoyed cooking so his wife "does most of the dishes, but we

alternate that. If I cook she does the dishes, vice versa." As described when introducing

Family, this was in line with Martyn's strongly held belief that he and his wife were equals.

In contrast, Jure and Anne tended to have separate duties, and it was Jure who did all the

cooking.

Jean had had little experience of cooking prior to moving to her flat, apart from

baking things like scones and chocolate cake, because her mother did most of the cooking

when she was living at home. So when Jean acquired a flatmate, the flatmate "took over the

cooking" because she did not like Jean's attempts. However, the flatmate used to buy

expensive food, Jean said emphatically, "like buying bags of tomatoes in the *middle of*

winter." Once her flatmate had left, Jean started to develop her own cooking skills. She described her favourite dishes in detail:

> But really, over the last two years, I've really sort of taught myself, starting off with something simple, like a cup of noodles or something … I can do a packet of noodles, a few vegetables added to it, and soya sauce or Worcestershire sauce and things like that. A pasta dish, you know, cheese sauce, cauliflower cheese. Things like that. Put it under the grill for a little while. Put a bit more grated cheese and breadcrumbs over the top of the sauce, and then put it under the grill for a while. And that's a meal in itself.

Terrie also enjoyed cooking and went into similar detail about a fried rice dish which she prepared on a Friday, and which lasted her until the next Monday. She also cooked pasta dishes "because I want to lose weight." She had lost two stone by using a herbal weight loss drink and drinking "eight glasses of water a day".

Anthony's situation was a little different because he lived in the group home. He helped to cook "the meals for the house" on a Sunday. He explained that "the cooking is designated by the staff. They're in charge of making sure that we cook the meals." He mentioned having toast and eggs for breakfast during the week, but it was not clear whether he or one of the other residents prepared it. He was very clear about how he liked his eggs, though. He volunteered that he preferred "the ones where you have the egg in the egg cup? You cut the top off and dip the toast in it. We love that. It's one of our *favourites*."

Grocery Shopping

Grocery shopping appeared to be a social event for several of the participants. For example, it was when Brett popped down to get cigarettes and milk at the local store that he met his friendly store owner, the person he talked to most frequently in his life. His weekly grocery shopping to the nearest town was also a social event. It gave him "a break from sitting at home". He would take time to have a cup of tea and "a good look around". Jure

and Anne did their weekly shopping together, and as pointed out previously, they considered the people they bought their fruit and vegetables from as their friends. One of these friends lived about a ten minute walk away from them, and the other was only a few minutes drive away. For Terrie, shopping was also an outing with her girlfriend from work, as her community support worker took them both shopping together on a Friday after work.

Property Maintenance

Apart from Jean who mentioned in passing that she sometimes tended to her flowers, Brett appeared to be the only participant for whom gardening and maintaining his property was a regular occupation. Because his house is on a few acres of land, this was a major undertaking, and he was grateful for the help he received from his community support worker who sometimes worked alongside him. When his father was alive, Brett used to mow the lawns and help his father with planting trees, but he now reflected that he "didn't do a heck of a lot when Dad was alive," and that he "should have been more helpful for him." Brett continues to mow the lawns, but also digs the vegetable garden, sweeps the concrete, and prunes back the jasmine, honeysuckle and other creepers. Pruning was not a job he enjoyed. He described all the creepers as "terrible stuff. It gets on every tree and pulls it down. Half the time, I'm cutting it back, in the heat, trying to clear away vines, cut trees out that are getting in the road. It's hard work." Brett did not seem to enjoy maintaining the property, and used the word "work" to describe all the activities associated with it, rewarding himself with a cigarette when he completed a task. He explained: "I force myself to do the work. I don't like doing it but I feel better once I've done it. I can have a cigarette and think, oh well, I earnt that one."

Finances

Only Martyn and Frank have been earning full wages from their employment. Frank viewed his income as an important tool in attaining the lifestyle he was planning for his future. This included being able to go out to restaurants and socialise with friends who also had a good wage. Martyn did not discuss finances, but he and his wife live in comfortable surroundings, and he appeared to be able to afford the social activities he valued, which are described later in this Chapter.

Although Terrie worked daily, people at the rehabilitation centre did not receive market wages for their efforts. So she and the five non-working participants have had to manage their limited incomes very carefully. Although Terrie has had problems with money in the past when she was unwell and imagined she was a "millionaire", she stated she can now "manage my affairs quite well." Other participants have needed assistance with money management. Jean currently receives help from a budgeter. But budgeting advice from District Health Board workers was not sufficient to enable Jure and Anne to manage. Eventually, their money worries became too stressful. Jure was consequently very relieved when the non-government agency which supported them in other ways, took over responsibility for paying the major bills. He described what happened:

> I saved … and with that money I bought my own place … And, uh, unfortunately because it was a bit too much for me to think about paying rates, telephone, electricity, so I decided to sell the house to Housing New Zealand. Which they agreed to buy it off me, and ah … we made agreement. We've got this [arrangement] that we stay still in this house and, ah, now I don't have to, think about all the bills that comes for me, you know?

Jure continues to pay a few minor accounts, especially the pharmacy bills and his international phone calls, but the agency manages all the rest.

Anthony pays board to the group home, but this is automatically deducted from his benefit entitlement. All of the remainder is therefore available for discretionary spending. He said: "There's $230, all right, one fortnight, and the other fortnight there's $130. That's all the money I've got to spend." He often spent some of this on CDs when he went shopping (not for groceries) every second Tuesday. Anthony worried about money, but not about how to pay his current expenses. Instead, he was concerned that when he moved into his own home he would have problems managing on his limited income. "I don't have much money," he said, "so I have to take care."

Use of Leisure Time

In addition to spending some of their week undertaking various household tasks, all participants were involved in a number of leisure activities. These are described below, starting with those pastimes which the greatest number of participants have in common, and progressing to activities which only one participant has mentioned. The final category, other pursuits, is a list of occupations mentioned in passing by participants without elaboration.

Watching Television

Television was specifically mentioned by five of the participants, and performed an important function in each of their lives. For Jure, television kept him company overnight when he had trouble sleeping. He said: "And during the night I go – if I feel like it, I watch BBC News on TV, and ah, I follow that." He also named a favourite soap opera in the

evening which he enjoyed watching. Anne stated that she watched television when Jure was out during the day.

For Jean, television appeared to be a major source of entertainment. She sometimes switched it on in the morning, and explained:

> I like the breakfast shows. Or even earlier, like the BBC News. I like to watch a bit of telly. I used to like to get up early on Saturday mornings and put TV1 on because they have an old-fashioned play on. It's a repeat but I loved it.

Jean also watched television in the afternoons if she was at home. She named all the programmes on one particular channel from noon to 4pm, all of which she enjoyed.

As a working person, Terrie used television during weekdays as her relaxation after work. She described getting home in the afternoon and switching it on. She listed all the programmes (on a different channel from Jean) in the late afternoon. She stated that at six o'clock she watched the News. She would go to bed following this as she had to get up at 5am. on weekdays. On Sundays, Terrie often watched the afternoon programmes on a different channel. Sometimes she would watch horse racing, and liked to pick out horses, but she told me she did not bet on them.

Like Terrie, Frank also enjoyed television in the evenings after work, with a daily soap opera and comedies being his favourites. However, his flatmate preferred to watch science fiction programmes, so they had two televisions in the flat. Frank's other evening pastime was watching videos, which he did regularly.

Physical Exercise

Not one of the participants appeared to take part in organised sports. However, walking formed a regular part of the recreational lives of Brett, Jure, Anne and Jean. Brett enjoyed walking "over the back of the farm". He believed it "scares most of the voices" and

generally assists his "mental outlook". Fitness was the reason that Jure gave for Anne and him walking. After breakfast, he and Anne "go for a walk about one kilometre there and back, about two kilometres walk each morning, yeah. So that keeps us fit." They usually found somewhere scenic to walk which was also "nice and peaceful". This was in contrast to their home, where the sound of passing cars could be heard constantly. Jure believed walking was particularly beneficial for Anne, who otherwise did little exercise, whereas he was "mostly standing on my feet, you know, and walking around the table" when he played snooker. Although walking was a necessity for Jean, she also walked for enjoyment. She said: "And I like walking. Like today, I think it's going to get hotter today. So I might get into shorts later on and go up the road and get my coffee." Terrie did not comment on whether she enjoyed walking. However, like Jean she did not own a car, so was reliant on walking and catching buses to get to work, and to visit her friends and mother.

Socialising

Social contact with family and friends formed an enjoyable part of both Martyn and Frank's lives. When asked to describe what socialising meant to him, Martyn responded, it included having "a bit of a yabber. Have the odd drink. I, um, I used to smoke but I gave that up about five years ago. Can't stand the smell of it now." He and his wife's family would get together for meals. He also spent time talking to friends on the phone, and visited his father as well.

Socialising was also a regular part of Jure's life. He and Anne used to attend a drop-in centre together, where they both played pool. But they left recently because as Anne said, "there were too many roughs there." Since then, Anne has stayed at home, but Jure has been going regularly to the local Cosmopolitan Club to play pool and snooker.

Anthony's Club was a drop-in centre. He enjoyed sitting outside the venue with other people with mental illness. He said, "We just talk about things, you know, just relax and have a cup of coffee, have a cigarette."

Both Jean and Brett made comments suggesting that they wished they had more social contact. Jean said that she was "very lonely". Even other mental health consumers who used to visit her when she had her flatmate, no longer came now that Jean was on her own. Brett had recently come to realize that his life had been "barren". Despite being a "loner", there were times when he liked to be with people, and he missed listening to his parents talking together when they were alive.

Religious Participation

As has been stated, Martyn believed he did not have a mental illness, but was enveloped in spiritual warfare. He had psychic abilities, and the power of spiritual healing. He described himself as an "avid Christian". His beliefs were a part of his everyday life. Apart from citing a number of incidents to illustrate his psychic abilities, and occasions when he had used his healing power, Martyn explained that wherever he is he "can feel a gentle breeze as if He's all around." It is not surprising, therefore, that his occupations included developing his religious knowledge and beliefs. He attended church regularly on Sundays. He has participated in Promise Keepers, which he described as a "men's ministry", a "two day workshop all devoted to Christian men." He had also attended a preaching course "down at the local church" and hoped one day to become a pastor.

Both Anthony and Jure also discussed their religious beliefs. Jure no longer attended church but pointed out that "that doesn't mean we don't believe in God, you

know?" Anthony continued to attend church regularly, and made a number of references to praying as a part of his everyday life.

Sharing Experiences

Sharing their experiences of relating to Illness, Mental Health Workers and Agencies, and Psychiatric Medication, was an important part of both Jean and Frank's lives. Jean was writing about her psychiatric experiences. She said: "I've nearly finished a book, one book. But I'm planned on writing more." She wanted people to know about the many bad experiences she had had with health workers in the past, as well as some good ones. She was unsure about how to get her book published, but was determined to find a way, because she knew "psychiatrists and psychiatric staff" would benefit from her experiences. She said, "Because it *will help*. Each book *will help*, you know? Because your dignity goes right out the door in all ways. Not only in the family, within the community, you know, the staff there as well, you know?"

