HOW PEOPLE WHO HAVE A RELATIVE OR FRIEND WITH MENTAL ILLNESS ARE SUPPORTED BY THE AUCKLAND BRANCH OF SUPPORTING FAMILIES IN MENTAL ILLNESS

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DECLARATION

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This dissertation entitled: *How people who have a relative or friend with mental illness are supported by the Auckland branch of supporting families in mental illness*

Is submitted in partial fulfilment for the requirements of the Unitec degree of:

Master of Social Practice

Candidate's declaration

I confirm that:

This dissertation project represents my own work.

The contribution of supervisors and others to this work was consistent with the Unitec Regulations and Policies.

Research for this work has been conducted in accordance with the Unitec Research Ethics Committee Policy and Procedures, and has fulfilled any requirements set for this project by the Unitec Research Ethics Committee.

Research Ethics Committee Approval Number: **UREC 2009-996**

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ABSTRACT

This dissertation reflects on the historical impact of mental illness on family/whānau, the deinstitutionalisation of mental health hospitals and their replacement by assertive community treatment, and the integration of people who suffer from mental illness back into society or, as often was the case, to their family/whānau who now occupied a central carer role. This shift in care ideology ushered in challenges for family/whānau as they sought for support to be seen, heard, and included in the care process for their relatives or friends when receiving services from the mental health system.

The community organisation, Supporting Families in Mental Illness (SFMI), assists family/whānau so that they can cope with the stress of their experiences, as well as increasing their ability to care for their relative or friend who has a mental illness. This study explored the experience of families/whānau as they came to grips with the mental illness of their relative or friend, and their evaluation of the effectiveness the various services of SFMI. In order to study the services being provided, eighteen clients of SFMI were interviewed.

The research showed that mental illness of family member had a powerful impact on families. This included initial challenges in getting information about mental illness, diagnosis, mental health services and support strategies, considerable levels of stress were suffered by these families and whānau, financially, emotionally and often physically, with violence occurring.

Participants also indicated that strongly positive assistance was received from SFMI particularly in relation to counselling services, face-to-face and telephone support services and information services. Although highly positive overall, there some areas of concern around support for diagnoses other than schizophrenia, for non-parent family members, and the effectiveness of the SFMI website.

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CHAPTER ONE - OVERVIEW

1.1 Introduction to this research project

This dissertation concentrates on the experiences of family/whānau that are caring for a relative or friend with serious mental illness (SMI), and the evaluation of the effectiveness of family support services, offered by Supporting Families in Mental Illness (SFMI). The purpose of this study is twofold: to comprehend the experiences of family/whānau with a relative or friend (carer) who suffers mental illness, and to analyse their level of satisfaction with the services of the Auckland Branch of SFMI. This study has been carried out by assessing families/whānau opinion by interviewing current SFMI service users, and those who have used the services in the last two years.

1.2 Defining Families and Whănau

The Ministry of Health in conjunction with the Australia and New Zealand College of Psychiatrists, developed a publication titled, 'Guidance for Involving Families and Whănau of Mental Health Consumer/Tangata Whaiora in the Care, Assessment and Treatment Process' (Ministry of Health, 2000). This publication set out what family and whānau could mean:

> A family is a set of relationships that is defined as family by the tangata whai ora. Family is not limited to relationships based on blood ties, and may include:
> - relatives of the tangata whai ora (including a spouse or partner)
> - a mixture of relatives, friends and others in a support network
> - only non-relatives of the tangata whai ora. (pvii)

This definition is closely aligned with the definition of family/whānau used in this thesis, with the caveat that consumers are not the sole arbiters of who is family, and who is not family.

The Ministry of Health (2000) argues that in situations where there is conflict over definition of the family, mental health providers must be guided by best clinical practice, and the consent of the tangata whaiora. Explaining further on the concept of family/whānau from multicultural perspectives, The Ministry of Health went on to say that for Māori, it includes whānau, hāpu, iwi, and a support group for tangata whai ora. Pacific People described family as containing – aiga, kopu tangata, and magafaoa.

The New Zealand European concept of family includes the nuclear and extended Pākehā family. For the cultural groups such as refugees and other migrants, families will be constructed as per their culture. Particular recognition is given to other community-based interpretation of family (e.g., gender based, gay, lesbian or Deaf communities.)

In this study, *family/whānau* includes blood and non-blood relations of a person who suffers from mental illness, and/or a person who occupied a major carer role, but not as a paid professional. *Carer* includes any family/whānau member (e.g., wife, husband, partner, parent, son, daughter, brother, sister, cousin, or friend) who occupies a carer role in the life of a person who suffers from mental illness.

1.3 The historical context

The deinstitutionalisation of mental health services has increased the number of people who suffer from mental illness who live in the community, and who rely to a considerable extent on the support of family members or friends. Even in 1995, before deinstitutionisation got fully underway, Solomon and Draine (1995) stated that (in United States of America) between 40 and 65% of adults with SMI lived with their families, and 75% of people with schizophrenia had contact with their families. The Internal Affairs report (2007) showed that New Zealand, over the period from 1990 to 2007, closed all of its psychiatric hospitals, 'moving from large stand-alone psychiatric hospitals to mental health services that were integrated with other health services (predominantly based in the community and at general-hospital sites)' (Ministry of Internal Affairs, 2007, p819) .

The Ministry of Health's *Moving Forward* report (1997a) explained that from 1994 community health services had been purchased and provided, and 'a stock-take undertaken late in 1995 showed a major increase in community mental health teams and community-based residential services for adults. There had also been a large increase in new community providers from the non-government sector.' (p9).

The patients in psychiatric hospitals across the country were transferred to the community, some to live with their family/whānau and others to the community-based

aresidential services for adults from where they received care via the community mental health teams in their various locations. Miller, Anita, and Dawson (2006) make the point that families and caregivers began asking to be included as collaborators in service delivery - principally which are listened to as individuals. The The World Health Organisation (2009) quotes the World Fellowship for Schizophrenia and Allied Disorders in their emphasis on:

> mutual sharing of knowledge - the professional knowledge of mental health workers, and the knowledge gained by families and consumers through their lived experiences - is vital for the development of trust. Without trust, an effective therapeutic alliance is often not possible and clinicians, families and consumers can find themselves at odds with each other. (Box 3.5).

In New Zealand, too, the families/carers were 'seeking more influence over how mental health services develop. In particular, they were seeking access to the information they needed to enable them to participate positively in treatment and support planning.' (Ministry of Health 1997a, p22) These demands required a perspective shift from the mental health professionals in the way they had operated in the previous institutionalised environment where families were rarely involved or consulted in the care of patients.

Sherman (2003) looking historically at the best practices for family intervention quotes Gantt, Goldstein, & Pinsky (1989) 'that the inclusion of family members in the patients' care has been 'fraught with ambivalence at best; neglect or hostility at worst' due to the hierarchical, adversarial and 'family blaming' mentalities that pervaded the mental health system' (p1). Marsh (1992), however, notes more recently, that the views many mental health professionals have shifted dramatically with regard to family inclusion and that rather than viewing families as the source of problems, they are much more likely to see them as part of the solution.

The implementation of community-based practice in mental health ushered in the establishment of family support organisations. The *Moving Forward* report (Ministry of Health, 1997a) recommended the development of family advisory, peer support, education and training services, 'run by family members for family members'. The largest organisation to receive funding under the *Moving Forward* targets was SFMI, a mental health organisation with 19 branches. The Auckland Branch of SFMI, with a

budget family support well in excess of $1 million per year, is by far the largest branch in the organisation. The District Health Boards and the Ministry of Health funded SFMI to provide support and information to the families and whānau who have a relative or friend who suffers from mental illness.

1.4 The Objectives of Study

The main objectives of this research are:

- To describe the challenges faced by families/whānau as a result of the mental illness of a relative or friend
- To evaluate these challenges in relation to the contexts in which they occur
- To describe the role and activities of SFMI Auckland in providing support and information services for the well-being of families and whānau
- To evaluate the extent to which those services are judged effective by families and whānau, and how well they meet the objectives of SFMI Auckland, government policy and best practice guidelines
- To offer suggestions for new services or adaptations to services that will better meet the needs of families and whānau

1.5 Dissertation Organisation

The dissertation has the following chapters:

Chapter Two involves the review of current literature on the history and development of mental health practice in New Zealand including deinstitutionalisation, community care and modern treatment systems (modern antipsychotics, dual diagnosis treatment and psychotherapy). This review will also cover experiences of family engagement with mental health services, key strategies for successful family/whānau involvement in mental health practice, and a brief overview of SFMI and its organisational performance measurement.

Chapter Three discusses the research methodology and presents the framework that underpins the implementation of this research, including the sampling process, the data collection tools, and method for the analysis of the data.

Chapter Four concentrates on the results of the research covering the demographics of the participants, the patterns of family engagement with SF services, the levels of satisfaction of family/whānau with SF services, and finally, the general recommendations that arise from the analysis.

Chapter Five of this study presents the discussion of the results in relation to SFMI objectives, government polices and best practice, and creates recommendations and draws conclusions.

CHAPTER TWO - LITERATURE REVIEW

2.1 Introduction

The study of family engagement in the field of mental health has become increasingly concerned with the needs and wants of families and whānau with a relative or friend who suffered mental illness.

> 'People with serious mental illness are not ill in isolation. Their families, extended whānau and significant others, whatever they may think about the illness, cannot escape being affected by it. The lives of people with serious mental illness are inextricably involved with the lives of those they love and care for, and the lives of those who love and care about them'. (Mental Health Commission, 1998, p3).

Therefore, mental health support organisations exist to alleviate some of the problems faced by family and whānau, especially to make them better carers among other services that are to be provided to them.

The first part of my literature review briefly discusses mental illness, deinstitutionalisation and the history of mental health services in New Zealand, looks in-depth at the experiences of carers with a relative or friend who suffered mental illness and the history of and theory around family engagement and practice. The second part looks the structure of mental health services in New Zealand, and the development of family support services, and in particular of Supporting Families in Mental Illness (SFMI).

The success of any organisation is directly linked to providing high levels of consumers' satisfaction. Gronroos (1982) defined service quality as 'the outcome of an evaluation process where the consumer compares her expectations with the service she perceives she has received' (p3). I have therefore included literature on performance measurement, the literature on evaluation of service quality, and an overview of SFMI as an organisation.

2.2 Severe Mental Illness – The focus of state funded mental health care

The Diagnostic and Statistical Manual version IV (DSM-IV - American Psychiatric Association, 1994 - the mental health practitioners' manual) defines mental illness as a psychological and emotional unwellness that may incapacitate an individual in their family, community, vocational, and physical well being.

> ‘It is a psychological or behavioural pattern that occurs in an individual and is thought to cause distress or disability that is not expected as part of normal development or culture’ (p.vii).

Rawlings and Sophronia (1988) further elaborate on the internal construction of mental illness and its capacity to cause distress:

> ‘Mental illness is a substantial disorder in one’s thoughts or mood that significantly impairs judgment, behaviour, the capacity to recognise reality, or the ability to cope with ordinary demands of life’ (p2).

In 1997 *Moving Forward* (Ministry of Health) stated that 20% of the population in New Zealand are said to have a diagnosable mental illness at least once in their lifetime, with 3% diagnosed with serious mental illness at any given time. Mental illness is often categorised as either severe mental illness (SMI) or ‘mild’ mental illness. More recent statistics show higher levels of mental illness in New Zealand as shown in the Table 2.1 below

Table 2:1 Prevalence of mental illness in New Zealand

General ratios of mental illness	European/ Others **%**	Māori %	Pacific Island **%**	Total **%**
Lifetime risk of mental illness				46.6
Lifetime prevalence of mental illness				39.5
Prevalence of MI in the last 12 months:	19.3	29.5	24.4	20.7
Mood disorders (depression and bi-polar	7.5	11.4	8.6	7.9
Anxiety disorder	5,7	8.6	7.5	14.8
Substance Abuse disorder	9.1	19.4	5.3	3.5
Eating disorder	0.4	1.0	1.5	0.5

(adapted from Browne, Wells & Scott, 2006, p210).

From Table 2.1 we can see mental disorder is common in New Zealand - 46.6% of the population are predicted to meet the criteria for a mental disorder at some time in their lives, with 39.5% having already done so and 20.7% having a disorder in the past 12 months. The prevalence of disorder in any period is higher for Mäori and Pacific people than for the European/Others composite ethnic group. For disorders in the past 12 months, the prevalence indicates that Mäori and Pacific people have a greater burden due to mental health problems (Browne, Wells, & Scott, 2006).

Browne *et al* go on to say that ‘much of this burden appears to be due to the youthfulness of the Mäori and Pacific populations’ and their relative socioeconomic disadvantage’,

particularly as ‘younger people have a higher prevalence of disorder in the past 12 months and are more likely to report having ever had a disorder by any particular age’ (p210). Brown *et al* also showed that ‘females have higher prevalence of anxiety disorder, major depression and eating disorders than males, whereas males have substantially higher prevalence in substance abuse disorders’ (p57).

2.2.1 Mild and other mental illness

About seventeen percent of people in New Zealand suffer from mild mental illness annually. These are in form of temporary and mild depressive moods, anxiety causing a general feeling of unease, or other sorts of mental illnesses that are temporary and do not disrupt the functional ability of an individual. These conditions do not required long-term treatment when given a timely and adequate treatment in the primary care settings.

In 1996 and subsequently the National Advisory Committee (National Advisory Committee on Health and Disability, 1996) issued guidelines for the treatment and management of depression, anxiety and substance abuse disorders by primary healthcare professionals. These guidelines ‘cover the detection, treatment and management of the majority of mental health disorders encountered in primary healthcare’ (p52). Mental Health Commission (2010) reported that the Ministry of Health dedicated funding to primary mental health care through piloting 26 initiatives across 41 primary health organisations (PHO’s) targeting mild to moderate mental health and substance misuse disorders. The pilots aimed at increasing patient access to talking therapies and other psychosocial interventions. The evaluation suggested the outcomes of these initiatives were very positive and the programme has been rolled out to all of the 80 PHO’s. The effective treatment of mild and other mental illness at the primary health care level is expected to reduce the cost associated with severe mental health cost, and, most importantly, people can remain healthy and be part of their family and whānau.

2.2.2 Severe mental illness (SMI)

Moving Forward (Ministry of Health, 1997a) claimed that 3% of New Zealander’s suffer severe mental illness that requires ongoing treatment and support at any given time. For people who have a severe mental illness or disorder, their experience of disability will be very different from those suffering milder forms. Anxiety, for example, may be so severe that it disrupts the person’s whole life. Defining serious mental illness can be a difficult thing to do

because severity will depend on individual sufferers, and the level of support available to them.

Narrow, Reigier, Goodman *et al* (1993) argued that the widely accepted definitions of severe mental illness for children and adolescents were drawn from three sources. The first of these is relevant to this study and is the definition of severe mental illness set forth by the US Department of Health and Human Services in 1993 stating:

> 'Severe mental illness is defined through diagnosis, disability and duration, and includes disorders with psychotic symptoms such as schizophrenia, schizoaffective disorder, manic depressive disorder, autism, as well as severe forms of other disorders such as major depression, panic disorder, and obsessive compulsive disorder. (1993 National Advisory Mental Health Council *Health Care Reform for Americans with Severe Mental Illnesse*s' - cited in Narrow, Reigier, Goodman, et al., 1993, p3)

Individuals who experience severe mental illness require long-term treatment, and sometimes it could be lifetime.

The United Kingdom Health Outcome Indicators (National Centre for UK Health Outcomes Development 1999) do not give a specific definition of SMI but a number of factors and criteria were clearly identified for recognising SMI. These included 'people diagnosed with mental and behavioural disorders due to psychoactive substance abuse, schizophrenia, schizotypal and delusional disorders, mood (affective) disorders, neurotic, stress-related and somatoform disorders, behavioural syndromes disorders of adult personality and behaviour' (p6). Exclusions to this definition were also considered and it was decided that SMI would not include 'people with dementia, people with learning disabilities (unless with a co-existing mental illness) or children and adolescents' (p6).

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Rethink (2011a), a UK family support organisation similar to SFMI, explains that

> 'severe mental illnesses are generally seen to be those in which psychosis is likely to occur.....where the individual experiences a loss of a sense of reality, [and] where they cease to see and respond appropriately to the everyday world as they used to [prior to their illness]' (p2).

Psychosis is to be a symptom common in most definitions of serious mental illness. DSM IV (American Psychiatric Association, 1994) link psychotic symptoms to a five different

versions of schizophrenia as well as bi-polar, personality disorders, and severe forms of other mental illnesses.

2.2.3 Signs and Symptoms of Psychosis

Symptoms of psychosis will vary from person to person, and the nature of the illness. However, most common observations will include having hallucinations delusions, or other types of unusual or disorganised thinking and behaviour. Rethink (2011a) describes having hallucinations as someone hearing 'their own thoughts as if they are coming from a source outside their own body. They may also see, smell or taste things that appear to be real but which are not being experienced at that time by anyone else' (p3). Rethink makes the point that people who hallucinate 'often try to find an explanation for them, and may invent and attribute the hallucination to beliefs that others may see as strange' (p3). These are delusions. The person may believe that that the voice coming from the radio or TV talked directly to her, or that animals talk to her, or she may become afraid of her parents, family members, or neighbours, taking them for enemies who want to harm her. This kind of distorted thought pattern is called 'paranoia', and may cause very severe anxiety levels for the person.

Rethink (2011b) explains that psychosis may also involve 'mania', when someone's mood is very overactive or 'heightened'. 'There will be increased energy and physical activity, racing thoughts and speech (which may be confused)' (p2), irrationality, and episodes of aggression and pacing are sometimes displayed. Observable opposite behaviour could be extreme withdrawal, inactivity (perhaps neither moving nor speaking), and continuous gazing at no particular object. These conditions may be present in intervals of high or low moods.

Disorganised thinking is another feature of psychosis and 'can feel as though you are thinking less clearly. It might be hard to concentrate, or it might be hard to put words together and you might not be sure if you are making sense' (Waitemata District Health Board, 2010., p2).

2.2.4 Causes of psychotic illness

It is generally held that a genetic vulnerability can lead to psychosis. Fraser (2004:p1) also makes the point that environmental factors that may trigger mental illness 'include being born in the winter months, being brought up in a big city, immigration, a childhood head-injury,

stressful life events and the use of drugs' and alcohol. However, these environmental features are common and present in various degrees in all severe mental illness.

2.3 Deinstitutionalisation

Up until the 1990's in New Zealand, services people with SMI were largely based in psychiatric hospitals. As noted in chapter 1, deinstitutionalisation changed all that. Deinstitutionalisation was part of a world - wide movement that started in the USA and Scandinavia in the late 50s. Millon & Groassman (2004), described the problems of the large psychiatric institution as including

- Social isolation through disengagement from families and friends
- Loss or deprivation of basic freedoms and human rights
- Threatened or real loss of home
- High rates of suicide and self - harm
- Overcrowding, with consequent problems in hygiene, safety, quality of care and public scandals about sub-standard conditions
- Inability to provide rehabilitation plans for patients that would re-establish them in the community
- Poor recovery rates meant that many patients were institutionalised for life and that more and more of these expensive facilities were needed.

Whichever way we view deinstitutionalisation, two major reasons are given for it. The challenge of controlling the growing financial burden of institutional care for people with mental illness, and the lack of holistic therapeutic care in the mental hospitals was found to contribute to a worse outcome for the patients in the institutions. Smark (2002) explains that the costs of operating mental institutions soared after the Second World War, rising faster than the general level of inflation, and pushed by increased unionisation of state workers, leading to increased wage costs and (helpfully) improved working conditions in the sector.

Smark (2002) makes the point that the anti-psychiatry movement, together with self-help, liberation and other movements of the twentieth century contributed to break the monopoly of knowledge and power held by psychiatrists up until the 1960s. Around the same period, the discovery of psychoactive drugs such as anti psychotics, anti-depressants, and other effective

medicines, substantiated the push for deinstitutionalisation. As noted by Scull (1984), the humanists believed that active psychoactive drugs allowed for treatment outside the asylum.

The call for deinstitutionalisation addressed the above problems, aiming at providing subsistence living outside the institution for people with mental illness through the state welfare/benefits system. Deinstitutionalisation after the Second World War was actually the shifting of bearing the huge cost of care from the state via mental hospitals to social welfare, and eventually to families of people with mental illness. 'Government successfully shifted the burden of care to family or into other alternatives as just noted'. (Jones, 1985, p63).

The critics of assertive community therapy were sceptical about the idea from its inception on the ground that people who suffer mental illness would be worst off in the implementation, and that it was about cost control rather than in the interest of the consumers.

> 'Depopulation of the state mental hospitals did indeed take place, but not really because more enlightened public attitudes towards mental illness made it possible to relocate sufferers to more suitable settings within the community. It took place because the state could not afford to provide lifetime care for a huge and growing chronic caseload inside enormous crumbling hospitals built in the nineteenth –century, which proved to be expensive to run at twentieth–century prices'. (Johnson, 1990, xxii)

However in the process of implementing the transformation, there have been systematic errors of omissions and commission that tend to raise the question of whether deinstitutionalisation was actually worth the pain, because not enough preparations were made to cope with the potential challenges that the change entails. Due to an inadequate provision of resources and alternative care for people with mental illness under a deinstitutionalised care system, various social problems have emerged that need the attention of government, and society in general.

Smark, (2002) explains that such problems include *transinstitutionalisation* - people with mental illness were placed in another form of institution after they were discharged from the psychiatric hospitals, such as charitable shelters for the homeless, jails, nursing homes, boarding houses, and general hospitals. *Sleeping rough* has become a major problem in big cities, with many of the rough sleepers previously being, institutionalised patients.

2.3.1 *'Community care'*

Bassuk and Gerson (1985) stressed the inadequacy of the few community-care systems put in place after deinstitutionalisation to provide follow-up care for ex-patients. The high rate of readmission into institutions that were often inadequate for meeting the expectations of basic comfort, let alone for providing any psychiatric treatment for their illness, reflected the weakness of deinstitutionalisation. To address the problems in the community treatment approach, there was a need for adequate follow up from the Community Mental Health Teams to provide solutions in the early phase of deinstitutionalisation.

One response to solving problems of deinstitutionalisation was the model of community integration and treatment called Assertive Community Treatment (ACT). This involves the deployment of a multidisciplinary team to serve a defined group of mental health clients by ensuring they had good accommodation, then visiting them at home, helping them to manage their illness, improving their material and social environment, and providing training in activities of daily living, social relations, and work (National Alliance on Mental Illness, 2011).

To make deinstitutionalisation effective, the following are important for the improvement of the wellbeing of the patient, community, and family carers. *Our lives in 2014*, a Mental Health Commission (2004) publication recognises the need for improvement in the following areas among others:

- Community Mental Health Centres that are available, active, and supportive of the patient, the family carers, and community care partners, e.g. NGO's.
- Good Housing facilities to accommodate patients discharged into the community.
- Social Welfare that pays a sustainable benefit to the mentally sick persons that meet their daily needs for food, clothing, shelter and other necessities.
- Effective integration that addresses stigmatisation problems being faced by people who suffer mental illness e.g. able to get jobs for which they are qualified, a, good home, freedom from unnecessary monitoring, and name-calling.

Community rather than institutional care remains an ultimate objective for people who suffer mental illness, and their families, because it reinforces their dignity and reinstates them with

their families, and their community. New Zealand's progress in this area is the subject of the following section.

2.4 A Short History of Mental Health Services in New Zealand

New Zealand, being a British colony, inherited most of her health care system from the British public health model. Our mental health care system embraced the 'contemporary Victorian model of custodial care' (p2) of mentally ill persons in large mental hospitals or asylums. (Joseph and Kearns, 1996). This model in increasing large and authoritarian institutions became the 'dominant form and symbol of society's responsibility for the mentally ill' (p6). This approach lacked productive outcomes for the clients and their family members who were ignored or denied input or consultation regarding the process of care. The clients of institutional mental health services received poor care, were alienated from their families and society, and in most cases had no hope of reintegration into normal productive life. (Haney, 2001).

In New Zealand statutes backed this model of care. The Mental Health Act of 1911 renamed the lunatic asylums as psychiatric hospitals and provided for compulsory admission and. 'remained in force until 1969' (Haines and Abbott, 1985, p25). The relevance of legislation here is to ensure that no individual is able to refuse treatment, especially when they are a threat to themselves or other people in the community.

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James (1988) states that passing the 1992 Mental Health (Compulsory Treatment and Assessment) Act resulted in the possibility of treatment for mental illness moving from psychiatric hospitals to all hospital settings. When, in 1993, Regional Health Authorities (RHAs) were introduced so that mental health services could be competitively purchased from a range of 'providers' that were both public and private and included voluntary agencies, the scene was set for rapid change (Joseph and Kearns, 1996). The semi-autonomous RHAs resulted in greater local of decision-making, and a more rapid process of deinstitutionalisation of mental health services than had been possible under the previous structure (Blaine & Donaldson, 1998).

The bi-cultural nature of New Zealand contributed to the deinstitutionalisation process. Māori had much higher psychiatric admission rates than non-Māori - 850/100,000 per annum for

Māori, compared to 560/100,000 for Pākehā (Durie, 1996). Others noted higher Māori admissions and re-admission rates in the 20 -29-age bracket (Te Puni Kōkiri, 1993). The over-representation of Māori in mental hospitals encouraged the RHAs to consider ways to in which Māori could have greater input into treatment services. Durie (1994) argued that services for Māori had to be culturally appropriate and for this to happen funding had to be given to Māori groups to develop their own programmes; and that Māori perspective had to be included the existing services.

The first Māori psychiatric unit was Te Whare Ora, set up at Tokanui Hospital in the 1980's followed by similar units in Auckland and Wellington in the late 80's. These expanded treatment ideas, shifting away from the domination of the western medical model and incorporating Māori models of health, psychotherapy, therapeutic communities (Durie, 1994).

In New Zealand the process of deinstitutionalisation was driven by a series of public health inquiries. Brunton (2005) believes that 'public inquiries have helped shape New Zealand's mental health policy both directly and indirectly at different stages of evolution. In both its advisory and investigative forms, the public inquiry remains an important tool of public administration' (p14). In particular, the recommendations of Royal Commissions and Ministerial Commissions of Inquiry made a significant input to the deinstitutionalisation process, and the development of community care models.

The Mason Inquiry into Mental Health Services, New Zealand in 1996 (The Mason Report, 1996), came as the process of the closing down the large psychiatric hospitals was gathering steam, but the models for a new era of community services were only partially developed.

> A new framework for service delivery had been developed, based on community mental health teams and other forms of community support, such as housing, backed up by inpatient hospital services for people in acute crisis. The 1994 articulation of the national mental health strategy directed that these services be provided for the 3% of the population with the most severe disorders and highest needs at any one time.' (Mental Health Commission, 2007, p3)

Gibson (2007) explained the recommendations of the Mason Inquiry which recommended that the Government undertake to set up a Mental Health Commission, and which would 'act as a catalyst to improve performance and lift the priority given to mental health in New Zealand'(p1 cited in Mental Health Commission, 2007). The Mason Inquiry only made four

other recommendations They were to set up a implementation monitoring team comprised of the current inquiry members to prepare a blueprint that set out the resource requirements for mental health services; to increase the amount funding to mental health to $124 million over a five-year period; and to 'ring-fence' the monies allocated to mental health and drug and alcohol services so that other health services could not capture them (Pearson, 2000).

The Mason Inquiry had wide impact. The Mental Health Commission was established in 1996, and an ongoing funding stream for sector improvements was developed (the *Blueprint* funding). Also developed was a anti-stigma campaign - *Like Minds, Like Mine* - and a widening of the focus of the Commission in that it was prepared to work with 'any government agencies whose policies and services impacted on people with mental illness.. [and thus encourage] social inclusion' (Mental Health Commission 2007, p6). However, the most important impact of the Mason Inquiry is the implementation of the community treatment model resulting in the establishment of Community Mental Health Centres and a wide range of community support services within the District Health Boards (DHBs), which has led to constructive integration of clients back into their family/whānau, and their community.

2.5 Experiences of carers with a relative or friend who suffered mental illness

2.5.1 *Background to Challenges with Family/Whănau Community Integration*

A family or whānau with a person severely affected by mental illness faces many challenges under the current mental health treatment approach of community integration, in addition to the challenges they encounter as result of the illness of their relative or friend. Marsh (1999) stated such challenges include the following among others:

- The challenge of coping with pressure of caring for sick persons
- The challenge of burden of mental illness on dependants of relative or friend
- The exclusion of family members from the multidisciplinary care plan and especially the clinical team
- The lack of timely information about the nature of the sickness of the family members (often resulting in late or wrong diagnosis)
- The challenge of stigmatisation of mental illness on the family and the sick relative or friend.

I will explore these issues in greater depth.

2.5.2 *The Impact of Mental Illness on Individuals*

Serious mental illness has significant negative impacts on individuals who suffer it to various degrees, and the impact of symptoms of psychosis and other psychological manifestations of the illness. The experience of stress that is automatically part of mental illness has its own physical consequences. Family/whānau must be aware of these effects in order to be able to care for the relative or friend who suffers mental illness.

Major depressive disorder is a condition associated with continuously increased stress; the client with this illness cannot sleep, cannot eat, often cannot sit still or stop worrying. This condition is associated with psycho-neuro-immune response to the chemical imbalance in the brain. This is where the psychoactive medication plays a major role in the regulation of this chemical imbalance.

The tendency to neglect the care for basic necessities of life is usually of concern as such people do have poor diet, live a sedative lifestyle, and lose weight. These factors in turn could result in high blood pressure, diabetes, respiratory tract infections, and bedsores. Strine and Chapman (2007) led research on how mental illness causes physical illness in the United States, and she and her team concluded that there was a significant relationship between depression and anxiety and chronic diseases such as asthma, cardiovascular disease, and diabetes, as well as the adverse health behaviours such as smoking or inactivity that are risk factors for these diseases. She further states that because of the immune system is chronically exhausted, infections are more likely to generalise into septic conditions.

Self harm and physical injury is another factor. A major effect of psychotic episodes is the loss of reality testing due to evidence of hallucinations and delusions which do manifest in misperceptions in visual and auditory experiences. SANE (2010) explains that self-harm includes

> ‘behaviour which involves the deliberate causing of pain or injury to oneself. This includes cutting, burning or hitting oneself, overdosing on prescription or illegal drugs, or even binge-eating or starvation, abuse of drugs or alcohol or repeatedly putting oneself in dangerous situations’ (p1).