Frank's experiences with the system had been more positive. Like Jean, he had written about his time of illness, and intended to send the story to a film director for consideration. However, his major activity, apart from his job, was his regular visits to the forensic hospital in which he had spent four years. He talked to groups there, sharing with the men what he had learned, and encouraging them to keep trying. He wrote down what he wanted to say on cards "so I know what I'm saying, you know?" He believed he was well accepted by the men "because I've been through there … I know what it's like. I know what the process is, you know?" He focused on telling them how each of the different units at the hospital worked. Frank told me why this was important:

> … so when they go there, they already understand what's going to be going on before they get there. And to encourage them to, you know, to be patient. It's very tough on those, some of those sitting there for months and months. And you don't know … what's happening to you, don't know how long you are staying there, are you going to move on, you know, things like that … So I explain to them about things like that, you know, or court issues and things.

He advised them about what to ask their lawyers, and also informed them about the role of the Patient Advocate because "it's very difficult when you are in a place and you don't know what's happening." He also gave them advice about the need to control their anger. He believed that "if you can walk away from arguments or things like that while you're in there, when you get outside you are going to be able to do the same thing." He advised the men to take their medication and stop smoking drugs and drinking beer because "you're going to be back in here for another two or three years, and you *don't* want that." Frank wanted the men to know that life is "too good in the community" to waste by using drugs or alcohol.

Artistic Pursuits

Brett enjoyed art work and described it as a "bit of a hobby". Previously, he had combined his interest in art with his interest in cars. He had decorated each car he had owned over the years with his own art work designs. As stated previously, Brett's brother described his designs as "ugly", but he said "some people said, 'Oh no, it looks great', so I don't know whether it looks all right or not." Brett also used to make and sell ornamental wooden bird houses from home. He estimated that over the years he had made about fifty. However, he did not do this any more "because people have gone off my type of hut now." He described the ones he made as "old-fashioned" and explained that people seemed to

prefer more ornate ones with curves now. In addition to these activiites, Brett sometimes sat and drew "all day" in books.

Anthony also enjoyed art, and said that at the Club he attended he had done "a lot of art work", and "some sketches and poetry". Anthony referred to "things I have built" or "made myself" that were in his room, but he did not elaborate on these creations. He also stated with enthusiasm that he had invented "the Honda Busby hover car", "gyroscopic television" and "artificial stereophonic intelligences which is an *amazing* idea." He did "a lot of writing", saying he had had "eleven children's books published". He also wrote many letters, but appeared to get few replies.

Music and Filmmaking

For Anthony, music and the film industry were major interests. This stemmed from when he was a member of a band in England as a teenager and taught himself to play the guitar. That was over twenty years ago. He still hoped to become a pop star in the future, to act in and direct a film. Anthony experienced much pleasure from the objects in his rooms, and emphasized the music and entertainment equipment he owned. He said with pride: "I have a lot of music, you know. I've got LPs, videos, cassettes, singles. I've got a television. I've got a radio. You know I've got *lots* of CD players. I've got *plenty* of stereophonic equipment." He then went on to list in less detail items like clothing, cushions and his couch. He also had posters from films on his walls: "The Exorcist, Star Wars, Saturday Night Fever, Lost in Space. So it's very colourful." He volunteered that his musical preferences were "the Beatles, and, um, I also like the Rolling Stones, Pink Floyd, you know, that sort of music." He found music very relaxing, saying "If I hear a lovely song usually I feel like I'm OK, there's nothing wrong with me, you know?"

Personal Development

Martyn reflected a great deal on his actions and behaviour. In addition to participating in courses connected with his spiritual beliefs, he has also undertaken counselling for his own personal development. The initiative for this came from his wife, who gave him an ultimatum to deal with his anger. From the counselling he had gained an understanding of the source of his anger, which stemmed back to his childhood. He also learned coping techniques, and was eager to pass on this knowledge:

> And when I get angry with wife, whoever, I say, 'I'm not going to talk to you now, I am angry. I don't want to say anything to you I may regret. I'm going for a long walk.' That's one of my therapeutic ways. I've got a twelve-step plan I've written. I'll give that to you once you've finished. Remind me to do that.

Martyn has passed on his twelve step plan to other health workers, who have in turn distributed it to other people with mental illness, which pleased Martyn because he wanted others to be able to learn from his experiences.

Other Pursuits

In addition to the major leisure occupations already described, some of the participants also mentioned other activities in passing. Brett, Anne, Jean, Terrie and Anthony all mentioned reading books as something they did from time to time. Jean and Terrie also listened to the radio. Anthony sometimes went on organised trips to the beach or swimming pool with the other residents in the group home. Frank enjoyed looking around shops and markets, watching videos, and going to the pictures. Jure and Anne sometimes played the card game Euchre together. Anne also stated that they spent time together "just relaxing on our own".

In this chapter I have attempted to present the everyday lives of the heroes. It was apparent that those in paid employment needed to adhere to more fixed routines during the week, and reserve socialising and undertaking household tasks for the weekends. Although all participants performed most household tasks to their satisfaction, managing finances proved to be problematic for some. Brett was the only participant who spent substantial periods of time in maintaining his property. For those not working, walking and watching television were common leisure occupations, and they generally had few social contacts. The other recreational activities discussed were enjoyed by only one or two participants, reflecting their particular interests and circumstances.

Chapter Seven: The Moral of the Stories

This chapter presents the Heroes talking about the moral of their stories. Chambers English Dictionary (Schwarz et al.1992) defined the moral as the "practical lesson that can be drawn from anything: an exposition of such lesson by way of conclusion: a symbol" (p. 930). As stated previously, stories of morality tended to end with Virtues being Victorious over the Vices (Cassell & Company, 1968). The end of one story also often signals the beginning of the next one (Ricoeur, 1980). It will be seen that, as well as describing what they have discovered about life so far, most of the participants also expressed their hopes and intentions for the future.

Philosophy of Life

All the participants told a story about struggling in the past. For example, Brett described the last few years by saying: "It's slightly better than it used to be … between the ages of … 23 and 38. Those years were bad. I didn't have much of a good outlook on life. Since then I've sort of come a bit better. Took me a long time though." It will be seen that, like Brett, all the participants viewed their present life in positive terms, and their aspirations for the future were consistent with their overall philosophy of life. Despite each person experiencing his or her own unique journey in life, the philosophies of the eight participants seemed to fit into one of two main themes: taking one day at a time, and progressing from vices to virtues.

Taking One Day at a Time

The lesson which appeared to symbolize the moral of the stories for Brett, Anne, Jure and Terrie, was that taking one day at a time was what worked best for them. In the past, Brett would have liked "to have got a job and, had friends and that and hang around, but I'm older now and it sort of, doesn't worry me any more." Now he preferred to "sit back a bit, just have to take it easy a bit sometimes." He considered that over the last few years he had been doing

> fair enough, yeah. As long as I don't miss my pills. … I would say it was all right. Ah, I had me ups and downs over the years with mental and emotional problems, but for the most part it was fair enough, could have done a lot worse.

Terrie's philosophy was very similar. She said: "I think I've done pretty well." She did not "look to the future. I just live each day as it comes." Later she commented, "It's no good worrying about yesterday. It's no good worrying about the future." These sentiments were echoed by Anne and Jure. Anne described her current life as "Very quiet. Very quiet, mmm", which was "quite good". Her husband, Jure, commented that "at the moment, one day is no different from another day. For us it's every day the same, see?" The tenor of his voice suggested that he was content with this. Neither of them thought much about the future, apart from Jure wanting to go back and visit his family in Eastern Europe one day. He said that other than this, "I don't feel like any changes." Anne summed up her thoughts by saying, "In the future? Oh my God, it's too far ahead for me to say [laugh]. It's miles too far ahead now. Like I don't know at the moment."

Progressing from Vices to Virtues

In contrast, the stories of Anthony, Martyn, Jean and Frank tended to be stories of progressing from a bad place to a position which was now acceptable, with the plan that the

future would be even better. Anthony and Frank both told stories of being involved with

drugs in their teens, resulting in attending court, and eventually being admitted to a

psychiatric hospital. They both described their progression through hospital, as Anthony

summed up, as "taking steps to improve, you know?" He viewed the chores he did now in

the group home as part of his work toward his goals of getting "a real job" and moving into

his own home. He believed if he continued to try hard, he would succeed in these goals.

> And the bed's nice though, but I don't really understand why it's taking so long to get settled because once I am settled, my father can take me home. Now I've been praying now for three years, three or four years, for a way of being able to make the bed work, you know, so that if I'm lying down, right, I can get a good night's sleep. And I wake up and I think, look, this is *my* bedroom. It's *my* responsibility to keep it clean and if I behave myself, I'll, I'll reap the harvest I've sown and get better and more and more things will come unto me. … But um yet the bed is fine. There's nothing wrong with it. Once it's settled, then I can go home, so the sooner the better.

Anthony believed he had "grown up a lot" and "learnt to mature" over the years, and that

by continuing to do his best he would soon be ready to live his life his own way. He said:

> You know, I want to get a real job and start working. Get back to living the way Anthony should live. Anthony is Anthony. Anthony has the right to live the way he wants to live. And I think Anthony is responsible for that by believing that he can set things up with the team by trying his best … he can to get on with his own life, you know?

> Frank gave the impression that he was already getting on with his life. He had left

behind the world of drugs and beer which had caused him so many problems. He was

confident that as long as he could detect his "warning signs" there was no reason for him to

have to return to the forensic hospital. He believed he had "done very well. I've been

working since I left the [hospital] two years ago. I've got myself a steady job, run a car, all

the, you know, comforts of home." He was motivated by the fact that "Life is too good. It's

too good in the community, man. You don't want to be spending years in places like the

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forensic system." He summed up his current position as: "Overall, no. I'm just enjoying

life, enjoying life without drugs, without beer."

As previously discussed, Martyn described his problems as "spiritual warfare"

rather than mental illness. He viewed his life as the struggle between God and the Enemy,

in which he was trying to harness his psychic powers with the help of medication to use for

God's work.

> The thing is, when you stand out for God, and you say, 'I want to be a soldier for You, I want to be a person who will stand up and say I'll be counted', the Enemy, being Satan, will try his utmost to knock you down. And that's what, that's been, that's my life history – the ups and downs of spiritual warfare where the enemy has tried to destroy me at any cost.

Martyn considered that the progress he had made in his life was "a miracle. It's a walking

testimony to God". He believed that the struggle was part of what had made him strong,

and he would not want to change anything in the past because of this.

> I have a philosophy. Yeah, of course I wouldn't like to be unwell but it's probably the best thing that ever happened to me *because* of where I am now, I am strong. … You know, say if you are a navigator on a ship? And you *deviate* the degrees by say a couple of millimetres? If you go along that track, you will be about 200 km away from where you are. If I changed anything in my life slightly, the future would turn out *completely* different. I wouldn't be here. I wouldn't be married. I wouldn't have a family which I've always wanted. This, this and this. You see what I mean? Everything falls in the path. If I change that slightly, a little bit, I don't know what my life would have done. So, to answer that question – No, I'm happy where I am.