People with Schizophrenia have a serious predisposition for heavy nicotine dependence. Cigarette consumption is high in whichever environment they are located. The reasons range from personal habits, effects of psychoactive medication, or the link to a certain neuro-humoral factor, alpha TNF, which drives nicotine craving and seems to be overactive in schizophrenia. This excessive use of nicotine could result in multiple physical diseases, and have a negative impact on the client (Thienhaus, 2003). These direct impacts on the sufferer of mental illness require that the family/whānau understand the nature of the illness, and the appropriate support they should be giving to their relative or friend.

2.5.3 *Impact of Mental Illness of a Relative or Friend on Family/Whănau*

Marsh (1999) noted that researchers have extensively documented 'the devastating impact of mental illness on families in terms of family or caregiver burden, which is the overall level of distress experienced as a result of the illness' (p4). The burdens can be either subjective or objective. A subjective burden is one where the personal suffering experienced by family members stems from their perspective on the nature and events of mental illness, whereas an objective burden involves the practical problems and hardships associated with the illness. Subjective burdens include the grief that families undergo as they mourn for their loved one who was once a focus of attraction and beauty and now suddenly has become ill with mental illness; with in many cases no immediate hope of a full recovery. As one grieving mother said

> 'In the dark soul of the night, I grieve for all of us, for the anguish of the past and the present, and for the uncertainty of the future. Most of all, I grieve for my son and his lost hopes and dreams'. (Marsh, 1999, p348).

That grief can become prolonged to the point where it begins to become a threat to the wellbeing of family members. A family member expressed this feeling by saying, 'It is like someone close died, but there's no closure. It's never over' Marsh (1999). Even where grief is managed, the shattered dreams concerning loved ones remain consistent issues that confront the families and friends of people suffering from mental illness. SMI is a non-discriminatory illness, occurring in situations where many resources has been poured into the life of the family member, creating so much expectation that when he/she becomes ill, the family members constantly experience loss that is irredeemable. Episodes of remission and relapse set up an 'emotional roller coaster creating turmoil and distress for family members. A

mother remarked of her daughter's relapse, '*It is like a small death*, as if she were more vulnerable for having dared to hope again'. (Marsh, 1999, p362).

The objective burdens consists of practical day to day problems associated with mental illness which affect the community, families, and significant others that may have to deal with it. These will include the economic burden to the country, and families. There is no available comprehensive data on the cost of treatment or mistreatment for mental illness in New Zealand.

However, citing example from United States, Rice & Miller (1990) found that in 1990, the direct healthcare costs of treating individuals with schizophrenia totalled 17.3 billion dollars (2.5% of total US national heath expenditure), while the cost of lost productivity amounted to another 12 billion. These estimates do not include the costs to families, which had been estimated previously to be about 11% of the total cost. Using statistics like these illustrate that developing effective treatments used early in the course of schizophrenia have the potential to curb some of the costs associated with this illness

In Australia, SANE (2002) reported that for schizophrenia the

> 'Real financial costs of illness totalled $1.85 billion in 2001, about 0.3% of GDP and nearly $50,000 on average for each of more than 37,000 Australians with the illness. Over one third of this cost is borne by people with the illness and their carers'. (p1)

Over and above the cost of treatment and rehabilitation is the alarming rate of 60% suicides among men who suffered schizophrenia during year 2000. One consumer expressing his opinion on the cost of schizophrenia to individuals said

> 'It's actually very painful to look at the economic costs because it reminds you of what you've missed out on in your life — the lost earnings, the lost security, the lost housing — things like that that so many Australians take for granted'. (SANE, 2001:p3)

The cost to the family/whānau is difficult to quantify, and is a good area in which further research could be done, but Schizophrenia Fellowships' Halliday and Bridgman (2004) explain the economic burden as a daily ordeal, as it affects working families, who are not able to combine their jobs with an effective caring role. There is loss of leave entitlements at work, and of income in the process of caring for relative or friend who suffers mental illness. For example, it is very difficult for sufferers to attend counselling sessions for themselves in

work time or deal with their own reactive depression. Hence, the carer must give up their work to attend such appointments.

People in semi professional and professional occupations fare better in relation to wage and salary rates and conditions such as sick leave. However, these conditions are not unlimited and such workers face pressures on their time. The stress on carers' finances is very important, and sometimes carers are not able to combine their roles with meaningful economic activities, thereby leaving them in a poor financial state.

Describing the limitations of service delivery system, Marsh (1999) citing Lefley (1996), states

> 'family members assume roles for which they are unprepared and untrained for to cope with the requirements of daily life with someone who has mental illness, to obtain services from the mental health, welfare, and medical systems; and perhaps to negotiate with the legal and criminal justice systems'.

These are demanding tasks that the family/whānau often have to do.

Then there often is the 'lack of services for families themselves, who often report unsatisfactory handling of crises and emergencies, insufficient communication, lack of availability on the part of professionals, and absence of programs and relevant services for families in treatment planning.' Lehman, Steinwachs et al (1998:p7) found that few families (less than 10%) were able to access minimal education and supportive services from Mental Health Services.

2.5.4 *Stigma*

For both parents and families, one of the most challenging aspect of the stress experienced is social stigma. Larson and Corrigan (2008) explains stigma 'as the mark that distinguishes someone as discredited' (p2). They continue claiming that 'family members experience stigma through their association with the person with mental illness' and recall that Goffman, in 1963, called this 'courtesy stigma, namely, the stigma experienced by parents, siblings, spouses, and children of people with mental illness' (p1).

The stigma mental illness extends to housing, employment, insurance, socialisation, etc., intensifies the sense of loss and hopelessness for family members (Marsh, 1996). The most vulnerable members of the family that suffer most in the event of a relative's mental illness are the children and teenagers that still require parental care and nurture. It becomes difficult or impossible for the sick mother to carry out these responsibilities and children in the middle of this unfortunate experience.

Family/whānau experience stigma in different ways; some cultures sometimes stigmatise family members once a relative becomes mentally ill, as the group conventionally believes that one of the parents must have done something evil for the relative to become afflicted with mental illness. Family/whānau are affected as they isolate themselves from community activities to avoid the blame and shame attached to the illness.

The exclusion from treatment plans by the clinical team who sometimes hold a strongly genetic theory of the cause of mental illness, holding parents responsible, make stigmatisation very painful as family are sometimes not consulted in making decisions for the relative or friend with mental illness. The lack of care for the family/whānau carer is evidence of stigmatisation, and proof of prejudice against carers. McQueen, (2006) the Executive Director of the; Mental Health Foundation of Australia expresses her concerns on the effect of stigma on the children-experiencing parent with mental illness:

> he fears, stigma, isolation and conspiracy of silence which continue to be major factors for a child's experience of parental mental illness are painful reminders of how our community can ignore the most vulnerable. …It indicates why we as a community must remove the stigma related to mental illness and why we must protect our future by providing children with simple strategies for dealing with life's challenges by early development and maintenance of mental health and wellbeing through resilience, self-confidence and self-esteem. Positive mental health is their right. (cited in Camden-Pratt, 2006, p5).

Larson and Corrigan (2008) point out families have major responsibilities for the care of their relative's mental illness. They would like to see families members involved with recovery planning as much as possible, and regret that even in 2008 stigma gets in the way.

2.6 The structure of services for people with a severe mental illness.

Having discussed the nature of severe mental illness, what support is available to the people with a severe mental illness and their carers in the New Zealand context? The *National*

aMental Health Plan for More and Better Services (Ministry of Health, 1997b) and the *Blueprint for Mental Health Services in New Zealand* (Mental Health Commission, 1998) are key documents in the setting up of the post-deinstitutionalisation framework for mental health services. They focus on mental health services for those with serious mental illness, driving higher community-based service expectations, and providing funding increases to enable community-based services perform well.

The *Blueprint* estimated the needed resources based mainly on an input (full-time equivalents [FTEs] and beds) perspective. At the same time, a mental health ring fence was set up which forced DHB's to spend mental health funding only on mental health services. The range of needs requiring resource allocation were spelt out in *Moving Forward* (Ministry of Health 1997a).

Moving Forward explains the implication of severe mental illnesses in New Zealand as involving a range of differing needs that affect 3% of the population.. It suggests levels of serious mental illness and the services to be provided at each level. These were:

- *People with short term but significant illness* .....access to clinical services for a limited time;
- *People who are acutely unwell or in crisis experiencing severe and acute symptoms* …….rapid access to a comprehensive range of crisis services (including compulsory treatment)
- *People with severe ongoing or recurring illness*..... access to a range of services (including early intervention), within a framework which ensures continuity of care and follow-up
- *People with severe illness and [ongoing] disability* ……access to comprehensive needs assessments, and to service co-ordination which ensures that their needs are met in an integrated way across the continuum of services which include:
    - more flexible accommodation options
    - self help/consumer run employment and activity co-operatives
    - more employment and education supports
    - greater involvement in treatment and service decisions
    - improved service responsiveness and integration, and
    - a valued role in the community.

- *People with needs for long term structured support in a safe environment.* [People with severe behavioural challenges] .... access to long-term safe accommodation, with intensive support and education for recovery..... within either hospital or community long-term care facilities.
- *People with high and complex needs* such as mental illness with severe alcohol and drug disorders, [head injury and/or intellectual disability: eating and] borderline

personality disorders; .....and post-natal depression .....[access to] very specialized services.

- *People with [predominant] alcohol and drug problems....* access to alcohol and drug services (including methadone services). (Ministry of Health, 1997b).

More recently, the Mental Health Commission in a 2010 publication on mental health and addiction funding, explained that there is funding available for packages of care across mental health providers, and flexi funds attached to the other services provided under contract – such as home-based treatments, family/whānau support agreements, and kaupapa Māori day programmes. This recognition of family/whānau in the service funding was a move in the right direction.

Also more recently, there has been a move away from the term 'severe mental illness'. The latest Mental Health and Addiction Action Plan 2006-2015, *Te Kōkori* (Ministry of Health, 2006) talks of people who are severely affected by mental illness. The focus of *Te Kōkori* covers much the same ground as *Moving Forward*, but puts even sharper focus on services for children, Māori and Pacific people, whānau and families, prevention, complex mental illness and community integration.

2.7 The Development of Family Support Services and SFMI Auckland Branch

Professional attitudes to families with a member with schizophrenia have in the past harsh (Miller, 2000). In particular, sometimes the mothers of persons with mental illness were explicitly been blamed for their offspring's illness. The high hereditary component found in schizophrenia reinforced the family blame, resentment, and exclusion of families from the process of treatment and care for people with mental illness. However, this ideology has led to the strong family support movement around the world to resist the professional and institutional practice that excluded families from the process of treatment and care for relatives or a friend suffering from mental illness. The Schizophrenia Fellowship began its work around the world to work with people who suffer from schizophrenia and their families/whānau to address this problem.

SFMI (2010) records shows that the parent movement in New Zealand SF began in 1978 in Christchurch. At the 2008 AGM annual general meeting the name of the organisation was changed to Supporting Families in Mental Illness. However, by this time most branches of the organisation were calling themselves Supporting Families in Mental Illness, reflecting their

involvement with all form of severe mental illness, although in many cases (such as Auckland) their constitutional name remained Schizophrenia Fellowship, reflecting concerns about change of families in the organisation for whom schizophrenia is a lifelong concern.

2.7.1 *Brief Overview of SFMI Auckland Branch*

The Auckland Branch of SFMI started as a parent self-help group called Schizophrenia Fellowship in the 1970s and run by volunteers. Its aim was to inform, network, advocate and help each other, reducing the isolation and loneliness experienced by many families (Wallace, 2003). In 1983, a drop-in centre and office was established in the Auckland Town Hall. The branch appointed a full time staff member in 1986. The branch acquired the Housing New Zealand Corporation House in Grey Lynn, which the Fellowship has leased since 1987. SFMI Auckland started the piloting of Professor Ian Falloon's family inclusive Integrated Mental Health Care Programme in 1992. Between 1992 and 2009, the organisation grew from two full-time equivalent staff to around 18 staff (14 full-time equivalents) offering services from Kaitaia to the Bombay Hills[1].

The Mission of SFMI in 2009 was: 'The best possible quality of life for people with serious and enduring mental illness, their family, whānau and caregivers.' SFMI carries out their mission within a framework of community development, by:

- Developing peer support networks for families affected by serious and enduring mental illness,
- Promoting the rights and needs of individuals and families affected by mental illness,
- Offering advocacy and advice to people about services (and also to services about family issues for policy, planning, resourcing and provision), and
- Providing opportunities for mutual support, the sharing of experiences, and gaining strength and skills to cope better with daily living. (SFMI Auckland, 2004).

The above illustrates SFMI's dedication to community inclusion and public awareness of mental health issues. Bridgman and Brash (2003) explains in 2000 funding for family/whānau and caregiver support services was offered by the government. The Ministry of Health through the Northern Districts DHB's funds SFMI's community work. The contracts with SFMI Auckland are for family/whānau peer support work for families in mental illness. The

[1] Bridgman, G.D. (2009) Personal communication (former Board member and chair of SFMI Auckland and of the national organisation, Schizophrenia Fellowship)

funding basket is called family/whānau peer support – this includes fieldworker support, support groups, peer-to-peer support, information and advice systems, family/whānau support advocacy, etc (SFMI, nd). Some of SFMI Auckland services are funded from other sources, notably charitable donations and bequests. This allows SFMI to run comprehensive library, newsletter and website services, some support services for children of parents with a mental illness and generally to offer more in areas like telephone support which have been traditionally difficult to get DHB funding for[2]. The core work of SFMI is face-to-face support of family/whānau members in their own homes, at SFMI offices, and at meetings with mental health professionals.

Historically, SFMI's work derives from the government response to deinstitutionalisation and the actuality was that people suffering from mental illness were released into the community without proper support or knowledge of mental illness, for themselves or their families (Audit NZ, 2003). The Mental Health Commission's *Blueprint* (1998/2001) promoted the need for services 'to use a *recovery* approach. Such an approach requires services to empower its consumers, assure their rights, increase their control over their mental health and wellbeing, and to support them to fully participate in society' (p11). This encouraged peer-to-peer support work, and had clear emphasis on outcomes and community development.

2.7.2 Reasons for Family/Whănau Involvement in Mental Healthcare

As initially highlighted at the beginning of the this literature review, families are affected by the illness of their relatives or friends who suffer mental illness therefore, involving them in the process of treatment and care is very important. Falloon's early work on psycho education leading onto a bigger role of families as co-directors of the therapeutic process along with consumers and professionals (Falloon, Mueser, Gingerich, *et al*, 1998). This resulted in 2005 with the production of *Evidence-Based Practices: Shaping Mental Health Services Toward Recovery* manuals produced by The Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Mental Health Services. These manuals were revised several times and culminated in 2009 with the *Family Psychoeducation Kit*. The *Kit* along with other in the series answered the question - why work with families? Two

[2] Bridgman G. D. (2009) See footnote 1

important issues put into perspective were, firstly, the need to focus on collaborative treatments and rehabilitation that achieve best possible outcomes for people with mental illness and, secondly, the reduction of burden among family members by supporting their efforts to foster the recovery of their family member. This was done by ensuring that everyone worked toward the same goals, and that we all attended to the social, employment, educational and leisure needs as well as the clinical needs of the consumer.

Furthermore, SAMHSA recognised the importance of equal partnerships with family/whānau where the family practitioner explores family members' expectations and assesses a family's strengths and difficulties, and addresses feelings of loss. There is also a need to respond sensitively to the turmoil and family conflict that can occur by providing relevant information for family members and consumers at appropriate times, including training for family in how to manage challenging behaviours, and support on how to maintain and/or expand their social support networks (Jewell, Downing & McFarlane, 2009; Dixon, McFarlane, Lefley *et al*, 2001)

The Ministry of Health's (2000) *Guidance for Involving Families and Whănau of Mental Health Consumer/Tangata Whaiora in the Care, Assessment and Treatment Process* explains further the reasons for family involvement:

> Many families wish to be involved in assisting the recovery of their family member and they want mental health staff to work in ways that are inclusive of families. This means that mental health staff need to work with the family and tangata whai ora, sharing information, planning, decision making, and providing support and education when necessary. (p1)

In working with Māori consumers (tangata whaiora), mental health staff need to understand the principle of *whanāungatanga*. The Blueprint (MHC.1988) stated that 'to work effectively with Māori it is necessary to know and understand the components that contribute to their well being' (p60). The Ministry of Health's (2000) guidance notes on family involvement claim:

> Whänau want mental health staff to recognise the important principle of whanāungatanga when working with tangata whai ora. Whanāungatanga is about the interconnectedness and interdependence of all members of the whänau, including the tangata whai ora. Whänau health is intrinsic to the health of each member and the health of each member is integral to the health of the whänau. (p1).

In contrast to the definition of family suggested in these guidance notes (see chapter 1) where consumers appear to be the arbiter of who is family, under the principle of whaunāngatanga mental health staff are asked to not to treat 'tangata whai ora in isolation or [make] decisions for tangata whai ora and the whänau' (p1). It was further claimed that what staff learn through whanăungatanga should be applied to non-Māori families as well. Ihimaera (2004) further explained that the process of whanăugantanga - establishing relationships – is the key to having tangata whaiora and whānau open up and share their stories.

SFMI, itself, strongly advocate for the rights of their service users and operates under family/whānau Code of Family Rights (Schizophrenia Fellowship, 2000) When discussing the contentious privacy versus family involvement issue states that: 'when a person with mental illness chooses to involve their family and whānau as partners in care, there are improved opportunities for recovery' (p1). The involvement of family/whānau in the care and recovery process is important in the community treatment approach, therefore carers must know their rights when taking up such role.

The Code asks that families have good information about illness, diagnosis and treatment and the relevant services and resources available. Families should be able to provide information (be listened to) and have this treated in confidence. They should expect 'open, honest, and effective discussions' (p2) with mental health staff, even where specific information may not be released as per direction of the relative or friend who suffers from mental illness. This is in line with privacy legislation. However, while family members have rights of involvement, 'the extent to which they are involved in treatment and support is ultimately the decision of the consumer, and the mental health services need to respect his/her wishes' (p1).

A family-centred approach must be collaborative and inclusive. They must be treated with respect, supported, and their rights protected. 'Information on the range of relevant services and supports available in the community' (p2) must be offered to families by the health service providers. Knowing who to call for advice and assistance is vital, and that they can receive a rapid response to their enquiries, especially in emergencies. The 4 to 6 hours response time that mental health service aim for in emergencies, is often too slow.

Family members need coordinated care. Inclusion in care planning, implementation and review must be with mutual agreement by everyone involved in the care process, and families have the right to be treated as equal partners in care so that the chances of recovery are maximised. The right to be consulted about changes to a family member's discharge plan, often a key time for collaboration. Where compulsory treatment occurs, primary care givers have a legal right to information about discharge.

2.8Modalities of family practice in mental health

There are various theories about family practice and counselling procedures that include one-on-one with a practitioner, and family conferencing including members of the family, interdisciplinary professionals and the family counsellor/practitioner. The relevance of a few of these theories will now be examined, and thoughts on how to carry out effective family conferencing.

2.8.1 *Psychodynamic Approach*

Wikipedia (2010) describes the *Psychodynamic* approach as 'the theory and systematic study of the psychological forces that underlie human behaviour, especially the dynamic relations between conscious motivation and unconscious motivation' (p1). Sigmund Freud (1856–1939) developed 'psychodynamics' to describe the processes of the mind as flows of psychological energy. Fisher (2002) is one practitioner who has adapted Sigmund Freud's psychoanalytic theory for family practice.

Under psychoanalytic theory people are viewed as insight oriented. Psychodynamic treatment (as this approach is named) involves making the unconscious conscious through a range of processes including analysis of dreams, transference of feelings, experiences and motivations to or from another person, and of defence mechanisms such as denial and repression. Rees (2001) explain the unconscious and conscious aspects of an individual as:

> The unconscious part of our mind contains memories, thoughts and feelings which we have repressed. It is thought that we do this in order to avoid the pain and conflict that may arise. Although this material is hidden from us, it continues to have a profound influence on our behaviour, thoughts and feelings. Psychodynamic thinking is that as long as these thoughts and feelings are repressed then they will continue to have an effect on our lives. Psychodynamic therapy aims to bring this unconscious material into our consciousness, so we can gain insight and understanding. (p1).

Transference is the shifting 'of past feelings, conflicts, and attitudes into present relationships, situations, and circumstances' (Hilz, 2011 p2). These feelings, etc are typically negative and can unconsciously become attributes of the people, places and objects that generated them. Counter-transference is when transference occurs in the counsellor, but unconsciously the counsellor attributes the transferred feelings, etc to their client. For example, if the transference recalled aspects of abuse the counsellor has experienced, it is possible for her to unconsciously imply that her client has been in abusive relationships.

In family therapy being fully conscious of transferences and counter transference issues is vital. The effect of mental illness on family members is huge - the actions of other professionals on the family member could be an issue to deal with and there is a need to deal with emotional issues when working with families. The practitioner must focus on specifics and not be carried away by the emotions of the client, nor his/her own emotions when dealing with a specific issue, as there is a need for objectivity and remaining calm and professional. Managing issues of transference often means dealing with defence mechanisms. It is natural that people would want to repress memories of strongly unpleasant experiences.

A family therapist must establish healthy therapeutic relationships with families in working through resistance and transference factors. Negative ideas around the use of medication, and action or inaction of medical teams might be resolved through education and trust building. By talking about issues with family member/s, a family/whānau field worker can help release tension (catharsis), thereby allowing energy to be redirected positively or prevent family members from becoming defensive (using defence mechanisms) by focusing on what can be done, not on the problem (Fischer, nd).

2.8.2 *Existential approach*

In contrast to psychoanalytic theory where ideas of identity are confined by history, existentialism opens up endless possibilities for identity. Existentialism begins with Kierkegaard who beloved that 'an individual is solely responsible for giving his or her own life meaning and for living that life passionately and sincerely, in spite of many existential obstacles and distractions including despair, angst, absurdity, alienation, and boredom' (Wikipedia, 2011, p1). Rollo May, Victor Frank and Abraham Maslow also hold that existentialism is a philosophy that postulates that the set of meanings that we acquire about

our identity is self created, that it is possible to construct and deconstruct those meanings to form radically new ideas of self-identity, and that 'people exist and are emerging or becoming' (Fischer, nd, p4). Existentialism emphasizes

> the importance of the fact that people have a capacity for self-awareness and a freedom of choice to decide their own fate. They also have personal responsibility to discover for themselves the meaning of their own personal existence. Because people are ultimately free and responsible, they have existential anxiety. People are in anguish over being ultimately responsible for their own lives (Fischer, nd, p6).

Family members' thus are encouraged to have courage. Courage will enable them to face their fears and commit to making a change. By creating new meanings for what has happened to them, they can take responsibility for their lives and, for example, step outside of the prejudicial beliefs and attitudes about mental illness. The counsellor must give family members the space so that they can then experience themselves more fully. For the counsellor to facilitate a family member's re-creation of meaning of life, the counsellor, themselves, must have had their own experience of deconstruction and reconstruction of identity so they are able to provide safe boundaries for that process with their family members.

Families are often searching for meaning in their lives, especially during the sudden onset of mental illness or relapse of a relative or friend, which sometimes results in them losing a job, encountering setbacks in the care process, and other unexpected adjustments.

2.8.3 *Person centred approach*

The person-centred approach of Carl Rogers (Fischer, nd) builds on the possibilities that existentialism offers, but without the theoretical coldness of the model.

> Person centred therapy is a form of talk-psychotherapy developed by psychologist Carl Rogers in the 1940's and 1950's. In this technique, therapists create a comfortable, non-judgmental environment by demonstrating congruence (genuineness), empathy, and unconditional positive regard toward their patients while using a non-directive approach. This aids patients in finding their own solutions to their problems. (Prochaska and Norcross, 2007:p143).

Carl Rogers believed that when working with an individual, there is a need to recognise that the client has the reality of self, and the task of the counsellor is to facilitate the process of self- actualization. Prochaska & Norcross (2007) further explains that Rogers stated that there are a number of necessary and sufficient conditions required for therapeutic change. Two of the most enduring are:

- Therapist Unconditional Positive Regard (UPR): the therapist accepts the client unconditionally, without judgment, disapproval or approval. This facilitates increased self-regard in the client, as they can begin to become aware of experiences in which their view of self-worth was distorted by others
- Therapist Empathic Understanding: the therapist experiences an empathic understanding of the client's internal frame of reference. Accurate empathy on the part of the therapist helps the client believe the therapist's unconditional love for them (p143)

In Person-centred therapy, *therapy* is all about the relationship between the counsellor and the client Fischer (nd), as the counsellor's role is non-directive. Having an engaging counselling environment that is clean and has pleasant and comfortable furniture and good lighting are components of practising *unconditional positive regard* and facilitating the relationship between counsellor and client. Unconditional positive regard also involves a shift in power relationships, where the family are allowed to drive the momentum of the intervention, and family therapists place much more emphasis on an effective listening and facilitating role.

In practicing unconditional positive regard, the practitioner may have to attend to wider elements of the family member's environment and support needs and therefore collaborate with all areas of treatment and rehabilitation to ensure that everyone is working toward similar goals. Family therapists are therefore encouraged to look at the relevant family circumstances, and work with these principles as may be applicable to a particular family/whānau.

Although SFMI does not specifically adopt a person-centred model of family practice, their fieldworkers usually create an atmosphere in which families have a safe space to understand themselves better and create positive meanings out of their previous negative beliefs about mental illness. On this point in one SFMI report, a client who participated in a family group commented about the facilitator:

> Brett attends monthly meetings and gives good input. He provides us with information we may not have. Our relationship with Brett is great. We refer on to Brett and vice versa. The relationship is unstructured and that works for us. (Wallace, 2003, p29).

2.8.4 *Cognitive – behavioural approach*

In contrast to the above approaches, CBT does not attempt to directly address identity issues; it seeks to change behaviours and thinking patterns that may form some of the building blocks of identity. CBT, like most modern therapeutic approaches, generally affirms the person-

centred therapy's injunction for unconditional positive regard. Aaron Beck is the founder of cognitive behaviour therapy. He believed that an individual's cognitions (the mental messages they gave to themselves) affected both what they felt and how they behaved (Jacobs, 2004). There are situations that challenge client's thinking patterns, and sometimes result in distorted, irrational, self-critical cognition or more specifically, *negative automatic thoughts*. Beck argued that these changes in thought patterns were not necessarily because of the challenging situations or events themselves but from the way that an individual interprets them and creates meaning from them.

> The central focus of cognitive approaches is the individual's thought patterns and beliefs and how these link with self–defeating behaviour. Clients are helped to alter the way they think; irrational and self–destructive thoughts are, through therapy, replaced by more realistic rational thoughts. (Jacob, 2004, p180).

To be more precise**,** CBT seeks to understand how a client thinks about himself/herself, the world and other people, and how what they do affects their thoughts and feelings. CBT can help clients to change their thoughts ('Cognitive'), and what they do ('Behaviors').

The application of CBT in family intervention demands the family therapist work with the family from the perspective of understanding what are the problematic messages and their contexts that need to be addressed from the beginning of the therapy. One example of how CBT works is where a family member identifies their thoughts regarding the problem (perhaps in writing) and indicates how these thoughts affected his/her emotional and physical well being using a scale of between 1-10, where 1 could equal *very positively* and 10 *very negatively*. The practitioner can then explore previous actions taken by the family, and the effects of such actions as to whether they felt better or worse, and implement behavioural action plans with him/her to change the negative effects being currently experienced.

Building from the above Jacob (2004) and McLeod (2004) explain the techniques to accomplish behavioural objectives after the initial stages of contracting, explaining the rationale for treatment, problem assessment and setting of goals or targets has been established. The techniques include:

- Reframing the issues, for example relabeling an internal emotional state such as fear as excitement

- Doing role plays in which self–statements are re-presented so they can properly heard and doing homework assignments in real situations with a new set of self–statements or practicing new behaviors and cognitive strategies.
- Thought stopping. Rather than allowing anxious or obsessional thoughts to 'take over', the client learns to do something to interrupt them
- Using systematic desensitization and relaxation techniques to effectively manage situations, people, etc that cause fear and anxiety
- Training in assertiveness and active listening
- In vivo exposure. Being accompanied by the counselor into highly fearful situations, for example clinical meetings or family conferencing with external providers for SFMI clients. The role of the counselor is to encourage the client to use cognitive behavioral techniques to cope with the situation (Jacob, 2004:p186)

SFMI does not use CBT as a named practice in their work with families, however, many fieldworkers have some training in CBT processes, for example around reframing, assertiveness and skills training.

2.9 Performance measurement and evaluation

The recent decade has witnessed tremendous economic destabilisation, involving the collapse of large organisations, huge national debts, and mismanagement of resources in some non-government organisations. Therefore, there is a need for balancing the potentially competing needs of service delivery with those of management, measurement and accountability. In times past, the reasons for the existence of NGO have centred on the delivery of a specific service or advocacy function rather than on performance-monitoring issues. However, Fink (1989) and Middleton (1987) noted that in response to the changing environment, the non-profit sector has vigorously engaged in developing its performance measurement and evaluation.

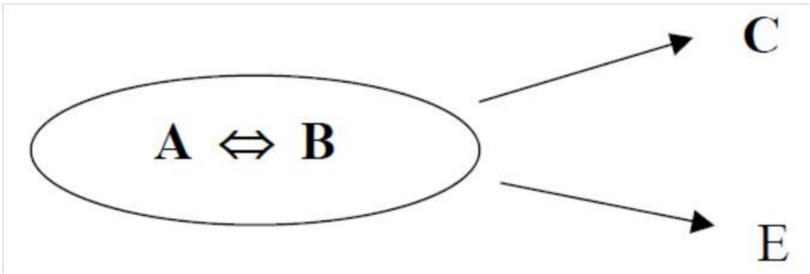
Starling (2003) states that NGO's have to demonstrate 'organisational performance in a competitive marketplace', and in doing so need to understand the relief and support work they generally do. This has to be done in context of scepticism about the value of charitable works in general, and needs to become more accountable to relevant stakeholders, such as clients, families, and funders. In the *Blueprint for Mental Health Services in New Zealand* (Mental

Health Commission, 1998) states the need for evaluation and monitoring of service effectiveness must be 'consistent and thorough' ...particularly new services' (p81) in order to identify what works well, and what will ensure that we make needed advances in mental health service delivery.