When considering both his current life and his future aspirations, Martyn's spiritual beliefs

predominated:

> My life is pretty good. I have my ups and downs like everybody. What I want in the future is to be a pastor. What I want to do in the future is to be able to use this, this power I've got, but to walk with God with it, not to use it for my own pride, because that's where the Fall comes. You only have to look at Solomon. He was a very astute man, but in the end he was corrupted by his own pride. So I want to harness this energy, but for good, not evil. Come off medication completely. Because like I said, medication's what stabilizes it.

Whereas Martyn's perspective on life's struggles had been that of a battle between God and Satan, Jean described her life until recently as a battle between her and the rest of the world. As discussed in the previous chapters, her interview was studded with examples of her feeling betrayed, blamed and rejected by people, feeling powerless and a victim. For her, the Vices were those of the people around her. She talked about the power and influence which others had had on her life in the past, but she believed that this had now changed.

Jean:	Only all through life, it's been a stage for me, and I've been a puppet … with a lot of powerful strips. Puppet.
Researcher:	Being pulled by other people?
Jean:	Powerful strips. Psychiatrist, staff there, staff in the workplace, community to insult and ridicule me, push at me.
Researcher:	Do you still feel like a puppet now?
Jean:	Not really. But that's what it's been like. Family included. Family power as well. Mmm.
Researcher:	So what made the change so that you stopped from being the puppet?
Jean:	I don't know. Just coming to terms with myself now off the needles. Rounder person.

Jean now took pleasure in living on her own and "over the last two years, I've really sort of taught myself" cooking. She was proud of the way she maintained her home, "I keep it nice, really nice now". She was proud of the fact that she was "doing three certificates now" and had "nearly finished a book". It became apparent that her current workers treated her well, that is, were people of Virtue. She declared that she no longer felt like a puppet "because now … when they do something wrong with me, I go nuts at them and they listen." Her "lovely doctor" recently dropped in on Jean without giving her warning. Jean "went nuts about it" and the doctor apologized, leaving Jean feeling respected. She was looking forward to the future with optimism.

Although the two morals of the participants' stories were different, they both left the Heroes experiencing satisfaction with their current life, thus forming a positive ending to

their current stories. This optimistic ending also set the scene for the participants to begin their next stories with some confidence about what the future may hold.

Hopes and Plans for the Future

Future Employment

Work had been, or was still, an important dream for most of the participants. How they built this into their future stories, however, appeared to depend on the life philosophies they brought with them from their life so far. For example, Brett, Anne, Jure and Terrie appeared content to take one day at a time, and not make any solid plans for changing their employment status in the future. Brett stated that he would like "to hold a job down one day, but, I think I'm getting a bit old for that now. Fifty-five is a bit old to start off on another job." This view seemed to be shared by Anne and Jure, who despite valuing work, considered themselves retired now. Terrie made no mention of her future work status. She was content working at the rehabilitation centre. At 66 years, one would suspect that this opportunity may not be open to her for much longer. However, when asked about her future, she made no comment about her work status, which was consistent with her philosophy of not worrying about the past or the future.

Anthony, on the other hand, continued to make plans in line with his philosophy of progressing toward a better life. He intended to get a "real job" when he moved into his own home. He was very keen to "have the responsibility of going to work each day". He was unsure about what type of work he wanted to do, but discussed doing "some charity work" for the Salvation Army. He believed he would need help to get started.

> I can't do that on my own in my situation as a mental patient. You know, I'm going to need help to get a job that would create that type of relationship with reality. I can't shoot myself on camera at the same time as I am acting.

His reference to being in front of a camera fitted well with his dream job, which was to "be a pop star – to get a job/part in a movie, you know?" He could see himself both in a recording studio and in front of the camera, and imagined that some of his former friends may come and work with him. He was aware that this project would take "a lot of work" and that it "takes a long time to become recognised, recognised as being famous, you know?"

Martyn and Frank already worked full time, but in line with their philosophy, both had plans to obtain better jobs in the future. Although Martyn had been a caregiver for years, his plan for the future was to become a pastor. He believed that he must wait until the time was right, and that he would then need to be properly trained for the job.

> It's just that I *know* it's not the right *time* because God hasn't told me it's the right time. And I mean *told* me. There's different ways: *verbally*, in my spirit, and circumstances. It doesn't *feel* like it's the right time. When it's the right time, I know it's the right time. I will get proper training. I won't just delve, go out, I mean, I hope, if you don't protect yourself with the blood of Christ, and you try to have spiritual warfare, the Enemy will just slam you right down and you'll get really slammed. You've got to be very careful what you do.

In contrast, Frank's desire for a better job was based on material rather than spiritual goals. In particular, he wanted a better job to enable him to buy a house and support a family one day.

Jean's future employment plans reflected her newly found belief in herself. She had been employed by others throughout her life, mostly doing secretarial work. She was now studying and hoped that when she completed her three certificates she "may be getting into a business of my own here." At the same time she was hoping to get her first book about

her psychiatric experiences published, and had started the process of finding a publisher. She was planning to "do lots more writing" in the future.

Future Family

Of the three younger participants, Martyn was the only one who was married, but both Anthony and Frank hoped to get married one day. Anthony felt "as if there is a cavity in my life like my sweet tooth, and little problems that can be fixed by people who love you, you know?" He stated he was very fond of 'H', but was unsure whether she reciprocated his love. He had "tried to convince myself that I'm old enough to have a relationship with a woman." He would like to marry 'H' and have children. He said:

> I'd like that too. It's a smelly problem, isn't it really? But it's a fun problem and I think we can make it work, you know? And it's fun. It's a lot of fun. It is so wonderful. And it's something like God wants us to do, you know? I'm not sure why I am against it. Perhaps I'm afraid that I'm not good enough. I've got an inferiority complex, you know. Something like that, anyway.

Frank was also hoping to marry and have a family. He would like to return to an area of the country where he had stayed in a commune previously, which he described as "just one awesome time, eh?" One reason for wishing to return was to meet up with the friends he had left behind there. "There's one lady, in particular", he said, and after he described his admiration for her creative occupational life, he added, "We had so much fun, eh? It was just unreal, amazing. I'd love to go back there for a year or two and see how it works out." He was also keen to have children "if I get hitched up, and stuff. That'd be cool." He was conscious that he wanted "to get that out of the way (much laughter) before too much more time" because he was 35 years old now, and "if I have kids this year, or in the next couple of years, by the time they're 10 years old, I'll be like 45, 50. Hey!"

Future Home

Most of the participants were established and happily settled in their homes, although Jean was "hoping one day to [have] the money to do it up." Frank wanted eventually to buy a three bedroom house in Auckland, and take in "a couple of flatties, or Asian students, or whatever. They can pay off the mortgage with their rent and stuff and then, you know, I can save a little." This would enable him to go and stay at the commune for a while and have "a place to come to, you know?"

Anthony was the only person living in a group home. He stated that he had bought a home with his father's help, and named the address several times throughout the interview. He believed that when he moved to this home "next week" he would be able to relax. He was looking forward to having

> privacy in my bedroom. I want nobody to interfere with me. When I am by myself, I am by myself. … I just want to be alone. I don't want to put up with all the other people's problems. I just want to have my freedom, to make my own rules, you know?

Anthony had made elaborate plans in his mind for the move. He had already thought through what the furniture removal people would need to do, and he wanted builders to go to his new home the day after he moved in. The new home was "probably four or five times larger than my apartment [in the group home]. So that's a lot better for me, you know?"

Future Travel

Travel was in the dreams or plans of three of the participants. Jure hoped to take a trip back to see his siblings and birthplace again in Eastern Europe, and Brett had always wanted to go "to Australia for a trip". Neither of them had made any plans, which was in keeping with their philosophy of taking one day at a time. In contrast, Frank wanted to

travel to Australia and other countries, and had already started to plan to appeal his Special Patient status to enable this to happen. This step by step planning matched his philosophy of progressing deliberately through life towards his goals.

Sources of Sustenance

Regardless of differences in life philosophy and aspirations for the future, each participant appeared to have found an occupation which provided him or her with particular emotional sustenance. In all cases, these occupations appeared to provide a continuing theme which threaded together the past, present and future stories for each person.

Anne: Housework. "But at the moment, a bit of housekeeping's quite good."

Anthony: Music. "I'm very drawn to music … If I hear a lovely song usually I feel like I'm OK, there's nothing wrong with me, you know?"

Brett: Walking. "I find walking over the back of the farm helps my mental outlook. It does me good."

Frank: Joking around whether at work, or with family and friends: "you know, just sit around and joke … and laugh and carry on."

Jean: Writing. "Well, as I say, I like to write."

Jure: Finding ways of being kind to his wife, Anne: "[Anne] is very kind to me and I'm kind to her and we get on all right, all right together, and we manage to survive anyway, so far we did."

Martyn: Spiritual work. "And this is why my life *is* good. Because I give the praise *to* God."

Terrie: Socialising. She mentioned three people with whom she regularly has "a cup of coffee and a couple of fags and a yarn."

In the last four chapters I have attempted to portray the stories of the eight participants, largely told from their perspective in their words. Each Hero was introduced in Chapter Four, including some details about his or her early life and the time spent in psychiatric hospitals. In Chapter Five, members of the Supporting Cast were introduced, that is, the main actors influencing the lives of the Heroes, ranging from Illness and Psychiatric Medication to Family and Friends. The stories of how the eight participants currently occupied their time were described in Chapter Six. In this chapter I have examined the moral of each person's current story, and the hopes and dreams which may form part of their future stories. In the next chapter these stories will be analysed and discussed further, within the context of the literature presented in the earlier chapters.

Chapter Eight: Discussion

In this study, I have set out to discover what has influenced the everyday occupations of people over the years since they were discharged from their long term stays in psychiatric hospitals. It is very apparent that the participants' occupations were not separate from other aspects of their life, but were an integral part of it. Draucker and Hessmiller (2002) stated that people talk most about what has most meaning for them. On this basis, the most important influences on the occupations of the participants appear to have been the impact of Illness and Psychiatric Medication, the role played by Health Workers and their Agencies, the presence and/or absence of Friends and Family members, and the attitudes of people in the Community. In addition, both the main actors and the Supporting Cast have been influenced by the opportunities and limitations provided within the wider socio-political environment of the last twenty years.

In my pre-suppositions interview I stated that I believed in the resilience of the human spirit, and that I expected to find that the participants had turned their adversity into stories which provided them with a positive view about their lives. In the last chapter it became evident that each person had indeed created a story with a meaningful moral, and was looking to the future with either some acceptance or contentment, or with some plans and dreams for improving life further. This would appear to confirm my pre-supposition. When reading the entire transcripts of the participants, however, three particularly compelling issues of concern have emerged: the lack of close personal relationships in some participants' lives; the limited range of occupations in which the non-working participants were involved; and the fragility of the current lifestyles of some participants.

Before examining these three issues of concern, I believe it may aid our understanding to consider the type of narrative plot each participant has told.

Narrative Plots of the Participants

The four participants who described their current stories in terms of taking one day at a time, appeared to share common narrative typologies: namely a combination of Frank's (1995) restitution plot and Gergen and Gergen's (1986) stability narrative. For example, Jure described his recovery to his current position, not in terms of his own struggles or actions, but in terms of the efforts of health workers and medication, themes which are central to the restitution typology. His views were echoed by Anne. Brett continued to hope that the new medication he had been given (rather than any actions of his) would restore his mental health a little further. Terrie gave the credit for doing so well now to the medication, and to the health worker who had placed her in the rehabilitation workplace.

In addition to their restoration based, in their view, on the efforts of the medical community, all four participants described their current situation in terms of a stability narrative, that is, they did not appear to have expectations of progressing towards any goals for a different life in the future (Gergen & Gergen, 1986). Even though Brett was hopeful of reducing the problems caused by his voices, he did not indicate that this was part of a goal for achieving more in his everyday life than he was currently doing. On the surface, the philosophy of taking one day at a time appears to fit well with the lifestyles of the four participants and stability narratives in general. When this philosophy is placed in the context of the issues facing the participants, however, one has to question the degree of

restitution which has taken place, and the quality of life which they are therefore experiencing in their stability narratives.

In contrast, the moral of the stories of Frank, Martyn, Jean and Anthony fit with Gergen and Gergen's (1986) progressive narrative. Each is moving from bad experiences in the past to better ones in the future. In contrast to the restitution narrative, the Heroes of the progressive narrative had a sense of their own personal agency. They also appeared to be on a quest, as described by the author Frank (1995). The participant Frank's account was a very clear example of the quest narrative. He described setting out on a journey into drugs and beer and becoming unwell. He progressed through a number of trials and tribulations over the years until placed in the forensic hospital. During this latter period of time he acquired the treasure of knowledge and experience which he is now beginning to share with others. He considered himself changed forever, which is also a feature of the quest narrative.

Martyn's experience was similar, but he told far more stories than Frank of the struggles he faced and overcame on his journey to date. He described five incidents of taking control of situations during his hospital stays. He explained his ability to get what he wanted in these situations in terms of his charm, and in terms of him doing God's will. He also described his leadership qualities, which had positively influenced his occupational performance, and his ability to overcome adversities. Martyn was also beginning to tell a story of stability. He still had dreams of progressing towards his goal of becoming a pastor, which was part of his quest, but was content with his relationship with his wife, with his social interactions, with his home, and with working full time. This suggests that in addition to continuing his quest, Martyn had journeyed a long way along Gergen and

Gergen's (1986) romantic 'happy ever after' narrative, that is, a journey from a progressive to a stability plot.

Jean's story of a quest was also more complex than Frank's. She described incident after incident of being insulted and ridiculed, betrayed and rejected. This onslaught appears to be consistent with Frank's (1995) chaotic narrative, and certainly met the criteria of being uncomfortable to listen to, because of the overwhelming number and degree of perceived assaults to her dignity and emotional well-being. On the surface it might appear that she regarded herself as helpless, with her description of her life as a stage, where she was the puppet being pulled by the powerful strings held by the health workers in particular. In an hour's interview, she recounted nineteen incidents of others having control over her. I believe that Jean's story nevertheless followed the pattern of a progressive narrative and a quest. The many incidents were in fact the struggles she faced on her journey. Throughout the story she had attempted to take control by expressing her own thoughts and feelings, but had been ignored time and again. Eventually her efforts were rewarded, and she succeeded in getting others to listen to her desire to change medication, and to her insistence on being treated with more respect. In recent years she has been writing about her experiences as part of her quest to take the treasures she learned from her journey and pass them on to others.

Anthony was the other participant who told a story of progression. In comparison to the other three, he appeared to still be in the middle of his journey. Now in his late thirties, Anthony's planned destination was to live in his own home, work in mainstream employment, and marry, all of which are typical expectations for people in their early to middle adulthood (Papalia & Olds, 1992). His story was full of episodes about striving to become a better person, to acquire more life skills and work skills, and to develop his

relationship with 'H'. His quest included speaking out to me on behalf of the other group home residents in particular, and people with a mental illness in general. At this stage he believed that it was not possible for him to achieve his quest without the help of others: Health Workers and their Agencies, Psychiatric Medication, and his father. This suggests that his story was also partially a restitution narrative over which he had little control. Anthony told me that he would be moving out of the group home within the next week but, at the time of writing this discussion chapter six months later, had not yet done so. It may be that telling a quest story gives Anthony hope and purpose in his everyday life, but that in fact he is waiting for others to take control of restoring him to the life which he thinks is expected of him by society.

This exploration of narrative typologies has reinforced the argument that Illness, Psychiatric Medication and Health Workers and their Agencies have exerted major influences on the lives of the participants. It has also demonstrated that the philosophy of life adopted by each person is a reflection of the narrative typologies which each appeared to have used for telling his or her story. The consequences these influences and stories have had on the everyday occupational lives of the participants appears to be related to the issues of concern alluded to earlier, which will now be discussed.

Lack of Close Personal Relationships

The significance of having few personal relationships should not be underestimated. Many of our occupational roles are concerned with interacting with others (Kielhofner, 2002). Some of these roles may involve casual relationships with people, for example, being an organisation participant or worker. However, roles such as family member and

friend usually require a closer commitment to people. For me, these roles involve the undertaking of numerous occupations including: preparing and sharing refreshments and meals; going on outings to the theatre or the beach; helping each other out with everyday tasks such as property maintenance, or providing transport and support at medical appointments; sharing in celebrations. When I am not at work, the majority of the phone calls and visits I make or receive are connected to my interaction with family and friends. The relationships tend to be mutual and reciprocal. We turn to each other when we wish to express our innermost emotions and thoughts, positive or negative. Thus the roles of family member and friend provide opportunities for undertaking a range of occupations. They fill our time, and add a richness to our mental and emotional health and well-being.

It is apparent from the stories that most of the participants have experienced difficulties in contact with their families. Many of Jean's tales of negative incidents in her life were concerned with her interactions with her family, and with people she had wanted to be her friends. Her focus on these relationships is an indicator that she placed considerable value on the role of people in her life. She described her current life as lonely. As with other participants, one cannot help but wonder about the effect that such a mismatch between her values and her reality has had on her everyday life. Brett has had little contact with his siblings and described his life as being barren. Anne's response about family contact was vague and suggested little contact occurred. Jure was isolated from his family by geographic distance. Although Martyn had indicated problems in the past, he stated that his relationships with both his father and wife have improved over the years, and are now good. Terrie and Frank appeared to be the only participants who consistently talked positively about their family relationships.

In addition to difficulties in family relationships, only three of the participants mentioned occupations related to socialising with friends. Although Brett, Anne and Jure described some people as friends, these were people who owned food shops, and the friendships did not appear to extend beyond the shopping experience. Anthony mentioned many people as his relatives or friends, but did not name any activities which he participated in with any of them. The fact that almost all of his references to these people were about how good they were to him, suggests that he had created a story in which he was part of a large, supportive social network, despite the lack of contact which he had with these people in reality.

There are many reasons why family relationships may not be supportive. Jean indicated that there had been dysfunctional relationships within her family from an early age. Both Brett and Martyn admitted to having had anger problems in the past, which affected their relationships with both family members and others. However, whereas Martyn's relationships improved once he had dealt with his anger, Brett has not enjoyed a similar result from controlling his anger.

Although sometimes difficulties experienced in relationships may stem from the actions of the person with a mental illness, it is apparent that often relationships have been affected by wider societal attitudes. As pointed out in Chapter Two, stigma associated with people with mental illness has continued to be prevalent in New Zealand over the last twenty years. Family members and friends are as likely as anyone else in the community to have been influenced by these attitudes. It is interesting to note that in their study on recovery, Lapsley, Nikora and Black (2002) found that their participants described a number of incidents of family members feeling embarrassed or ashamed about having a family member with a mental illness. However, their study also seemed to reflect stronger

family connections than I have found in my study. Many of their participants also described the support of friends, and making new friends as their recovery progressed. This raises the question as to what differences there were between the two studies that might shed some light on the different findings. It should be noted that the purpose of the Lapsley, Nikora and Black (2002) study was to recount the stories of recovery rather than explore everyday occupational lives, so the data collected did not always correspond. However, some issues emerged which were common to both studies: relationships with friends and family; interactions with health workers and their agencies; stigma in the community; and the significance of personal agency.

In my study, all eight participants had been diagnosed with an Axis I and Axis II diagnosis, and all had spent at least five years in a psychiatric hospital. In contrast, in the recovery study, only three quarters of the participants appeared to have been diagnosed with an Axis I or Axis II diagnosis. The remainder included some who identified themselves as having experienced a mental illness but had not been formally diagnosed. Nikora, Lapsley and Black (2002) reported that twenty-eight of the forty had experienced hospitalisation, but only about seven of these had spent more than six months in hospital. It is reasonable to assume that, quite apart from any interpersonal factors, the physical isolation caused by lengthy hospitalisation will have made it difficult for the participants in my study to maintain or improve relationships with people outside of the hospital.

All of the participants in my study continue to need and take psychiatric medication, and three of them discussed the difficulties experienced on the older medications available in the past. In contrast, in the recovery study, only a "few" of the participants continued to take medication (Lapsley, Nikora & Black, 2002, p. 30). Given that both studies were concerned with the experiences of people with a mental illness living in New Zealand, it is

likely that the comparatively poorer family relationships in my study were connected at least in part to the problems they faced which were not faced to the same extent by the recovery study participants: that is, a combination of the isolation caused by a generally longer length of hospital stay, greater severity of illness, and difficulties experienced with medication over many years.

From listening to the participants' stories, it is evident that their lack of close personal relationships has had a significant influence on their relationships with health workers. For five of the participants, the health workers were the only regular visitors to their homes. Although the health workers appeared to have been performing their professional helping role, these visits were virtually the only opportunity the participants had to be a host, provide refreshments, and have meaningful personal conversations. These conversations were about the sort of matters which people without a mental illness would probably discuss with a family member or a close personal friend. It is an integral part of the community support work role to be supportive, and to pursue plans in ways which reflect the values and wishes of the client (Framework Trust, 2003). This attentiveness and respect are concepts which many of us seek in a friendship, which further reinforces the role of the health worker as a professional friend.

The consequence of this reliance on visiting health workers is twofold. Firstly, it is likely that every statement made by the worker will be given more significance than the worker intended. One can imagine that, if a participant does not talk at length to anyone else for a week or two, the words of the health worker will be recalled and analysed for many days. Secondly, it means that the presence of each health worker has a special significance in a participant's life. The participant is therefore likely to be much more unsettled by events such as the visiting health worker transferring to another job, or the

participant being discharged from a health service, than people who have a stronger social network.

Limited Range of Occupations

It was evident from the literature that engagement in meaningful occupation provides benefits to both our physical health and our mental well-being (Wilcock, 1998a). In particular, New Zealanders valued most highly those occupations which were connected to their roles as family members, friends, and workers (Gold & Webster, 1990). As I have discussed, the roles of family member and friend were also valued by the participants of this study, even though their daily occupations did not reflect this.

With respect to the role of worker, only two of the participants were currently in mainstream employment, while a third was working in a rehabilitation centre. This is in stark contrast to the Lapsley, Nikora and Black (2002) study in which twenty-nine of the forty participants were in paid employment, many in helping occupations. The remaining participants were students (five), homemakers (two), or retired (two). Only two people in their study were unemployed, which is consistent with the unemployment rates of the general population (Statistics New Zealand, 2003).