At the turn of the century the Health Research Council funded research on 'case mix' basis. This was research that divided the population into specific diagnostic groups of needs and outcomes and tried to calculate the cost of services for each group. However, performance measurement and organisational development can be a puzzle in an NGO because funding is not based on case mix or diagnosis or need in general, but on the type of service that is provided with a focus on outputs and not outcomes. Starling (2003) points out that the assumption of a direct causal relationship between service inputs and outputs is an 'oversimplification' (p2). He asserts that the relationship between service inputs, outputs and impact is complex and 'change is the result of a complicated interplay of events, people and conditions present in a given situation; thus a similar project with identical inputs in a different context is unlikely to produce identical' (p2) outputs or outcomes.

Starling argues for Roche's (1999) model of change below which describes the interaction of service inputs (A) and outputs (B) and their relationship to intended impacts (C) and unintended impacts (E).

Figure 1 – Intended and Unintended Outcome of Service Delivery



Roche, 1999, p24.

This model recognises that contextual factors (e.g. employment, health, wider family support systems, neighbourhood quality and culture) play key roles in the development of outcomes.

Therefore, the performance measurement of NGO's must take into consideration not only the immediate intended outputs, but effort must be made to understand the nature of the long term intended and unintended impacts of their work, and the contexts in which these outcomes occur.

Service quality is further explained by Zaithaml (1985) as an instrument for measuring the gap between what consumers think should be provided and what they think actually has been provided. Factors identified that may impart on quality service delivery are:

- Physical resources – this includes the physical evidence of the agency, e.g. physical facilities, tools or equipments to provide the service and the physical representation of the service
- Staff skills – the quality of staff involves responsiveness and good communication that engages service users in service delivery process by keeping them informed in a language they can understand. Staff are to display a credible attitude and are to be trustworthy, honest, polite and respectful towards the service users. Finally, since they represent the image of the service, they must be decent in their appearance
- Location and neighbourhood resources – location close to social facilities, e.g. train station, bus stop, bank, accessible road network, safe and secured environment, and other auxiliary services could be advantageous for the security of the organisation as well as the consumer
- Good Administration - consistence of performance and comparability, e.g. accurate record keeping and performing service timeliness, and having operational policy in place as guideline for the service

2.9.1 *SFMI and its Performance Measurements*

SFMI outcome measurement tries to assess the extent to which it meets the objectives that derive from its vision and mission. In doing so it has to work with the framework of objectives policies of its funders and be an efficient and accountable organisation.

However, SFMI's performance is not just based on the output of one service, but on a range of services, 90% funded by DHB's, some through other sources and some run by volunteers (e.g. some support groups). SFMI works in collaboration with other health, social, education service agencies, and community groups. Performance measurement will involve considering the extent to which SFMI i*n collaboration with other services* has produced a lasting or

significant change, positive or negative, intended and unintended both for its clients, and for people who suffer mental illness themselves.

This is clearly not a simple task. Halliday and Bridgman (2003) state that:

> Outcome measures come in many shapes and forms. What outcomes are relevant to families? These can be as subjective as liking the key worker, to as objective as ticking off a task on a list that a service is contracted to do. The focus of outcome measurement can be on symptoms of the service user, the stress experienced by the family/whānau or the competency of the provider, and many other things as well. What shapes that focus, however, must ultimately be what works best for family/whānau and improves the quality of life for themselves and the person who experiences mental illness (p3).

Therefore, the position that I explore in this thesis is measuring the quality of SFMI services primarily through the lens of the users of SFMI's services.

CHAPTER THREE - METHODOLOGY

3.1 Introduction

This chapter discusses on methodology used in this study, and the research strategy applied. A brief description of the sample population and how the primary data was collected and processed is also included. The data collection tool and issues of validity and authenticity of the data collected are also covered.

3.2 Research Framework

Having considered various methods for the research, I have chosen semi-structured interviews and a questionnaire that has small number of confirmatory rating questions. The research thus is a concurrent (QUAL + quan) nested study which generates both qualitative and quantitative descriptive data during the interview sessions. Traynor (2007) classifies concurrent nested designs or concurrent mixed model designs on the basis of the paradigmatic priority of the study. In this design, a small quantitative strand/phase is embedded within a predominantly qualitative study, emphasising that the methodology is predominantly qualitative, exploratory and interpretive. Tashakkori and Teddlie (2003) considered QUAL+ quan as a mixed method.

> A mixed methods study involves the collection or analysis of both qualitative and/or quantitative data in a single study, in which the data are collected concurrently or sequentially, are given priority, and involve the integration of the data at one or more stages in the process of research (p29).

Saunders, Lewis & Thornhil (2007) defines exploratory studies as those which have means of finding out 'what is happening; to seek new insights; to ask questions and to assess phenomena in a new light' (p.91). Further, they define interpretivism as a theory of knowledge or paradigm. This paradigm states that it is necessary for the researcher to understand the difference between humans as social actors. (Patton, 2003) argues that 'interpretivism stresses understanding that focuses on the meaning of human behaviour, the context of social interaction, an empathetic understanding based on personal experience, and the connections between mental states and behaviour' (p.52). Thus, interpretive research seeks to understand the subjective intentions in a way that it is meaningful for these actors. Patton further explains the empathy that develops as a result of direct personal contact with the research participants enables the researcher to understand the stance, position, feelings,

experiences and worldview of others. Hence, this study was conducted in the interpretive paradigm, because the aim of the researcher was to understand the strengths and weaknesses of the services provided by the Auckland branch of Supporting Families in Mental Illness, as perceived by the users. This approach encourages a personal narrative from participants by having questions designed that assist the unfolding of the story of engagement with family support services.

In this study I use semi structured interviews. That is an interview with a small number of open-ended preset questions. Hanaan (2007) stated that the reason for using a semi-structured interview in research is that it allows exploratory, descriptive, and explanatory data to emerge. He goes on to say:

> A great deal of qualitative material comes from talking with people whether it is through formal interviews or casual conversations. If interviews are going to tap into the depths of the situation and discover subjects' meanings, it is essential for the researcher to develop empathy with participants and win their confidence and to be unobtrusive, in order to impose one's own influence on the interviewee. (Section 7)

Semi-structured interviews are used in qualitative studies. The method is most useful when one is investigating a topic that is very personal to participants.

Unstructured interviews, however, have the most relaxed rules (Drever, 1995). Here, researchers need only a checklist of topics to be covered during the interview and there is no order or script. The interaction between the participant and the researcher is more like a conversation than an interview. Unstructured interviews are used more in ethnographies and case studies (types of qualitative studies) and they are best used when researchers want to find as much information as possible about a particular topic. Unstructured interviews often reveal information that would not have been exposed using semi-structured interviews. The researcher and participant are not limited by the protocol and data sets when using unstructured interviews.

Semi-structured interviews have advantages over unstructured interviews (where there is no more than one compulsory preset question). Drever (1995) supports the view that the unstructured interview may not necessarily replicate all of questions used in initial interviews, because in engaging with the narrative many questions will be answered, without being specifically asked. The limitations of the unstructured interview include the possibility that

the researcher may become biased in the selection of questions and participants, and the participant may be subjected to leading questions/prompts that could influence the participant's response. The structured questions asked during my interview sessions will enable me to gather consistent descriptive and quantitative data as regarding the general demographic pattern of the service users, and confirmatory assessments of family support services.

Traynor (2007) also reckoned that semi-structured interviews are a bit more flexible. Researchers using this method are still expected to cover every question in the protocol - they have some room to explore participant responses by asking for clarification or additional information and also have the freedom to be more friendly and sociable. Advantages of the semi-structured interview method include a wide coverage of the issue: two-way communication between researcher and participants that facilitate more in-depth collection of information; allowing collection of concrete examples; providing supportive listening that allows for the more difficult or sensitive issues to be safely discussed and encouraging divergent views.

Using interviews for this study will provide a narrative perspective of individual family experience in the participants' own words, and understanding where the concerns of families lie in relation to SFMI activities. The interview is a type of data collection where people are asked to provide information and express their opinion on how those who have a relative or friend with mental illness are supported by the Auckland branch of Supporting Families in Mental Illness, within the context of their experiences.

3.3 Selecting the sample

The population for this research is the families and whānau of people who suffer severe mental illness. Given that the 12-month prevalence of mental illness in New Zealand is estimated to be 21% for people over the age of 16 (Ministry of Health, 2006) and that people with severe mental illness are about a quarter of that total the pool of families and whānau needing support is probably high.

SFMI has between 140-150 clients who require ongoing fieldwork support. Roughly, 80% of these clients are women, 75% are Pākehā and 25% are Māori, Pacific Island or Asian. A

majority of the clients are parents of a person with a mental illness, at least half of whom have a diagnosis of schizophrenia or psychosis[3]. In addition, SFMI has around 2300 significant contacts with family/whānau members who want information or need other forms of support. Clients in this group may contact SFMI or may be engaged with SF up to three times, but with a majority contacting SFMI only once or twice. There is no demographic breakdown available for this group, but it is probably similar in gender and culture to the group receiving regular fieldwork support, but with less challenging prognoses. People who are in contact with SFMI more than 3 times are typically transferred to the client group that receives regular attention from an SFMI field worker. These two groups make up the SFMI caseload for Northern Region.

In my sampling, I have used a purposive quota sampling process (Patton, 1995) with random selection in the sub-groups to avoid bias. I aimed to recruit 8 regular users of SFMI services and 8 short-term users (16 in total), and within this total the diversity of participants represents what we understand to be the general demographic features of clients who are regular service users (those with more than 3 contacts). I also limited the sample to families using SFMI services in the last 2 years and living in the greater Auckland region. The participants are selected on the basis of:

- Type of serious mental illness (50% schizophrenia vs. 50% other major mental illness)
- Client type (parents 67% vs. other carers 33% – partners, grandparents, aunts/uncles, siblings, friends, children of people with a mental illness)
- Ethnicity (Pākehā or European 63%, Māori, Pacific Island, Asians and others 38%)
- Gender of users (male 25%, female 75%)

I also wanted to ensure some diversity within the longer-term group (more than 3 contacts) as well as a balance between the short-term and long-term groups:

- Frequency of contact with SF (1-3 face-to-face contacts 50%, 4-6 face-to-face contacts 25%, more than 6 face-to-face contacts 25%).

Table 3.1 shows the planned distribution of the interview sample.

[3] Demographic data about SF has been provided by SFMI

Table 3.1 - Planned Participant Sample

Culture	Pākehā/European	Māori	Pasifika	Asians/other.	Totals
	10	2	2	2	16
male	3	1			4
female	7	5			12
schizophrenia	5	3			8
other major mental illness	5	3			8
parents	8	4			12
other carers	2	2			4
1-3 face-to-face contacts	5	3			8
4-6 face-to-face contacts	2	2			4
more than 6 face-to-face contacts	2	2			4

Recruitment was done by mail. An invitation from SFMI's President, Max Lloyd, was sent to prospective participants in three waves, totalling 100 invitations. The first wave of 30 was randomly selected from the total eligible sample, the second wave of 30 was randomly selected from those categories not filled in the first wave, and a third of 40 from those categories not filled in the first two waves.

3.4 Data collection tools

The research questions follow a general structure suggested by Larry Davidson (2003) who elaborates on essential factors to be considered when using interviews in the research process. He suggests having:

Descriptive questions: These allow participants to describe their experience of service use in simple terms and to re-engage with that experience so that it is sufficiently present when evaluative questions are asked

Evaluative questions: Once the experience of service has been laid out, participants are in a better position to deal with evaluative questions about service quality. These may emerge naturally during the descriptive discussion.

Resolving questions: As the evaluations identify problems by service users, this gives room to address how these problems could be resolved

Confirmation questions: Confirming evaluations of overall service provided or key issues.

After resolving issues raised with the participants, I planned to use a small questionnaire assessment (using a Likert scale) of the overall quality of the services received since engaging

with SFMI or confirmation of specific strategies and objectives that SFMI has recently introduced

Demographic questions: Finally, questions about service users' background relevant to the issues at hand were asked, thus giving a clear picture of the types of people that use the SFMI services. Some of these are in tick box questions

The general direction of the research questions covers:

- The experience of whānau and families of having a relative or friend that suffers from mental illness *(descriptive)*
- The benefits that whānau, families and significant others have derived from the services of Supporting Families in Mental Illness (*evaluative)*
- The improvements that can be made to services (*resolving)*. The overall assessment of specific services of SFMI as a whole *(confirmatory)*

Each question has a number of prompts that assist the researcher to listen carefully for particular issues and enable follow-up at the end of the question of the interview on areas not covered. The aim is not to disrupt the narrative.

The *demographic* background of participants in this research covers:

- Gender
- Culture
- Nature of mental illness of friend or relative (Schizophrenia, bipolar, etc)
- Nature of relationships (parents, child, brother, etc)
- Length of time engaged with SF (< 3months, 3-12months, etc)
- Number of times the services were used
- Which services were used (telephone, counselling, group meeting, library, etc)

The interview schedule and questionnaire used is in Appendix 3, along with the Application for Ethics Approval (Appendix 5), and the Information Sheet (Appendix 1), Consent Form (Appendix 2) and the SFMI letter of support (Appendix 4) used in this research.

3.5 Data collection and analysis

The data will describe the ways in which SFMI is doing/not doing a useful job in supporting families to cope with their difficult experiences with their relative or friends who suffers mental illness. We will be able to assess SFMI against its own mission, service objectives and best practice ideas from Te Kōkiri – The Mental Health and Addiction Action Plan 2006-2015 (Ministry of Health, 2006).

The use of an electronic voice recorder and note-taking were employed during the interview process. A verbatim transcription of each audio tape was made. Quantitative tables will be produced from the quantitative demographic and confirmatory data.

Thematic analyses were carried out using Microsoft Word and Excel. Themes explored issues of satisfaction with a range of SFMI services, in relation to SFMI's vision and goals and given the context in which families and whānau find themselves:

- The dimensions of family burden due to mental illness
- The relationship of the participant to the person with mental illness
- The perceived quality of mental health services in relation to standards
- The other factors of culture, age, length of engagement
- Other factors on which the sample has been constructed.

The thematic analysis used discourse analysis techniques (semiotic analysis, deconstruction) which engage with issues that are central to families and whānau, while being sensitive to the roles and power of families, whānau, consumers, professionals, agencies and funders. The tape recordings were erased following completion of the transcripts.

3.6 Conclusion

This chapter has highlighted the research philosophy, techniques and methods used for the research. The study relies on a concurrent (QUAL + quan) interview plus a questionnaire-nested method, in order to assess the level of satisfaction of families and whānau with the services being provided by SFMI. The participants are a diverse group of family and whānau members who are engaged with the service, and reflect the mix of clients of that service.

CHAPTER FOUR - RESULTS OF THE RESEARCH

4.1 Introduction

This chapter contains the results of the data collected from the interviews, and questionnaires that were gathered from families/whānau who are the service users of SFMI. Demographic information from the participants and patterns of families' engagement are presented in tables. Further, I analyse how family/whānau were referred to SFMI, their levels of satisfaction and what they found missing in the service of SFMI.