Four of the participants in my study appeared to have never attempted, nor been encouraged, to enter the workforce following hospitalisation, despite describing previous work experiences with animation and pride. Given that all of these participants appeared to be telling restitution narratives, it is likely that they were waiting for their health workers to create the expectations that they should and could work, as well as provide them with the opportunities for them to be assisted into suitable employment. In addition, Jean had been

employed for many years in mainstream employment but had been subjected to many incidents of discrimination. She had felt unsupported by health workers throughout this experience. Consequently, she was now undertaking courses with the intention of becoming self employed. This will be a difficult task, given her lack of contact with family and no close friends to support her.

Although each participant talked positively about his or her current life, I was struck by the limited range of leisure occupations undertaken, particularly by the five participants who were not in paid employment, and who therefore had more time available for discretionary pastimes than the general adult population. Not one of these five people appeared to be engaged in occupations connected with the roles of family members and friends. Their most common occupations apart from housework were watching television and going for walks. These were the occupations listed in the literature in Chapter Two as the most common pursuits during people's long term stay in psychiatric hospitals, and in the first year following their discharge. Grocery shopping was virtually the only social activity undertaken by these five participants, apart from hosting health workers when they visited.

I was particularly interested in the occupational routines of the participants. As previously discussed, routines enable us to do some tasks automatically so that we have more time and energy for more challenging occupations (Clark, 2000). I wondered whether the participants were continuing to undertake patterns of everyday living which stemmed from their hospital experience, or whether as Rowles (2000) argued, they had adapted to their new circumstances. Not surprisingly, for the five participants who were not working, routines provided only the most basic of structures to their days. For example, most had a

regular occupation immediately after breakfast (doing housework or going for a walk), but there were no time pressures, and the remainder of their day appeared largely unstructured.

In contrast, the two participants in mainstream employment had their weekday activities structured by their employment hours. They were also involved in helping out family members and socialising with family and friends. Martyn also actively participated in a variety of church activities, and Frank enjoyed going out to meals, the cinema, and the flea markets. These findings are consistent with those of Zuzanek's (1998) study reported in Chapter Two, in which he found that those who were in paid employment often spent more of their time in leisure activities despite feeling pressured by time constraints. This group also reported higher levels of satisfaction with their lives than those who were unemployed and had little to do. In telling their stories, Martyn and Frank appeared to be more enthusiastic about their current circumstances and optimistic about their future than the other participants.

When people shape their lives through a restitution narrative and depend on others to initiate change, this is likely to have a significant effect on their occupational opportunities and participation. At the time of deinstitutionalisation, people who had spent lengthy periods in hospital considered they lacked the knowledge and skills to make informed choices. They were unsure how to explore the range of leisure and recreational occupations available in their communities, and lacked confidence to make the approaches necessary to engage in new occupations (Ng & McKinlay, 1986; Sheerin & Gale, 1984). It may be that Brett, Jure, Anne, Terrie and Anthony are waiting for their health workers to suggest and initiate their participation in new occupations. In addition, the experience of being regarded as different in the community may have impacted on their expectations, so they may have believed that some occupations were not for 'people like them'.

In reviewing the literature in Chapter Two, I argued that it is important for our health and well-being to undertake a variety of occupations, and to have sufficient challenges in our lives to enable us to experience a sense of flow. This meaningful occupational engagement gives us feelings of achievement, satisfaction and happiness (Csikszentmihalyi, 1993). Our 'doing' enables us to express our inner self or 'being', and through our occupations we develop our potential of 'becoming' (Wilcock, 1998b). The five participants who have insufficient occupations and challenges in their lives, have few opportunities to express themselves, to experience the positive benefits of flow, and to develop their potential. It would appear that the physical emptiness caused by a lack of things to 'do' to fill their day, has resulted in few opportunities for them to either experience emotional well-being, or undertake the process of 'becoming'.

Fragility of Current Lifestyles

Despite their optimistic outlook about their current lifestyles and future prospects, I was left with an overall feeling that most of the participants were in a vulnerable position. For many of us, the loss of one role or occupation or circumstance in our lives may create a temporary disruption, and perhaps feelings of grief, but is unlikely to cause substantial risk to our lifestyles or health and well-being. The participants in my study had few roles and a limited range of occupations. For them, the loss of one of these is likely to have a significant effect. For example, Terrie attended a work rehabilitation centre five days a week. She was 66 years old and it would therefore seem likely that she would not be attending the centre for much longer. Work not only provided her with a source of interest and pride. It was also an environment in which she enjoyed the social company of her

fellow workers throughout the day. She had built a routine around work which involved meeting her best friend early each morning for a coffee, and she and this same friend went grocery shopping together with their community support worker after work on a Friday. Her major activities apart from this were doing housework at the weekends and watching television in the early evenings. She visited her mother most weeks, but her mother was in her 90s. For Terrie, retiring from (or being asked to leave) work will be an enormous loss, especially given that she told her story as a restitution narrative, in which health workers had found her work, and initiated the grocery shopping trip. It is difficult to imagine her initiating new leisure occupations and making new friends to fill her day.

All eight participants were still clients of a District Health Board (DHB), and all except Frank received an ongoing service from a non-government organisation (NGO). The priority of the DHBs is to assist people to a point where they are medically stable and able to have their medication managed by their general practitioner. The NGOs are contracted to assist people to achieve their goals with respect to the social issues in their lives. It is conceivable, therefore, that Brett may be discharged from the DHB if his new medication proves to be successful. This would immediately remove one of the two people who regularly visit him in his home. Brett's story is predominantly a stability narrative. If he were to tell his community support worker that he was satisfied with his current lifestyle, and did not want to set goals or make any progress in any social areas, it is possible that he would be discharged from the NGO as well. This would leave him with no regular visitors or telephone calls. Alternatively, if the local rural store were to close, Brett would lose his regular conversations with the shopkeeper, the person who he talked to most often, and the only non-health worker in his everyday life. Being discharged from health services would also place other participants in a precarious position. The only regular conversations Jean

had were with her health workers. Anne and Jure depended on their NGO to manage their finances, and were adamant that they could not cope with living in the community without this and other assistance provided by the NGO.

Another circumstance which would significantly disrupt the lives of all of the participants would be if they were to decide to discontinue taking medication at this point. This is not out of the question, given the side effects experienced by some participants, and Martyn's goal to live without medication one day. Even though he and Frank appeared to be managing comparatively well at present, they would both have extreme difficulty in coping with their family relationships and jobs if they missed their medication, or if Frank were to give in to the temptation from those around him and start taking drugs once more.

Where to From Here

From the above discussion, it is apparent that the lives of the eight participants have been disrupted more by their experience of mental illness, hospitalisation and medication problems than those people with mental illness who have spent shorter times in hospital. In particular, the disruption caused by lengthy hospitalisation appears to have impacted on the ability of the participants to initiate and/or maintain close personal relationships with family members and friends, and on the number and range of occupations in which they have engaged since hospitalisation. As a result, they are more vulnerable than most of us when there is a significant change in their roles or occupations.

This suggests that this group of people have not been served as well by the deinstitutionalisation policies as they could have been. From the literature, I am left with the impression that the emphasis of the policies since the mid 1980s has been on assisting

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those people who have become unwell in the years since the deinstitutionalisation era. I am aware from my own professional experience and anecdotal evidence that there have been many positive initiatives undertaken in recent years to ensure hospital stays are shorter, to coordinate hospital and community services to people, and to offer more education and support to family members. Current policies have understandably been targeted primarily either at the majority of people with mental illness served by government and non-government agencies, or at special interest groups such as people who have been recently diagnosed, the acutely unwell, and Maori and Pacific people (Northern DHB Support Agency, 2002).

The experience of the participants in this study suggests that their lengthy hospitalisation has caused this group to have special needs which may not be shared by other people with mental illness. When I approached consumer groups, and staff in the government and non-government agencies earlier in the year, it was apparent that people living in the community who had spent lengthy periods in psychiatric hospitals were not represented in the policy consultation processes. Although they may be a decreasing minority in the population of people with mental illness, I believe it is important for their special needs to be recognised and addressed. They are a group of individuals who were subject to a government driven experiment on behalf of New Zealand society. The problems they have faced over the last twenty years, and continue to face at present, are a result of this experiment. It seems to me, that they are therefore owed the right to have government policies created which target their specific needs.

Making Friends

For various reasons, not everyone will have supportive family members. However, every participant in this study valued having meaningful relationships with other people: friends, family or life partner. How should they go about finding friends? Given that it is at least ten years since most of the participants were discharged from their last long term stay in hospital, it is reasonable to assume that if they had been able to make friends without assistance, they would have done so by now. It is also reasonable to suggest that having friends is particularly important to people who have few other roles in their life. Their time is not taken up with occupations associated with the roles of family member or worker.

Undertaking this study has been my 'employment' for this year. Consequently my friends and acquaintances have frequently asked me about my progress. In recent months I have responded in part by mentioning the apparent lack of close personal relationships in the participants' lives. This has led to discussions about how people make friends. There seems to be a prevalent belief that participating in leisure activities and joining clubs is a good way to make friends. A number of people I have spoken to have confirmed that they have experienced enjoyable times in such communal leisure activities. However, they also admitted that they have rarely formed close friendships in this way. My own experience is that throughout my lifetime I first met each of my closest friends when we crossed each other's paths in one of three settings: educational establishments, workplaces, or as neighbours.

Given these informal discussions, I decided to examine the literature about making friends. As discussed in Chapter Two, the occupational therapy literature acknowledged the importance of the social environment and social roles in people's lives, and the need to help people undertake the leisure activities which had value and meaning for them. It also

discussed how best to assess and improve people's communication skills (Canadian

Association of Occupational Therapists, 1997; Davidson, 1991; Kielhofner. 2002). In

reviewing the literature concerning social skills training, Anthony, Cohen and Farkas

(1990) pointed out that these programmes did not appear to have resulted in making a

significant difference to people's lives. An online search of the Cinahl, PsycINFO and Web

of Science databases revealed a number of studies which confirmed the importance of close

friends in the lives of people who were experiencing acute mental or physical health

problems, or were marginalised in the community (people with an intellectual handicap,

single parents, homosexuals). However, in all of these studies the friendships already

existed as part of the person's social network. I was unable to find references about how

and where people form friendships, and therefore how health workers should go about

assisting people to create these social roles.

The importance of people having friends has been recognised in New Zealand for

some time. Initially, the Community Support Work services included the concept of

befriending, but over time have developed a more professional helping role in their work.

This is in line with a general trend within New Zealand noted by Dyce as long ago as 1979.

He stated that many of the agencies which had started out as being community based, had

through their increasing professionalism "separated from the community", and the worker's

role of being a friend ended up being one of simply "visiting" (p. 16). Community support

workers have continued to be expected to help people to set and achieve social goals

(Framework Trust, 2003). However, it is my experience as both an occupational therapist

and a community support work team leader that, in practice, goals are often set about

occupations or skills, rather than roles. For example, one goal may be for a person to play

tennis regularly. This goal is achieved when the person is travelling to the venue, has the

skills and knowledge to actively participate in the sport, and socially interact with the other players without the support of the worker. This may give the person the role of team player or participant in an organisation, but it may not result in any friendships being established. It seems to me that goals should be set which have the most meaning for the person concerned. The goal of forming a close friendship may take a considerable time to achieve, but this is not a sufficient reason to ignore it. The process of finding friends may result in additional benefits such as participating in social leisure activities or paid employment, but these are merely stepping stones toward the bigger overall goal.

Wiseman (1995) described lonely people as experiencing social isolation and feelings of unpleasantness and distress. People with mental illness are not the only ones who experience these feelings. All of my acquaintances named at least one person they knew who had only one friend, and who had expressed feelings of loneliness. None of these people were considered to have a mental illness, but their loneliness was just as unpleasant and unwanted. This suggests that there is a general unmet need in the community for the building of formal and informal social networks, in which people who are lonely may find ways of feeling included, useful, and valued as part of the community. I briefly explored some of the literature within the community development field. Fitch (1998) argued that just as it is thought that it takes a village to raise a child, so "it takes a community to form a friendship" (p. 1). She pointed out that every community is enveloped in the multifaceted cultural norms of the country in which it is situated. This was echoed by Williams and Robinson (2002) who pointed out that, in the Maori world, relationships are formed through informal networks rather than formal structures evident in European societies. This suggests that it is important not only to establish generally where and how people make

friends, but in particular, where and how people make friends in the diverse communities in New Zealand.

My examination of the community development literature was only cursory. Although I was still unable to find specific information about where and how people form friendships, the literature did appear to value the importance of informal social networks in people's lives. Community development may not be within the job descriptions of most health workers. But it is within the domain of most community health workers to liaise and network within their communities. By contributing our expertise in healthy living, programme planning and development, we may be able to support others to develop community initiatives for this vulnerable group of people with mental illness who have been socially isolated for so long.

Expanding Range of Occupations

It is evident that the majority of participants in this study lacked occupations connected with the roles of being friends and family members. Five of the participants were not involved in paid employment, and appeared to have developed few leisure occupations since leaving hospital. It is possible that they no longer wish to be introduced to new activities, and that they are genuinely content with their current level of occupational participation. However, it is also possible that they are used to living within their restitution narrative, and are waiting for others to increase their awareness of the realistic occupational opportunities which are available to them in their particular communities. The comparison with the recovery study (Lapsley, Nikora & Black, 2002) appears to lead to the conclusion that people with shorter experiences of hospitalisation are more able to initiate change for

themselves, including locating community resources and engaging in social and recreational groups which interest them.

The participants of this study have indicated through their stories that they valued the same major roles as the general New Zealand population, that is, the role of friend, family member and paid worker. People with a mental illness who have been hospitalised for short periods have shown by their actions that they shared not only these values, but also that they valued having a range of social and leisure activities. I believe it is reasonable to assume that people who had been hospitalised long term would have similar aspirations. When Brett spends a winter's day sitting and staring at the walls and waiting to smoke his next cigarette, it is difficult to imagine that he would deliberately choose this from a long list of available leisure occupations. Everyone needs a number of occupations in their lives which they enjoy doing, and which enable them to make an informed choice about how to spend their time. It is already acknowledged in the National Mental Health Standards that health workers need to encourage people like Brett to try new experiences, and sample a variety of work and/or leisure opportunities (Ministry of Health, 1997b). This study reinforces the importance of this in the lives of people who have been hospitalised long term. Support needs to be provided for as long as it takes people to become well established in the work or leisure occupations which they find give them satisfaction and enjoyment.

Long Term Support

Given the vulnerability of people who have been hospitalised for many years, I believe that many of this group will require the support of paid workers long term, perhaps for the rest of their lives. The special needs of this group have been acknowledged to some extent by the Regional Coordination Service (RCS, 2003). Although group homes are

generally intended to be a stepping stone for people in their recovery, the RCS pointed out that approximately one hundred of the over nine hundred people living in group homes in the Auckland region were people from the era of hospital deinstitutionalisation. They acknowledged that these people were likely to need such accommodation indefinitely.

It seems to me that there needs to be a formal acknowledgement made at a government and regional level, that some of the people who are living in their own homes following deinstitutionalisation will also need assistance long term. They may not always need the clinical services of the District Health Board. However, it seems to me that, unless people have a strong social network involving close personal relationships and a variety of occupations in their lives, they will need continuing long term input from people such as community support workers, occupational therapists and social workers.

Recommendations for Future Research

As a result of the findings of this study, I recommend that further research be undertaken with some urgency into the following areas:

1. Studies into the ways in which people make friends in New Zealand. This knowledge may then be used by health workers to be more effective in their efforts to assist people who were subject to long term institutionalisation, such as those in psychiatric hospitals. Other vulnerable populations are also likely to benefit from this knowledge, for example, refugees and immigrants.

2. A larger study of people who were subject to the policies of institutionalisation and deinstitutionalisation. To gain a more comprehensive picture, this needs to include those people who no longer access mental health services. I acknowledge that there

does not appear to be any easy way to locate this group of people. My own attempts revealed that when wards closed down, patient records were not stored consistently. Those records which remain are scattered across different buildings, and there do not appear to be lists of former patients or their discharge addresses.

3. Studies into the experiences of other groups who have been subject to deinstitutionalisation from New Zealand's psychiatric hospitals. This includes two groups in particular:

   (a) those people with a mental illness who are now living in supported accommodation such as group homes and rest homes;

   (b) people with an intellectual disability who had lived in the same psychiatric hospitals as those with a mental illness.

4. Studies into other groups of people who continue to be subject to institutionalisation policies, for example, those who have spent many years in prison.

Recommendations for Policy Implementation

5. That the special needs of people who have been hospitalised long term be recognised by both health and welfare funding agencies and service providers. This requires a consultation process with this particular group of people, who do not appear to be represented in existing mental health consumer networks.

6. That policies reflect an understanding that services to some of this group of people may need to be provided not in terms of meeting rehabilitation goals, but in terms of maintaining and improving quality of life. This may require the support of paid workers indefinitely.

7. That health workers actively assist people who express the need to develop social networks and form friendships.

8. That health workers continue to strive to increase the range of occupational opportunities and experiences of the people with mental illness with whom they work. In acknowledging the importance of a balance of meaningful occupations to health and well-being, this needs to include: opportunities to work full or part time; to participate in leisure occupations which enable people to experience flow; and to undertake culturally and personally valued roles in the community. Given the continuing stigma in New Zealand society with respect to mental illness, health workers need to be prepared to challenge prejudice, advocate on behalf of their clients, and assist their clients to develop their own skills to counter stigma.

9. That all involved in the provision of health services consciously take into account the significance which a visiting health worker may have in a person's life when other social relationships are absent. This underscores the need for health workers to be conscious of the impact of their words and actions, and for services to endeavour to minimise the need to change staff during periods of restructuring.

In this study, I set out to discover what had influenced the everyday occupational lives of New Zealanders who had been subject to the policies of both institutionalisation and deinstitutionalisation. From the stories of the eight participants, it became apparent that their choice and performance of occupations has been influenced by the severity and persistence of their illness, by the length of time they spent in hospital, and by the effects of psychiatric medication. For most of the participants, the effect of these often negative experiences has been to disrupt their relationships with family members and friends, and to

limit their engagement in paid employment and leisure occupations. In examining the narrative typologies used by the participants, it would appear that those who told a restitution narrative were the most vulnerable. They have spent up to thirty years receiving assistance from the mental health services. This dependence has arisen from the social policies which we as a society created. It is a matter of social justice that we continue to assist this particular group of people to achieve a quality of life similar to that enjoyed by the general population. This optimistic goal may reflect my need to have a 'happy ever after' stability narrative ending to the stories of restitution. It may be more realistic to acknowledge that, for many people, the best we can do is to start the next episode of their stories by recognising their vulnerability, and making a deliberate commitment to provide long term support.

References

Advocates, Inc., & Deegan, P. (no date). *Intentional care: Employee performance standards for client choice.* Framingham, MA: Author.

American Psychological Association. (2001). *Publication manual of the American Psychological Association* (5th ed.). Washington, DC: Author.

Anthony, W. A. (1979). *The principles of psychiatric rehabilitation.* Baltimore: University Park Press.

Anthony, W. A., Cohen, M. R., & Cohen, B. F. (1984). Psychiatric rehabilitation. In J. A. Talbott (Ed.), *The chronic mental patient: Five years later* (pp. 137-157). Orlando, FL: Grune & Stratton.

Anthony, W. A., Cohen, M. R., & Farkas, M. (1990). *Psychiatric rehabilitation.* Boston: Center for Psychiatric Rehabilitation.

Anthony, W. A., Cohen, M., & Kennard, W. (1990). Understanding the current facts and principles of mental health systems planning. *American Psychologist, 45,* 1249-1252.

Bean, P., & Mounser, P. (1993). *Discharged from mental hospitals.* Basingstoke, UK: Macmillan Press.

Bennett, J. A., & Detzner, D. F. (1997). Loneliness in cultural context: A look at the life-history narratives of older Southeast Asian refugee women. In A. Lieblich & R. Josellson (Eds.), *The narrative study of lives* (pp.113-146). Thousand Oaks, CA: Sage.

Bentz, V. M., & Shapiro, J. J. (1998). *Mindful inquiry in social research.* Thousand Oaks, CA: Sage.

Blain, J., & Townsend, E. (1993). Occupational therapy guidelines for client-centred

practice: Impact study findings. *Canadian Journal of Occupational Therapy, 60,*

271-285.

Bluck, S. (2001). Autobiographical memories: A building block of life narratives. In G.

Kenyon, P. Clark, & B. de Vries (Eds.), *Narrative gerontology: Theory, research,*

and practice (pp. 67-90). New York: Springer Publishing Company.

Bruce, M. A., & Borg, B. (1993). *Psychosocial occupational therapy* (2nd ed.). Thorofare,

NJ: Slack Incorporated.

Bruner, J. (1990). *Acts of meaning.* London: Harvard University Press.

Brunton, W. (1986). Deinstitutionalisation: A romance for all seasons. In H. Haynes, & M.

Abbott (Eds.), *The future of mental health services in New Zealand:*

Deinstitutionalization: Volume two of the edited proceedings of the Mental Health

Foundation of New Zealand's 1985 conference (pp. 44-63). Auckland: Mental

Health Foundation of New Zealand.

Burns, N., & Grove, S. K. (1993). *The practice of nursing research: Conduct, critique, and*

utilization (2nd ed.). Philadelphia: W. B. Saunders.

Canadian Association of Occupational Therapists. (1991). *Occupational therapy guidelines*

for client-centred practice. Toronto: CAOT Publications ACE.

Canadian Association of Occupational Therapists. (1997). *Enabling occupation: An*

occupational therapy perspective. Ottawa, Canada: Author.

Cassell & Company (1968). *Brewer's dictionary of phrase and fable* (Rev. ed.). London:

Author.

Castillo, R. J. (1997). *Culture and mental illness: A client-centered approach.* Pacific

Grove, CA: Brooks/Cole.

Charmaz, K. (2002). The self as habit: The reconstruction of self in chronic illness. *The Occupational Therapy Journal of Research, 22* (Supplement), 31S-41S.

Christiansen, C. (1991). Occupational therapy: Intervention for life performance. In C. Christiansen, & C. Baum (Eds.), *Occupational therapy: Overcoming human performance deficits* (pp. 3-44). Thorofare, NJ: Slack Incorporated.