4.2 Demographics

A hundred participants were invited to be interviewed for this research with intention to have 16 participants for the interview. However, 18 participants positively responded and were all interviewed. Two couples (I&J and O&P) were interviewed for the most part as single participants. Three of the participants (including one couple, I&J) would not have their voices recorded, but were happy to have notes taken, while all of them willingly completed the rating questions that were part of the interview (see table 4.2).

Table 4.1 shows the structure of the actual data collected. A comparison of the actual and expected sample (see table 3.1) using a chi-squared test showed that there is a significant difference in the gender ($p<0.05$) and contact ($p<0.05$) structure between the expected and actual sample. With gender, we had more men than expected and there were more participants who had more than three contacts. However, the actual pattern of diagnosis and caregiver role was in line with the expected sample. Age was determined in the planned sample, but this was added to the actual questionnaire along with other demographic data (see table 4.2). Eighteen people were interviewed, (I and J) and (O and P) were two couples – each couple is counted for the interviews as one participant this make up 16 participants, and the total number of people with mental illness supported by these carers was also 16.

From Table 4.1 we can see that roughly two thirds of the participant's family members with a mental illness are diagnosed with schizophrenia, while the remaining one third had another major mental illness such as bi-polar disorder or depression Of the 18 participants interviewed 39% were male and 61% were female. This is consistent with other research that points out that woman tend to be more involved as family carers for those with mental illness than men

are. However, this sample also has a proportion of male carers that is higher than we expected.

Table 4.1 Actual Participant distribution

Culture	NZ/European	Māori	Pasifika	Asians/ other.	Totals	Percent
totals	12	2	2	2	18	
male	3	4			7	39
female	8	3			11	61
schizophrenia	7	3			10	56
other SMI	5	1			6	38
parents	8	3			11	62
other carers	4	3			7	39
1-3 f2f contacts	3	0			3	17
4-6 f2f contacts	4	3			7	39
more than 6 f2f contacts	4	4			8	44
30 - 50	4	3			7	39
51 and older	8	3			11	61

Table 4.2 indicates that 61% of the participants caring for a relative or friend with mental illness are 51years and older. Three are retired and another three full time carers. Thirty nine percent of the participants are within the age bracket 30 -50years, and more than half (4) are full-time carers. None of the carers in this research fall within the age of 18 to 30 years. In this age range we would expect to find siblings of people with a mental illness. Only one of our participants was a sibling. About 78% of the participants are either full-time carers, retired, self-employed or students – roles that have the flexibility needed to perform major caregiver duties. The burden of mental illness on participants includes the need for major time allocation to the caring role.

Different cultural groups were included in the data collected, the majority being New Zealanders and/or European 67%, Pasifika (Samoan, Tongan, Niuean) 22 %, Asians (Indian and Malaysian Chinese) 11%, and Māori 11% (see table 6). There is a pattern of a lower level of engagement of cultural groups (other than New Zealand/Europeans) with the service of SFMI. This could be explained in various ways, but common among the Pasifika group is the lack of awareness of the service, while Māori will likely engage with other Māori mental health organisations or the marae where they can obtain a culturally appropriate Kaupapa

Māori service. Asians also lack an awareness of SFMI, and a language barrier was an issue noted during the research.

Table 4.2: Demographic profile of the 18 participants interviewed

Participants	Gender	Age	Relation to person with MI	Occupation	Culture	Diagnosis	Number of Contacts
A	female	51 years and older	mother	lawyer	NZ European	Other Diagnosis	4 – 6
B	female	51 years and older	mother	Retired	NZ European	Schizophrenia	above 6
C	male	30-50 years	partner	Self-employed	Asian	Other Diagnosis	4 – 6
D	male	51 years and older	father	teacher	NZ European	Schizophrenia	above 6
E	female	51 years and older	mother	Student	NZ European	Other Diagnosis	above 6
F	female	51 years and older	mother	Self-employed	NZ European	Other Diagnosis	4 – 6
G	female	30-50 years	partner	Full Time Carer	Māori	Schizophrenia	above 6
H	female	51 years and older	mother	Full Time Carer	Asian	Other Diagnosis	above 6
I	male	51 years and older	father	Full Time Carer	NZ European	Schizophrenia	4 -6
J	female	51 years and older	mother	Full Time Carer	NZ European		4 -6
K	female	30-50 years	partner	Full Time Carer	NZ European	Schizophrenia	above 6
L	female	30-50 years	friend	Full Time Carer	NZ European	Schizophrenia	1-3
M	female	30-50 years	mother	teacher	NZ European	Schizophrenia	above 6
N	male	51 years and older	friend	Retired	Māori	Schizophrenia	4 -6
O	male	30-50 years	father	Full Time Carer	Pasifika	Schizophrenia	4- 6
P	female	51 years and older	mother	Retired	Pasifika		1-3
Q	male	51 years and older	partner	Manager	NZ European	Other Diagnosis	above 6
R	female	30-50 years	sister	Researcher	NZ European	Schizophrenia	1-3

There are different family/whānau members that engage with SFMI, all in carer roles for a relative or friend with mental illness as indicated in table 7. During the interview, participants were asked to identify their relationship to the person who suffered from mental illness. The majority are mothers (44%), but they were also fathers (17%), partners (22%), friends (11%), and siblings (sister - 6%).

The length of time service users are engaged with SFMI was one of the criteria used for the evaluation of satisfaction with the services being provided by the organisation, hence participants were asked to indicate how long they have been with SFMI. Table 6 shows that there were four participants within 0-3 months, six families from 4-12 months, three from 1-2 years, and five other families have been engaging with SFMI for two years or more.

The patronage of SFMI by families/whānau seems to be consistent, as we noted a higher rate of retention of families/whānau who remain users of services within 3 months to 1 year and 2 years or above (61%). The sustainability of services can be determined by the number of service users who are regular, and the patronage of new consumers, hence the entrance of 4 new service users into the organisation within 0-3 months and 4-12 months (39%). This indicates a good performance by the organisation and the satisfaction of families/whānau who are the service users of SFMI. Seventeen percent of the participants had 1-3 contacts, 39% engaged with the service 3-6 times and 44% patronised the service more than six times at the time of this research.

4.3 The structure of the thematic analysis

The first question was to generate a history of mental health issues - the effects on wider family/whānau, what help was sought/received, when did mental illness become an issue in the family/with your friend and what happened then? The areas below were explored and the general patterns of responses from participants are analysed as themes under these headings.

- The history and stressful effects of mental illness of a relative or friend on family/whānau
- The lack of knowledge of families about diagnosis, mental health services and other support agencies
- What happened when participants got in touch with SFMI
- The quality of follow-up and evaluation of SFMI consumer contacts
- Evaluation of family/whānau satisfaction with SFMI services
- Evaluation of service quality and improvements
- What is missing – recommendations for change

4.4 The history and stressful effects of mental illness of a relative or friend on family/whānau

The first question looked at the assessment of the history and impact of mental illness of the relative or friend of the participants on the family/whānau. One participant in this research had a long history of mental illness in his family. A's family history of mental illness and disability extended to the past two generations:

> My father was brought up in an orphanage. His mother died from abortion, his oldest brother, you can imagine he grew up in a Catholic orphanage with paedophiles and homosexuals. My mother is one of 13 children. Two of his brothers were in mental hospital, his older brother was very rich, mother was a solo mum, possibly my grandfather had mental illness. I do not know how many generations go back there, I do not know. I am oldest of eleven, all my sisters except me are at one time or another are on antidepressants. My father was Aspergers, my brother who died three days after I got married was Aspergers and another brother died when I was 4 years old. At 60 my mother was diagnosed with mental illness, I do not know if she had it all her life.

A few participants traced the history of mental illness in their relative or friend to substance abuse. For example, B said 'Our younger daughter who is 28 years is schizophrenic. It became an issue when we are in the States, when N was teenager she started by not paying attention in the classroom and grew to trying marijuana use'. F talked about her son who was 'self medicating with drugs. He reached a stage where he wanted to make himself better and he came to us. He tried to get help from Odyssey House but was turned away because they said that his case was not severe'.

The majority of the participants said there was no specific history or beginning point for the illness of the relative or friend they cared for other than the sudden onset of mental illness, and later diagnosis of schizophrenia in many of the cases. For example, D said 'Four years ago around Christmas, my daughter completed her degree at the University, facing the next decision of what next to do. Her psychosis started suddenly, she basically hallucinated, and her thought patterns became disjointed, and she cannot make any sense anymore'.

O & P state their own history thus, reflecting the challenges that Pasifika can have in understanding the onset mental illness:

> When mental illness is an issue, we do not know it was an issue until our son was really sick - having violence at home, verbal and physical up to the stage when we see that our son becomes lazy and refuses to go to school. We did not know it was an issue, we think for some reasons he did not want to go to school, we think that someone at the school

> made him angry. At that time we did not understand ... but when he stayed at home and was talking about his girl friend, but we, as his parents, know he could not talk to girls. He said he wanted to go to watch film with his girl friend, we sat back, and took him to psychologist, and psychologist gives us advice, at that time we know nothing about hearing voices.

Mental illness comes from many sources, and the participants in this research identify that it could be hereditary, from substance abuse or have an unaccountable (to them) sudden onset.

The negative impact, however, on the family/whānau is wide ranging, and each participant has their own story. It was clear that *stress*, in general, was a major issue. Thirteen of the 16 participants described aspects of stress due to the illness. The levels experienced were in many cases extreme. 'It consumed, it consumed my life… ' (F)', 'It is just life as a whole - the stress…' (K)' and '19 years is a long time… '(N)' are examples showing how pervasive the experience of stress was. Participants spoke about specific causes like 'he always fights with [his] father' (H), trouble in communicating (C), 'traumatic' experiences in hospital (Q), and rejection by the unwell person (G). For O and P life had become very uncertain 'spiritually' as well as in other ways.

Other means by which participants experience stress are through separation, violence, stigma, financial problems, grief and loss. Partner separation due to mental illness was a major impact. Seven of the 16 participants experienced separation as a problem for various reasons. The consequences of parental separation include: involvement of the police in domestic disputes with claims of abuse (C); exacerbation of the child's mental illness (A); damaged relationships with other children (particularly noted by parents and new SFMI clients) and other partners (E); involuntary separation of a parent from their child (G); and rejection by the partners family 'because schizophrenia is not a good sickness' (N).

Violence: This remains a stressful matter for many of the participants. Twenty eight percent of participants had to deal with unexpected outbursts by a relative or friend with mental illness, sometimes through physical action. 'I already have seen my son make arguments with my husband, and always fight his father' (N), verbal abuse towards participants ('our son was really sick having violence at home - verbal and physical' (O&P and M)), and displaying other unacceptable violent behaviours - 'Her behaviour was very irrational with violence' (H).

Stigma: The prejudicial attitudes of the community towards participants and their relative or friend with mental illness, contribute to stress and cause disturbance in the process of caring for a person with mental illness. These attitudes are expressed via discrimination and blame against family/whānau - 'mental illness in our culture means we have done something bad and as a result, our son gets sick' (O&P). These effects frustrate the family and mean they not only have to deal with the challenge of care for the sick person, but also with the shame and loss of face with others who refuse to accept the illness as just any other illness. Twenty eight percent of participants, all carers of people with schizophrenia, expressed their concerns about stigma associated with mental illness.

Financial worries: Friends and family/whānau may suffer loss of income when caring for their relative or friend who suffers mental illness. Among the 16 participants in this research 25% stated that they sacrificed part of their income to take care of the person. A said 'I was running a volunteer organisation with about 400 staff and had invested a lot of money into it. I could no longer work full time'. Others have to depend on one member of the family working to provide for them while another stays at home to care for their child.

Grief and loss: The continuing uncertainty of recovery and healing of a mentally ill person constitutes frustration for the participants in this research who had only up to 6 contacts with SFMI. These carers (22% of the sample) expressed their loss of hope in the future for their relative or friend with mental illness. O &P stated that 'his future is unpredictable ... we do not know how long we will deal with this issue'. They expressed concerns about not seeing the possibility of light at the end of the tunnel. F tells us 'I have to come to terms that it is going to be like that for a long time. My son is going to need our help probably for his lifetime', and I & J note 'he is now 45 years old, and still needs to be cared for'.

Stress summary: The grief of loss is expressed about the future of the person being cared for, as this contributes to the stress for the family/whānau when caring for a relative or friend with mental illness. Also, the past efforts and financial resources poured into the life of the person with mental illness; the level of violence during care; the dealing with the whole issue of stigma; the cutting short of a whole life of expectations; and the pain of knowing that the current daily effort will likely not result in total recovery; all contribute to stress generally.

4.5 The lack of knowledge of families about diagnosis, mental health services and other support agencies

The second major area of impact of mental illness was frustration and confusion from the participant's general lack of knowledge about mental illness and mental health services. Nine out of the 16 participants (and 71% of the Māori, Pasifika and Asian participants) expressed a general frustration in different ways. Ignorance made things 'difficult' (G), some were at a loss –'I do not know what to do' '(H)' and for others the sudden onset of psychosis was a shock. Still others were confused by their own misdiagnosis and not knowing the difference between badness and madness ('I thought it was alcohol problem' (A)), or by bad advice from helping agencies. However, frustrations also lead to early and helpful consultation with professionals.

The impact of culture in the understanding of mental illness cannot be underestimated. Trying to understand *youth culture* sometimes poses problem about where to draw the line between badness and madness. One participant expressed her dilemma at separating binge drinking from mental illness - 'I was not aware my daughter was mentally ill, I thought it was alcohol problem' (A). People who are not from Western cultures want to make sense of mental illness in terms of their own culture. As previously discussed in our literature review, various cultural groups and communities still hold different ideas about mental illness. A Pasifika couple stated 'In our culture it affects us in other ways, culture wise. Mental illness in our culture means we have done something bad, and as a result, our son gets sick' (O & P). One outcome here was that this family now rarely participate in their community occasions, so that they do not have to face the shame and stigma attached to the illness of their son because of the lack of knowledge about mental illness among their own people.

4.5.1 *Access to services*

Lack of knowledge included a lack of knowledge of mental health services available in the community and how to access those services and the organisations that provides such services. Seven out of the 16 participants were caught up in the process of finding services for a relative or friend with mental illness -'We are just tossed from one end to another' (F). Not knowing the appropriate service to approach during relapse could make it difficult for the carer as well as the sick person. 'Every day he becomes sick, and he was taken to the mental

hospital by the police. Before this happened, I did not know what to do' (H). Participants expressed their positive appreciation toward SFMI giving them the necessary information about appropriate services in the community. M stated 'I really appreciate the information and moral support. My son is now engaged with other services at xxxxxx - my son is still there but he comes to see me'.

4.5.2 *Diagnosis*

Once participants found services, the next hurdle was trying getting some clarity around diagnosis. Twenty eight percent of the participants stated their frustration with the uncertainty of diagnosis or lack of it, and the long waiting times for diagnosis. For example F said 'He went to family doctor try to get help, went to Cornwall House, they said nothing was wrong with him'. In this case, the appropriate mental health authority was identified and approached but their inability to give specific diagnoses of the illness was a concern. Not knowing the specific nature of mental illness creates confusion for the carer who keeps wondering what is wrong with their relative or friend and how can they care for the person when they do not know what the illness is.