Christiansen, C. H. (1999). The 1999 Eleanor Clarke Slagle lecture: Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy, 53,* 547-558.

Christiansen, C., & Baum, C. (1991). Understanding occupation. Definitions and concepts. In C. Christiansen & C. Baum (Eds.), *Occupational therapy: Enabling function and well-being* (pp. 2-25). Thorofare, NJ: Slack.

Clark, F. (1997). Reflections on the human as an occupational being: Biological need, tempo and temporality. *Journal of Occupational Science: Australia, 4,* 86-92.

Clark, F. A. (2000). The concepts of habit and routine: A preliminary theoretical synthesis. *The Occupational Therapy Journal of Research, 20* (Supplement 1), 123-137.

Clark, F., Carlson, M., & Polkinghorne, D. (1997). The legitimacy of life history and narrative approaches in the study of occupation. *American Journal of Occupational Therapy, 51*, 313-317.

Coppock, V., & Hopton, J. (2000). *Critical perspectives on mental health.* London: Routledge.

Crepeau, E. B. (1997). Social biography and research. *The Occupational Therapy Journal of Research, 17*(2), 105-109.

Crossley, M. L. (2000). *Introducing narrative psychology: Self, trauma and the construction of meaning.* Philadelphia: Open University Press.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process.* Crows Nest, NSW: Allen & Unwin.

Csikszentmihalyi, C. (1993). Activity and happiness: Towards a science of occupation. *Journal of Occupational Science: Australia, 1*, 38-42.

Csikszentmihalyi, C., & LeFevre, J. (1989). Optimal experience in work and leisure. *Journal of Personality and Social Psychology, 56,* 5-22.

Davidson, H. (1991). Performance and the social environment. In C. Christiansen & C. Baum (Eds.), *Occupational therapy: Enabling function and well-being* (pp. 143-178). Thorofare, NJ: Slack.

Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal, 11*(4), 11-19.

Deegan, P. E. (1993). Recovering our sense of value after being labelled. *Journal of Psychosocial Nursing and Mental Health Services, 31*(4), 7-11.

Department of Social Welfare. (1986). *Puao-te-ata-tu: The report of the Ministerial Advisory Committee on a Maori Perspective for the Department of Social Welfare.* Wellington: Author.

Department of Statistics Te Tari Tatau. (1992). *1991 New Zealand census of population and dwellings: National summary.* Wellington: Author.

De Vries, B., Blando, J. A., Southard, P., & Bubeck, C. (2001). The times of our lives. In G. Kenyon, P. Clark, & B. de Vries (Eds.), *Narrative gerontology: Theory, research, and practice* (pp. 137-158). New York: Springer Publishing Company.

Dickie, V. A. (1997). Insights from a focused autobiography. *The Occupational Therapy Journal of Research, 17*(2), 99-104.

Dowland, J., & McKinlay, R. (1985). *Caring, curing and controlling: An outsider's look at life and work in New Zealand psychiatric hospitals.* Wellington: Department of Health.

Draucker, C. B., & Hessmiller, J. M. (2002). Telling stories of suffering and survival: Women and violence. In N. Diekelmann (Vol. Ed.), *First do no harm: Power, oppression, and violence in healthcare* (pp. 204-250). London: University of Wisconsin Press.

Dunn, W. W. (2000). Habit: What's the brain got to do with it? *The Occupational Therapy Journal of Research, 20* (Supplement 1), 6-20.

Durie, M. (1994). *Whaiora: Maori health development.* Auckland: Oxford University Press.

Dyce, T. (1979). Community in New Zealand. In T. Dyce & W. Willcox (Vol. Eds.), *Opportunities for Change: Vol. 1, Community in New Zealand* (pp. 3-36). Auckland: Community Forum.

Ellis, C., & Berger, L. (2002). Their story/my story/our story: Including the researcher's experience in interview research. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 849-875). Thousand Oaks, CA: Sage.

Emden, C., & Sandelowski, M. (1998). The good, the bad and the relative, part one: Conceptions of goodness in qualitative research. *International Journal of Nursing Practice, 4,* 206-212.

Farkas, M. D., Cohen, M. R., & Nemec, P. B. (1988). Psychiatric rehabilitation programs: Putting concepts into practice? *Community Mental Health Journal, 24,* 7-21.

Fitch, K. L. (1998). *Speaking relationally: Culture, communication, and interpersonal connection.* New York: The Guilford Press.

Framework Trust. (2003). *Community Support*. Available: www.irongate.co.nz/wa.asp?id WebPage=3706.

Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics.* London: University of Chicago Press.

Frank, A. W. (2000). The standpoint of storyteller. *Qualitative Health Research, 10,* 354-365.

Frank, A. W. (2002a), Why study people's stories? The dialogical ethics of narrative analysis. *International Journal of Qualitative Methods, 1*(1), Article 6. Retrieved 31.01.02 from http://www.ualberta.ca/-ijqm/.

Frank, A. W. (2002b). *At the will of the body: Reflections on illness*. Boston: First Mariner Books.

Freckelton, I. (2002, August). *Portholes on mental illness: A century of opportunities for insight.* Paper presented at the National Centre for Health and Social Ethics Narratives of Mental Illness and Involuntary Detention Seminar, Auckland University of Technology, Auckland.

Frid, I., Ohlen, J., & Bergbom, I. (2000). On the use of narratives in nursing research. *Journal of Advanced Nursing, 32*, 695-703.

Game, A., & Metcalfe, A. (1996). *Passionate sociology.* London: Sage.

Gergen, K. J., & Gergen, M. M. (1986). Narrative form and the construction of psychological science. In T. R. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct* (pp. 22-44). New York: Praeger.

Gold, H., & Webster, A. (1990). *New Zealand values today: The popular report of the November 1989 New Zealand study of values*. Palmerston North: Alpha Publications.

Goldstein, J. S. (1996). International relations and everyday life. In R. Zemke, & F. Clark, (Eds.) *Occupational science: The evolving discipline* (pp. 13-21). Philadelphia: F. A. Davis.

Harding, C. M., Brooks, G. W., Asolaga, T. S. J. S., & Breier, A. (1987). The Vermont longitudinal study of persons with severe mental illness. *American Journal of Psychiatry, 144,* 718-726.

Hasselkus, B. R. (2002). *The meaning of everyday occupation.* Thorofare, NJ: Slack.

Haynes, H., & Abbott, M. (Eds.). (1986). *The future of mental health services in New Zealand: Deinstitutionalization: Volume two of the edited proceedings of the Mental Health Foundation of New Zealand's 1985 conference.* Auckland: Mental Health Foundation of New Zealand.

Health Funding Authority. (2000). Tuutahitia te wero, meeting the challenges: Mental health workforce development plan 2000-2005. Christchurch: Author.

Irwin, K. (1988). Racism and education. In W. Hirsh & K. Scott (Eds.), *Getting it right: Aspects of ethnicity and equity in New Zealand education* (pp. 49-60). Auckland: Office of the Race Relations Conciliator.

Jack, A. (1986). Deinstitutionalisation and the intellectually handicapped. In H. Haynes, & M. Abbott (Eds.), *The future of mental health services in New Zealand: Deinstitutionalization: Volume two of the edited proceedings of the mental health foundation of New Zealand's 1985 conference* (pp. 85-89). Auckland: Mental Health Foundation of New Zealand.

Jacob, K. K. (1999). Mental disorders across cultures: The common issues. *International Review of Psychiatry, 11,* 111-115.

Kaplan, H. I., Sadock, B. J., & Grebb, J. A. (1994). *Kaplan and Sadock's synopsis of psychiatry: Behavioral sciences, clinical psychiatry* (7th ed.). Baltimore: Williams & Wilkins.

Kearney, M. H. (2001). Focus on research methods: Levels and applications of qualitative research evidence. *Research in Nursing & Health, 24,* 145-153.

Kenyon, G. M., & Randall. W. L. (2001). Narrative gerontology: An overview. In G. Kenyon, P. Clark, & B. de Vries (Eds.), *Narrative gerontology: Theory, research, and practice* (pp. 3-18). New York: Springer Publishing Company.

Kielhofner, G. (1984). An overview of research on the model of human occupation. *Canadian Journal of Occupational Therapy, 51*, 59-67.

Kielhofner, G. (1995). *A model of human occupation: Theory and application* (2nd ed.). Baltimore: Williams & Wilkins.

Kielhofner, G. (2002). *A model of human occupation: Theory and application* (3nd ed.). Baltimore: Lippincott Williams & Wilkins.

Kirkman, M. (1999). *Revising the plot: Autobiographical narratives after infertility.* Paper presented at The International Conference of the Association for Qualitative Research: Issues of Rigour in Qualitative Research, Melbourne, Australia: 6-10 July 1999.

Kleinman, A. (1988). *The illness narrative: Suffering, healing, and the human condition.* New York: Basic Books.

Krefting, L. (1990). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy, 45,* 214-222.

Lapsley, H., Nikora, L. W., & Black, R. (2002). *"Kia mauri tau!" Narratives of recovery from disabling mental health problems.* Wellington: Mental Health Commission.

Law, M., Baptiste, S., & Mills, J. (1995). Client-centred practice: What does it mean and does it make a difference? *Canadian Journal of Occupational Therapy, 62,* 250-257.

Lawler, S. (2002). Narrative in social research. In T. May (Ed.), *Qualitative research in action* (pp. 242-250). London: Sage.

Leibrich, J. (1999). *A gift of stories*. Dunedin: University of Otago Press.

Lorencz, B. (1988). Becoming ordinary: Leaving the psychiatric hospital. In J. M. Morse & J. L. Johnson (Eds.), *The illness experience: Dimensions of suffering* (pp.140-200). Newbury Park, CA: Sage.

Lothian, J. (1998). *From paternalism to participation? Consumers' views and experiences of the initial assessment process in mental health.* Auckland: University of Auckland.

McColl, M. A., & Pranger, T. (1994). Theory and practice in the occupational therapy guidelines for client-centred practice. *Canadian Journal of Occupational Therapy, 61*, 250-259.

Manning, P. K., & Cullum-Swan, B. (1994). Narrative, content, and semiotic analysis. In N. K. Denzin, & Y. S. Lincoln, (Eds.), *Handbook of qualitative research* (pp. 463-477). Thousand Oaks, CA: Sage.

Martin-McDonald, K. (1999). Once upon a time … Narratives and research. *Contemporary Nurse, 8,* 221-226.

Mason, K. H. (1988). *Psychiatric report.* Wellington: Government Printer.

Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience.* Cambridge: Cambridge University Press.

Mattingly, C. & Lawlor, M. (2000). Learning from stories: Narrative interviewing in cross-cultural research. *Scandinavian Journal of Occupational Therapy, 7,* 4-14.

Mental Health Commission. (1998). *Blueprint for mental health services in New Zealand: How things need to be.* Wellington: Author.

Mental Health Commission. (1999). *Employment and mental health: Issues and opportunities: A discussion paper.* Wellington: Author.

Ministry of Health. (1996). *Mental health data 1993* (Rev.ed.). Wellington: Author.