Wrong diagnosis and treatment was part of the problem for F who 'found out that [her son] has been taking wrong medication [and that it would take]… a long time for his body to get rid of the medication'. The concerns here are doubt about the subsequent diagnosis, and the increasing non-compliance to medication by the sick relative or friend. When this happens, carers are stressed by having to convince the sick person to take medication, and where non-compliance becomes a pattern, the rate of relapse may increase. The family now has to keep reminding him of his medication, as he tends to miss it once he feels that he is better, thinking that he did not need the medication in the first instance.

4.6 What happened when participants got in touch with SFMI

The issues of accessibility, service engaged with, and outcome for participants are discussed in this section**.**

4.6.1 *Sources of Referrals*

Table 4.3: Sources of referral to SFMI

Source of referral	N
MH Hospital	9
Family/whānau/friends	3
Court	1
School	1
Community Centre	1
Media Advt.	1
Total	16

Table 4.3 addresses the question of how the participants came in contact with SFMI. Fifty percent of the participants said they were referred from the medical team via the inpatient unit or the Community Mental Health Centres. For example R's 'key worker from hospital gave [her] the contact details', or 'my son was hospitalised - they gave me information about SFMI'.

Another 17% came through family/whānau or friends ('a friend told my husband about Schizophrenia Fellowship' – B) or possibly a SFMI service user ('I was going to the hospital every day. Somebody said that SFMI could help me'). A quarter came from a variety of sources such as 'John's advertisement on TV about depression' (F), 'court clerk who gave me the phone number' (C), referral from the 'nurse from our daughters' school' (O&P) and a community centre at which a 'psychologist who said [SFMI] will be no help' (E).

4.6.2 *What happened with the first contact*

The first contact with SFMI is a phone call routinely followed by a home visit, or in a few occasions by giving support at a meeting with mental health professionals or at family meeting. Issues such as the need for counselling, understanding of mental illness, family education, and boundary setting and safety were covered, and the help was very well received with virtually all participants noting that it was 'helpful' (E), 'very good' (I&J), 'in depth' (G), and 'very nice' (M). C said 'Yes, my hope was met, I was completely satisfied. Yes, it is fantastic'. The first meeting set up the framework of what was to follow. F felt secure - 'It is good. I feel, and I know they are there'. D and Q were able to gain 'confidence' in SFMI staff, 'especially with their library service' (D) and being able to feel 'very comfortable' when attending group sessions. B thought her meeting with a staff member in a coffee shop was 'amazing'.

4.6.3 *The quality of follow-up, and evaluation of SFMI consumer contacts*

Table 4.4: Follow-up services

Services	N	%
Telephone	11	65%
Counselling	7	39%
Field Worker visits	7	39%
Meetings with other providers & referrals	6	33%
Family group sessions	4	22%
Library	1	6%
Web site	1	6%
Peer Support	1	6%

The third question was to measure the quality of follow up with family/whānau after their first contact with SFMI and to know what happened after the first appointment.

Actions following from the first contacts show that 65% of the participants said they regularly receive telephone follow-up from SFMI field workers. The research highlights the importance of the telephone as a major facility in engaging with SFMI service users, for many said that they receive counselling via telephone. Others said that they called field workers to obtain information about other service providers, to book an appointment, and sometime to know the schedules of programmes within the week. A said, 'They did telephone counselling with me. I am very busy as I run a business so I am unable to attend the support group meetings'. C had many contacts via telephone, 'I had many phone contacts with SFMI' and H stated, 'Jenny always phones us'. O &P appreciate phone contacts as both are employed, 'The communication between us and SFMI is good, most are via telephone calls and we appreciate that'.

Thirty-nine percent received one-on-one face-to-face counselling. Among the people who received one-on-one counselling were the Asian participants, who found it very helpful because one of the staff was able to speak Mandarin. Others who received counselling were at a point where they were desperate and in need of support around care for their relative who had recently relapsed. E 'felt positive, sometimes. after those counselling session' and H said 'I and my husband had counselling sessions here in their office'.

Regular home visits were a point of support for those with other siblings to care for, and who had the problem of not knowing how to convey the experience of mental illness of one child to the other members of the family. Thirty-nine percent claimed that field workers visited them at home regularly. C said that 'I had many phone contacts with SFMI, and visits from staff'. H felt good having staff visit her at home, 'She has also come to our house many times. I felt good about them coming to our house, and have talk with my family'.

There is a need for family/whānau representation when there is involvement with other service providers. For example, discharge from hospital care, transfer of care to residential rehabilitation or when seeking support from other organisations. Family/whānau members often ask for SFMI field worker's support at such meetings, and 33% of the participants said they were supported at meetings with other service providers. 'As I mentioned, the field worker accompanied me to TWT [the mental health acute ward]' (M). C was able to contact the court via SFMI support, 'I could not contact my family, I do not even know where they were. SFMI staff had to contact the court for me'.

The family group is an important support service to family/whānau of people who suffer mental illness, as we have discussed in our literature review. It is the place where families discuss their experiences and explore solutions to difficult challenges together with the coordination of SFMI staff. Twenty-two percent of the participants attended the family group sessions and they expressed that they were satisfied. 'The family support group is very good, and I have joined the ADHB as family representative' (M), 'The meeting was very good' (L).

SFMI maintains a rich and resource-full library, but not many family/whānau use this service. According to (O&P) 'It is enough to get the information from the psychiatrist, I don't need the book'. However, 25% of the participants said they valued the information they got form SFMI. B said that SFMI 'provides the resources of information we need, and what is available'. In addition, M 'really appreciated the information and moral support' from SFMI. G found it a relief to receive pamphlets given information about mental illness, 'I found it a relief having SFMI to help me understand about the illness, sent me some pamphlets, and that help me to understand the illness more'.

Only one of the participants (D) commented on using the library, and he said that he 'loved' the library and that the resources were helpful. Also only one person commented on the website (R), who said that it contained a lot of information. She suggests that it would be helpful if a family chat room could be built into it. Finally, D felt that the peer support was helpful when initially joining SFMI, part of range of support received that was 'fantastic'

The participants were generally positive about of the outcome of their initial contacts and follow-up with SFMI. Some of their comments are: 'SFMI staff are good communicators, I have not properly engaged, but they are good negotiators' (A); 'I think the services are working perfectly well' (B); 'I am very grateful to SFMI, that woman was Father Christmas to my daughter in 2009' (C); 'Yes, my hope was met, I was completely satisfied. Yes, it is fantastic' (D); 'They are very supportive' (H); L, who had a serious misconceptions about mental illness of her neighbour, said 'They gave me a lot of understanding into mental illness'; 'I really appreciate the information and moral support' (M):, and 'it has been very, very helpful' (Q).

4.7 Evaluation of family/whānau satisfaction with SFMI services

4.7.1 *Assessments of Services*

A confirmatory assessment of the value of the services of SFMI was made by the participants at the end of the interview. The participants in this research filled questionnaires rating SFMI services in terms of how effectively each of the services met their needs,. using a nine point ranking scale (1=excellent, 2=very good, 3=good, 4=poor, 5=not available, 6=not offered, 7=not wanted, 8=not applicable, 9=not sure, don't know). The individuals interviewed as couples independently filled in the questionnaire, giving 18 potential participants. However, P only answered one question, and I, two, leaving it up to their partners. The results of user ratings 1-4 in relation to different user groups are shown in table 4.5a and 4.5b. When reviewing these results I was looking for average differences between groups of about 1.0 or more.

Firstly, from table 4.5a, looking at the total scores, counselling was rated as the most valuable service in meeting the needs of the clients with 14 of the participants giving an average rating of 1.1 (being almost 'excellent'). This is followed by the face-to-face support, information about mental illness and telephone support, all of which had an average rating of 1.7 or better (i.e. better than 'very good' on average). All the other services seemed to serve the clients' purposes well, all being on average lower than 3 or better than 'good', with the lowest rating being for the web site at 2.8. Overall, this is a very positive reflection on the work of SFMI.

Table 4.5a Confirmatory Assessment of Services										
Responses to the questions 'Looking back how valuable were the following services?: (Average of responses using 1=excellent, 2=very good, 3=good, 4=poor)										
Services	Total		diagnosis				contacts			
			Schizo-phrenia		other		1-6		above 6	
	N	av	N	av	N	av	N	av	N	av
counselling	14	1.1	8	1.3	6	1.2	7	1.3	7	1.1
face-to-face support from a staff member	16	1.6	9	1.4	7	2.2	8	1.7	8	1.8
information about mental illness	15	1.7	9	1.7	6	2.2	7	2.2	8	1.6
telephone support from a staff member	15	1.7	9	1.6	6	2.4	7	1.7	8	2.0
information about mental health services	14	2.0	8	1.9	6	2.8	6	2.8	8	1.9
direct support when meeting a MH professional	9	2.1	7	1.7	2	3.5	2	1.5	7	2.3
training in managing mental illness	10	2.3	6	2.2	4	2.5	2	1.5	8	2.5
SF library services	5	2.4	2	2.0	3	2.7	2	2.0	3	2.7
participation in support networks	8	2.5	5	2.6	3	3.5	3	4.0	5	2.4
opportunities to promote policies	6	2.5	3	2.3	3	4.0	1	1.0	5	2.8
seminars, lectures, discussion groups	11	2.5	5	2.4	6	3.2	4	3.7	7	2.4
participation in support groups	11	2.5	6	2.3	5	2.8	4	2.8	7	2.4
SF website information services	6	2.8	2	2.5	4	4.0	3	4.0	3	3.0

Table 4.5a also shows where there was a diagnosis other than schizophrenia, the experience of direct support when meeting a mental health professional and getting access to information through the website was a lot less favourable than where *schizophrenia* was the diagnosis. The *other diagnosis* group also felt less able to influence policy, suggesting that SFMI staff may not be as confident with diagnoses other than schizophrenia

Participants who had less than seven contacts with SFMI tended to be more positive about their opportunities to influence policy, training and direct support at meetings with mental health professionals that those with greater contact with SFMI, suggesting that those with fewer contacts may be in s stage of greater hopefulness. On the other hand, they were less satisfied with the general information services (seminars, the website, information about mental health services and the library) suggesting that they were still struggling to get the information they needed. They also felt less satisfied with the support networks.

Looking at all the ratings made, the difference between the average rating for the contact datasets is small (2.06 for those with 6 or more contacts and 1.86 for those with less than six contacts). The difference between the diagnosis datasets is larger with the schizophrenia group appearing to be receiving greater value (overall average = 1.84) than the other

diagnosis group (overall average = 2.19). However, the numbers for comparison are very small except for the overall comparisons and differences between the contact and diagnosis datasets for each line in table 4.5a seem small.

Table 4.5b shows that while non-parents were not as happy with the SF library as the parent group, the latter were less happy with the information they received about mental health services. Otherwise, there was little difference between the two groups. Similarly, with regard to the differences between European participants and the Māori, Pasifika or Asian participants, there was little to note, other than a much lower level of approval for the website from European participants (who were much more likely to have viewed it).

Table 4.5b Confirmatory Assessment of Services

Responses to the questions 'Looking back how valuable were the following services?: (Average of responses using 1=excellent, 2=very good, 3=good, 4=poor)

Services	Total		type of relationship				culture			
			non-parent		parent		European		MPA	
	N	av	N	av	N	av	N	av	N	av
counselling	14	1.1	6	1.2	8	1.3	8	1.4	6	1.0
face-to-face support from a staff member	16	1.6	7	1.4	9	2.0	9	1.9	7	1.6
information about mental illness	15	1.7	7	1.6	8	2.1	9	1.9	6	1.8
telephone support from a staff member	15	1.7	7	1.4	8	2.3	8	2.0	7	1.7
information about mental health services	14	2.0	6	1.7	8	2.7	7	2.2	7	2.3
direct support when meeting a MH professional	9	2.1	5	2.0	4	2.3	5	2.2	4	2.0
training in managing mental illness	10	2.3	5	2.0	5	2.6	4	2.8	6	2.0
SF library services	5	2.4	2	3.5	3	1.7	4	2.3	1	3.0
participation in support networks	8	2.5	4	3.0	4	2.7	6	3.0	2	2.5
opportunities to promote policies	6	2.5	2	3.0	4	3.0	4	3.3	2	2.5
seminars, lectures, discussion groups	11	2.55	3	2.7	8	2.9	8	3.0	3	2.3
participation in support groups	11	2.5	4	2.5	7	2.6	7	2.6	4	2.5
SF website information services	6	2.8	2	3.0	4	3.7	5	3.8	1	2.0

Again looking at all the ratings made, the difference between the average rating for the non-parent/parent datasets is negligible (2.0 for non-parents and 2.1 for parents) as it is also for the European/MPA datasets (2.1 for European and 1.9 for Māori, Pasifika or Asian).

Table 4.6 Confirmatory Assessment of Services neutral or negative responses				
Responses to the questions 'Looking back how valuable were the following services?' (Number using 4=poor, 5=not available and 6=not offered, 7=not wanted or 8=not applicable, 9=not sure, don't know)				
Services	4=poor	5=not available or 6=not offered,	7=not wanted or 8=not applicable	9=not sure, don't know
counselling				4
face-to-face support from an SF staff member				
information about mental illness	1	1		
telephone support from an SF staff member				
information about mental health services	1	2	1	1
direct support from an SF staff member when meeting with a mental health professional	1	2		3
training in how to manage the consequences of mental illness in a family/whānau member		3		3
SFMI library services	1	2	2	5
participation in family/whānau support groups - sharing of experiences, the developing mutual support systems, and/or gaining the strength and skills that enabled you to cope		3	2	2
opportunities to comment on or promote policies around the involvement of family/whānau in recovery processes within the mental health field	1	2	3	4
seminars, lectures, discussion groups on mental illness and mental health services		1	2	3
participation in family/whānau support networks - the sharing of experiences, the development of mutual support systems, and/or gaining the strength and skills that enabled you to cope	1	2	2	1
SFMI website information services	2	1	3	5
Total	8	19	15	31
percent of total possible responses	3%	8%	6%	13%

However, some participants had reservations about some aspects of the services. Table 4.6 summarises the level of dissatisfaction with the services. Three percent of the possible responses to the confirmatory assessment suggested that an aspect of SFMI services were poor. Only the *Website* had more than one participant labelling it as 'poor' (two of the eight 'poor' responses). Of more importance perhaps, is that 8% of responses were from participants who might have liked to have had access to a particular service but felt that it was either not offered or not available. Of these participants, five of the six were from the group that had had less than six contacts with SFMI. It is interesting that the areas of *opportunities to influence policy*, *training*, and *direct support at meetings with Mental Health professionals (*which some members of this group had rated very highly in Table 4.5a) were

perhaps perceived as needed by other members of the this group who had not had access to them. Additionally, five of the six participants responding positively to the issue of access were people caring for someone with schizophrenia.

A similar number of responses (6%) suggested that that SFMI was offering services that were not personally required. Seventeen percent of participants were not looking for opportunities to engage with policies or to use the website. None suggested that *counselling, training, face-to-face, telephone* or *direct support when meeting with a mental health professional* were not wanted or applicable. These clearly were the core services of SFMI.