Ministry of Health. (1997a). *Moving forward: The national mental health plan for more and better services.* Wellington: Author.

Ministry of Health. (1997b). *The national mental health standards June 1997.* Wellington: Author.

Ministry of Health. (2000). *New Zealand health strategy discussion document.* Wellington: Author.

Ministry of Health. (2001). *Building on strengths: A guide for action: A new approach to promoting mental health in New Zealand/Aotearoa.* Wellington: Author.

Mishler, E. (1984). *The discourse of medicine: Dialectics of medical interviews.* Norwood, NJ: Ablex.

Mishler, E. (1986a). Analysis of Interview-Narratives. In T. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct.* New York: Praeger.

Mishler, E. G. (1986b). *Research interviewing: Context and narrative.* Cambridge, MA: Harvard University Press.

Molineux, M., & Rickard, W. (2003). Storied approaches to understanding occupation.

    Journal of Occupational Science, 10, 55-63.

Moore, T. J. (1995). *Habilitation and rehabilitation in New Zealand: A paper*

    commissioned by the national advisory committee on core health and disability

    support services. Wellington: Ministry of Health.

Newton, L., Rosen, A., Tennant, C., & Hobbs, C. (2001). Moving out and moving on:

    Some ethnographic observations of deinstitutionalization in an Australian

    community. *Psychiatric Rehabilitation Journal, 25,* 152-162.

New Zealand Department of Health. (1983). *Mental health data 1983.* Wellington: Author.

Ng, G., & McKinlay, F. (1986). A comparative study of ex-psychiatric patients in Dunedin.

    In H. Haynes, & M. Abbott (Eds.), *The future of mental health services in New*

    Zealand: Deinstitutionalization: Volume two of the edited proceedings of the mental

    health foundation of New Zealand's 1985 conference (pp. 139-147). Auckland:

    Mental Health Foundation of New Zealand.

Northern DHB Support Agency. (2002). *Northern regional mental health plan 2002-2003.*

    Auckland: Author.

North Health. (1996). *Kingseat hospital: Relocating mental health services.* Auckland:

    Author.

Ohio Department of Mental Health. (1999). *Toward best practice: Top ten findings from*

    the longitudinal consumer outcomes study 1999. Ohio: Author.

Okasha, A. (1999). Nonconventional approaches to the treatment of mental illness. In J. J.

    Lopez-Ibor, F. Lieh-Mak, H. M. Visotsky, & M. Maj (Eds.), *One world, one*

    language: Paving the way to better perspectives for mental health: Proceedings of

the X World Congress of Psychiatry (Madrid, Spain, August 23-28, 1996) (pp. 41-
44). Seattle: Hogrefe & Huber.

Papalia, D. E., & Olds, S. W. (1992). *Human development* (5th ed.). New York: McGraw-
Hill.

Patterson, J. (1992). *Exploring Maori values*. Palmerston North: The Dunmore Press.

Peterson, D. (2003). *Government policy project: Issues paper 1: Discrimination in
employment.* Mental Health Foundation of New Zealand. Available:
www.likeminds.govt.nz

Poirier, S., & Ayres, L. (1997). Focus on qualitative methods: Endings, secrets, and
silences: Overreading in narrative inquiry. *Research in Nursing & Health, 20,* 551-
557.

Poland, B. D. (2002). Transcription quality. In J. F. Gubrium & J. A. Holstein (Eds.),
Handbook of interview research: Context and method (pp. 629-649). Thousand
Oaks, CA: Sage.

Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences.* Albany, NY:
University of New York Press.

Pomare, E. W., Keefe-Ormsby, V., Ormsby, C., Pearce, N., Reid, P., Robson, B., & Watene
H. N. (1995). *Hauora Maori standards of health III: A study of the years 1970-
1991.* Wellington: GP Print.

Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic
review of qualitative literature in health services research. *Qualitative Health
Research, 8,* 341-351.

Primeau, L. A. (1996). Human daily travel: Personal choices and external constraints. In R. Zemke, & F. Clark (Eds.), *Occupational science: The evolving discipline* (pp. 115-124). Philadelphia: F. A. Davis.

Ralph, R. O. (2000). *Review of recovery literature: A synthesis of a sample of recovery literature.* Edmund S. Muskie School of Public Service, University of Southern Maine.

Ratima, M. M., Durie, M. H., Allan, G. R., Morrison, P. S., Gillies, A., & Waldon, J. A. (1995). A culturally effective framework for the delivery of disability support services to Maori. *New Zealand Journal of Disability Studies, 1,* 60-75.

Rebeiro, K. L. (1999). The labyrinth of community mental health: In search of meaningful occupation. *Psychiatric Rehabilitation Journal, 23,* 143-152.

Rebeiro, K. L., & Cook, J. V. (1999). Opportunity, not prescription: An exploratory study of the experience of occupational engagement. *Canadian Journal of Occupational Therapy, 66,* 176-186.

Regional Coordination Service. (2003). *RCS Operational Manual.* Unpublished draft. Auckland: Waitemata District Health Board.

Rice, P. L., & Ezzy, D. (1999). *Qualitative research methods: A health focus.* Melbourne, Australia: Oxford University Press.

Ricoeur, P. (1980). Narrative time. *Critical Inquiry, 7,* 169-190.

Ricoeur, P. (1988). *Time and narrative,* vol. 1 (K. McLaughlin & D. Pellauer, Trans.). Chicago: University of Chicago Press. (Original published 1985)

Ridgway, P. (2001). ReStorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal, 24,* 335-343.

Riessman, C. K. (1993). *Narrative analysis*. Newbury Park, CA: Sage.

Riessman, C. K. (2002). Analysis of personal narratives. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 695-710). Thousand Oaks, CA: Sage.

Ritchie, J. (1992). *Becoming bicultural.* Wellington: Huia Publishers.

Robinson, J. A., & Hawpe, L. (1986). Narrative thinking as a heuristic process. In T. R. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct* (pp. 111-125). New York: Praeger.

Rogers, C. R. (1973). *Client-centred therapy.* London: Constable & Company.

Rogers, J. C. (2000). Habits: Do we practice what we preach? *The Occupational Therapy Journal of Research, 20* (Supplement 1), 119-122.

Rogers, J. C., & Holm, M. B. (2000). Daily-living skills and habits of older women with depression. *The Occupational Therapy Journal of Research, 20* (Supplement 1), 68-85.

Rowles, G. D. (2000). Habituation and being in place. *The Occupational Therapy Journal of Research, 20* (Supplement 1), 52-67.

Royal Commission on Social Policy. (1988). *The April report, II* (pp. 47-69). Wellington: Author.

Sarbin, T. R. (Ed.). (1986). *Narrative psychology: The storied nature of human conduct.* New York: Praeger.

Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin, & Y. S. Lincoln, (Eds.), *Handbook of qualitative research* (pp. 118-137). Thousand Oaks, CA: Sage.

Schwarz, C., Davidson, G., Seaton, A., & Tebbit, V. (1992). *Chambers English dictionary*. New York: W. & R. Chambers.

Seidman, I. (1998). *Interviewing as qualitative research: A guide for researchers in education and the social services*. New York: Teachers College Press.

Sheerin, I., & Gale, R. (1984). *Quality of life in the community: Consumer perspectives of the life situation of some people with long term mental disorders*. Christchurch: Health Planning and Research Unit.

Silverman, D. (2001). *Interpreting qualitative data: Methods for analysing talk, text and interaction* (2nd ed.). London: Sage.

Smith, L. T. (1999). *Decolonizing methodologies: Research and indigenous peoples*. London: Zed Books Ltd.

Snodgrass, G. (1985). *English at work*. Carlton, VA: Pitman.

Statistics New Zealand Te Tari Tatau. (1997). *1996 Census of population and dwellings: National summary*. Wellington: Author.

Statistics New Zealand. (2003). *Key statistics July 2003*. Wellington: Author.

Sumsion, T. (1993). Client-centred practice: The true impact. *Canadian Journal of Occupational Therapy, 60*, 6-8.

The Mental Health Foundation of New Zealand. (1997). *Te aro ake: Maori mental health promotion*. Auckland: Author.

Thorne, B. (1992). *Carl Rogers*. London: Sage Publications.

Tilt, C. (1838). *The dramatic works of William Shakespeare*. Vol. II, pp. 283-357. London: Author.

Turner, V. (1981). Social dramas and stories about them. In W. J. T. Mitchell (Ed.), *On narrative* (pp. 165-186). Chicago: The University of Chicago Press.

Warren, C. A. B. (2002). Qualitative interviews. In J. F. Gubrium & J. A. Holstein (Eds.),

    Handbook of interview research: Context and method (pp. 83-101). Thousand Oaks,

    CA: Sage.

Warren, H. (1997). The hard end of community care: Psychiatric patients and community.

    In C. Bell (Ed.), *Community issues in New Zealand* (pp. 35-50). Palmerston North:

    The Dunmore Press.

Watts, D., Lutz, W. J., & Dunbar, L. (1998). A longitudinal study of mental health services

    and consumer outcomes in a changing system. *New Research in Mental Health, 13,*

    104-112.

Wengraf, T. (2001). *Qualitative research interviewing.* London: Sage.

White, H. (1981). The narrativization of real events. In W. J. T. Mitchell (Ed.), *On*

    narrative (pp. 249-254). Chicago: The University of Chicago Press.

Wilcock, A. A. (1998a). *An occupational perspective of health.* Thorofare, NJ: Slack

    Incorporated.

Wilcock, A. A. (1998b). Reflections on doing, being and becoming. *Canadian Journal of*

    Occupational Therapy, 65, 248-256.

Williams, H. W. (1975). *A dictionary of the Maori language* (7th ed.). Wellington:

    Government Printer.

Williams, J. (2000). Effects of activity limitation and routinization on mental health. *The*

    Occupational Therapy Journal of Research, 20 (Supplement 1), 100-105.

Williams, T. & Robinson, D. (2002). Social capital-based partnerships: A Maori

    perspective and a comparative approach. In D. Robinson (Ed.), *Building social*

    capital (pp. 14-30). Wellington: Institute of Policy Studies, Victoria University of

    Wellington.

Wiseman, H. (1995). The quest for connectedness: Loneliness as process in the narratives

    of lonely university students. In R. Josselson & A. Lieblich (Vol. Eds.), *Interpreting*

    experience: The narrative study of lives: Vol. 3 (pp. 116-152). Thousand Oaks, CA:

    Sage.

World Health Organisation. (1946). *Constitution of the World Health Organisation*. New

    York: International Health Conference..

Wyatt, F. (1986). The narrative in psychoanalysis: Psychoanalytic notes on storytelling,

    listening, and interpreting. In T. R. Sarbin (Ed.), *Narrative psychology: The storied*

    nature of human conduct (pp. 193-210). New York: Praeger.

Yerxa, E. J. (1998). Health and the human spirit for occupation. *American Journal of*

    Occupational Therapy, 50, 412-418.

Zemke, R., & Clark, F. (Eds.). (1996). *Occupational science: The evolving discipline.*

    Philadelphia: F.A. Davis Company.

Zuzanek, J. (1998). Time use, time pressure, personal stress, mental health, and life

    satisfaction from a life cycle perspective. *Journal of Occupational Science, 5,* 26-

    39.