Thirteen percent of the responded with '*don't know'*, and these were most apparent in the services that rated lowest (e.g. the *SFMI Website*). The exception was the top-rated counselling service, where there were 4 responses of '*don't know'*, mainly from people new to the service. Otherwise the responses of '*don't know'* were evenly distributed across the questions. In addition, 12% of the answers to the confirmatory questionnaire were blank, predominantly from I and P who appeared to be happy to let their partners fill in the questionnaire and left theirs substantially blank.

4.7.2 *Overall satisfaction*

To produce a measure of overall satisfaction, I averaged the satisfaction scores on all the features listed in tables 4.5a, 4.5b and 4.6 that had been rated by individual participants. One participant rated as little as 2 areas, while 2 rated all 13 areas. Table 4.8 shows that 94% of the participants thought that the SFMI services were better than good and 50% thought they were better than very good. Table 4.8 also shows that the average rating of 2.0 given by participants represented an overall evaluation of SFMI as *very good.* This was generally true for the all subgroups with each of the four co-variables of diagnosis, contacts, type of relationship and culture.

Table 4.7 - Participants' overall satisfaction with SFMI services				
Groups	Overall satisfaction rating	Percentage of ratings that were:		
		less than good	good to very good	better than very good
schizophrenia (10)	1.9	10%	20%	70%
other diagnosis (8)	2.3	0%	75%	25%
1-6 contacts (8)	1.9	10%	50%	40%
more than 6 contacts (10)	2.1	0%	38%	63%
not parents 7	2.0	0%	29%	71%
parents (11)	2.1	9%	55%	36%
European 11	2.1	9%	45%	45%
Māori, Pasifika, Asian (7)	1.9	0%	43%	57%
Total (18)	2.0	6%	44%	50%

4.8 What is missing – recommendations for change

What might have enhanced the service that you received? The last question in this research asked the participants to state what might have enhanced the service they received, or to identify what they perceived as missing from the service received. A majority of the participants stated that the service received was good enough and could not think of anything that could have made it better - 'I think they are doing good work as it is now' (D). The quality of a work force of any organisation reflects its strength, and this came through during this research as a majority of the participants commended the staff of SFMI - 'They have capable field workers, and if I require anything, I believe staff will make efforts to help me' (F).

Table 4.8 What might have enhanced the service you received?		
Factors Identified	No of Participants	Percentage
Commendations of the services	9	50%
Improved referral practice	2	11%
Family support Group	2	11%
Earlier contact	1	6%
Child support	1	6%
Staff Care	1	6%
Office/Practice upgrade	1	6%

4.8.1 *Commendations of the services*

Table 4.7 shows that 50% of the participants expressed an appreciation of the service received. The quality of service being provided by SFMI was considered very good, meeting the needs of the service users. G thinks that the service was a great help, and believed that without

SFMI, there would be many unhappy families out there in the community. For others, just helping them so that they are able to manage the condition of their relative or friend with mental illness means that SFMI is doing well.

4.8.2 *Improved referral practice*

Eleven percent of the participants expressed a concern about referral. They felt that SFMI should create the awareness among the clinical teams to ensure that during treatment of a person with mental illness, families/whānau should be referred to SFMI immediately, thereby helping them to cope with the stress and concerns they have. A participant (B) said 'When my daughter was diagnosed with mental illness (depression), I expected that the psychiatrist or nurses should have referred me to SFMI immediately, but I am not sure if they saw any need for that. I think there is need to educate them'.

This may be a specific area that SFMI needs to improve upon. It is true that many of the referral points carry SFMI referral information packs, but organising a periodical interface meeting with those referring agencies and external service providers might improve upon referrals.

4.8.3 *Family support group*

Eleven percent of the participants believed that the family group sessions could be improved upon, if sessions could be divided into diagnosis groups, e.g. schizophrenia, depression, ADHD, and other mental illness. B was of the opinion that she would not want to sit down to listen to issues that are not relevant to her. There was a recommendation that there should be a family forum on the SFMI internet, so that those who could not attend family group meetings could be provided with a periodic family forum where they can share their experiences, and receive advice necessary for their own situation.

4.8.4 *Earlier contact*

One participant (B) was concerned that the gap between referral time and contacts from SFMI be improved upon, and was concerned that on their first encounter with mental health services information about family/whānau support should be provided. Proactive staff might help to improve services. 'Perhaps, what might help more is someone to contact the person, not to leave it for the person to ask for help' (B).

4.8.5 *Children's support service*

Although L did get support (counselling and information) from SFMI she felt that 'the staff could have helped me more'. In particular she felt that 'they should have supported [our grand] child as well because the child needed support. I expect them to go another step, and be supportive of the child' (L). It did not make much sense to the family that an adult could seek support to deal with issues around a mentally ill relative or friend, but the children of that adult could not receive support. Although, from a contractual point of view, SFMI was not contracted to support children, developing an appropriate means of dealing with this sort of situation in the future could be important.

4.8.6 *Staff care and office upgrade*

Another participant M was concerned that the fieldworker changes frequently. He recognised the fact that the job is demanding and staff will tend to move on quickly. Finally, the state of SFMI office was the concern stated by one participant (R) who said that she came in for counselling being her first contact with SFMI.

> Well after the first meeting, I thought it was not going to work, because their office is not very nice. I know they have budget constraints, but having meeting in a waiting room. I do not have problem with that, but having people moving in and out of the room does not make me feel comfortable, the room was dark too (R).

So, although R has a high opinion of SFMI and the service she received, she would like to see the SFMI office upgraded, with a comfortable family/whānau room free from noisy vehicle traffic, well lit, and without constant interjections during counselling or meeting sessions.

CHAPTER FIVE - DISCUSSION AND CONCLUSION

5.1 Summary and integration of key themes

This dissertation set off to study the narrative of the experience of carers with a relative or friend who suffered mental illness, the roles supportive or otherwise played by SFMI to alleviate the perceived negative experiences of the carers, and to evaluate numerically specific SFMI services.

5.1.2 *The challenges for family/whānau and friends*

Section 4.2 shows that 60% of our participants were carers of people with schizophrenia and 40% were carers for people with other diagnoses such as depression, bi-polar, ADHD, and other disorders. Just as the burden of schizophrenia is well attested in the literature, this view is well supported by stories of the carers in s4.4. Those carers for people with other diagnoses had similarly bleak tales to tell of family histories of mental illness, trauma, fighting and the way in which mental illness 'consumed' their lives. Half of these carers were separated from their partners, in part as a result of the impact of mental illness. Violence, stigma and financial worries were all part of the family burden carried by the participants in this research.

In chapter 2, schizophrenia (and particularly psychosis) was identified as likely to be a severe mental illness. Our carers identified hallucinations and voices, and experienced unpredictability, incoherence, violence, self-neglect, self-harming and substance abuse in their unwell relatives. Our carers also describe the grief, loss and spiritual uncertainty that they experience and that Marsh (1999) in 2.5.3 describes as 'the dark soul of the night' and 'the lost hopes and dreams' that persist with the understanding that many of the people that are the subjects of this research will possibly need life-time support.

As such the first objective of this research that was stated in chapter 1 of describing 'the challenges faced by families or whānau as a result of the mental illness of a relative or friend' has been met. It is clear that our participants are carers with considerable needs for support.

5.1.2 *The effectiveness of SFMI services for different participant features*

Our next objective was to evaluate these challenges in relation to the contexts in which they occur. In chapter 4 we looked at contexts of diagnosis, parents/no parents, number of contacts

and culture in relation to the themes that we addressed. With regard to participants' satisfaction with services, all the subgroups expressed a high degree of satisfaction overall and with most of the services that they had chosen to use. There were some differences noted in s4.7, particularly around the area of diagnosis and the level of support and information that SFMI was able to offer for the *other* diagnosis group. This was echoed to some extent in the transcripts of the participants. For example, when reflecting on their experiences before contacting SFMI, few in *other diagnosis* group felt that they had access to knowledge about the mental health services and one (F) commented that they could 'get help easily from Australia, they are open about mental illness, but [in New Zealand] we are just tossed from one end to another.'

While 40% of the *schizophrenia diagnosis* group felt that they had obtained useful information after the first contact (G: 'I found it a relief having SFMI to help me understand about the illness'), none of the *other diagnosis* group talked about getting quality information. This was despite the fact that they were receiving telephone, counselling and home visit support at about twice the level of the *schizophrenia diagnosis* group in the latter two categories. They were also more likely than the *schizophrenia diagnosis* group to just commend the SFMI services in the final question which asked for recommendations (e.g. F 'I am just happy that they came to see us. That for me is great')

In the literature, I reviewed the nature of severe mental illness and noted that, *apart* from the illnesses in which psychosis plays a major part, the other diagnoses of importance are major depression, and anxiety and obsessive-compulsive disorders. These disorders taken as a whole possibly represent greater complexity than psychosis, particularly for an organisation that has only recently changed its name from Schizophrenia Fellowship. Another difference between the diagnosis groups is that two thirds of *other diagnosis* were working, compared with only 30% of the *schizophrenia diagnosis* group, despite the fact that mothers were the main participants for the *other diagnosis* group. This suggests that the impact of mental illness may not be as great (particularly in the area of risk to others) for the *other diagnosis*, while none-the-less being considerable and ongoing.

Section 4.7 also spoke to differences between participants who had more than 6 contacts and those that had 1 to 6 contacts. This latter group struggled more to get information from SFMI

(perhaps as a function of their newness to the service), but they were more positive than the older hands about the prospects for change, including their own willingness to engage in change through training. Their response to my initial question demonstrated a degree of unresolved grief and loss which was not present in the group with more than six contacts. For example, O and P state: 'It becomes an issue when we see our son really sick, and his future is unpredictable… we do not know how long we will deal with this issue'. Elsewhere in the transcripts this group (1-6 contacts) does not appear to engage early with support groups, but was inclined to recommend processes that would facilitate support groups such 'group therapy' and 'including more families, and sharing ideas'.

Table 4.5b suggested there are difference between *parents* and *non-parents* (the former more valuing the library and the information received about mental health services). *Non-parents* received less telephone support after the initial contact, but otherwise were as positive overall as the *parent* group. I noted in s2.7 that SFMI started as a parent group, but over time its focus and those of funders and researchers had shifted to families and whānau, and that families and whānau include non-parent relatives and friends. However, thoughts that SFMI might have been slow to engage with *non-parents* seem hard to justify with the broad satisfaction and seemingly wide engagement of that group.

In chapter 2, I cite *Moving Forward* (Ministry of Health, 1997c) and *Te Kōkiri* (Ministry of Health, 2006) in relation to the importance of appropriate engagement of Māori and Pasifika clients. In Chapter 3, I note that 25% of SFMI clients are Māori, Pasifika or Asian. SFMI over the last few years has employed Māori, Pasifika and Chinese staff in order to provide more culturally appropriate services to these groups. The seven Māori, Pasifika and Asian participants in this research were clearly as pleased and satisfied with SFMI as their European counterparts. The first question did, however, bring out important differences between these two groups, showing that the Māori, Pasifika and Asian group had less knowledge about illness and a greater experience of family separation as a consequence of mental illness. Both these issues put considerable stress on carers, resulting in for example police action, 'claims of abuse', and families 'not wanting to have' the person with a mental illness.

5.1.3 *Meeting policy and best-practice guidelines*

In this next section I explore the extent to which SFMI meets its own objectives, government policy and best practice guidelines. SFMI's vision is for the best quality of life for people with mental illness and their family/whānau (s 2.7.1). and the detail of that vision (the mission statements) emphasise peer support, sharing of experience, promoting rights and needs of family/whānau and offering advocacy and advice. The Code of Family Rights (see s 2.7.2) also reinforces these positions particularly around access to information.

Tables 4.5a and b rank peer support and networking as one of the less valuable areas of SFMI's work, and the most valuable of the services offered (counselling) is not explicitly named in the mission statements (s2.7.1). However, counselling clearly is a *need* that is being addressed, and the next top five most favoured services – information giving, face-to-face and telephone support, being present with the family at meetings with a mental health professional – do reflect named issues within the mission statements. In s2.7.1 I also noted the services that were funded by the DHB. These did not specifically include counselling and telephone support services.

The work of SFMI aligns well with overseas frameworks such those advocated by SAMHSA (2010), and in some respects seem ahead of the of the US in terms of developing family support systems, cultural services, training and a general family advocacy platform. In 2006 Te Kōkiri argued for a wide range community mental health services including crisis management, early intervention, assertive community treatment, long term structured support in safe accommodation, and, finally, a range of dual diagnosis intervention services (mental health and alcohol and other drugs, mental health and intellectual disability) as well as family support services. Participants reported the lack of some of these services, particularly crisis management and early intervention, and SFMI may have struggled a little to deal with the increasing complexity of diagnosis (such as dual diagnosis). Te Kōkiri also emphasised the need for strong cultural services (which SFMI appears to have effectively provided) for the participation of family/whānau in the evaluation of services (which is what this thesis is in part about), and the importance of *caring for the carers*. The very positive ratings for counselling work suggests that SFMI is doing well in *caring for the carers*. It is also possible that SFMI is doing well in meeting the criteria for good family/whānau support services, while other services struggle to meet Te Kōkiri targets.

5.1.4 *Models of Counselling*

With reference to the models of counselling identified in s2.8, it is important to note that SFMI staff are not generally trained as counsellors. However, many of the attributes of the counselling models described in s2.8 have echoes in the transcripts of the participants. Many describe their change of state after engaging with SFMI as a form of catharsis consistent with the psychodynamic approach. Many participants clearly experience a form of existential despair, finding their hopes for the future of their relation dashed repeatedly, but through SFMI support, finding the courage to reconstruct that relationship. Many SFMI staff are themselves carers and the Person Centred approach of *unconditional positive regard* and *empathetic understanding* fits well with the participants' reports of SFMI staff practice. Finally, ten participants underwent and valued some form of training around self-management or management of their relationship with their mentally ill relative or friend. This training will have included many elements of a cognitive-behavioural approach, and given the overwhelming general positive response of the participants to SFMI support and the absence of any cry for support around behavioural management, it is not unreasonable to assume that many issues of behavioural management have been resolved. Overall SFMI's counselling approach is constrained by the different situations that staff find themselves in with participants – on the phone, at the participant's home, in a meeting with other professionals, at SFMI's office or perhaps in a coffee bar. In this respect it probably fits a brief intervention model.

5.1.5 *Performance measurement*

Finally, in s2.9 I have discussed the literature on performance measurement and the SFMI's perspective on it. Was there a 'gap between what consumers think should be provided and what they think actually has been provided' as Zeithaml (1985) enquired? We have above suggested some gaps, but these are small. Going through Zeithaml's list, the comment on the quality of SFMI's office space was the only comment about *physical* resources; a high turnover of staff was suggested in an otherwise complimentary report on *staff skills*; there were challenges in becoming aware of SFMI's services, suggesting that there may be *location* problems, and the weaker performance of the library and website might suggest that more *administration* support is needed for these services to flourish.

The challenge for SFMI is that it has been funded to deliver certain outputs such as face-to-face contacts with families and family support groups rather than telephone contacts or counselling. Using Rochie's (1999) model we can see that unintended impacts (telephone and counselling work) of this funding model are overwhelming positive – SFMI does appear to deliver the services that families and whānau need. It is difficult to suggest any negative unintended impacts.

5.2 Key limitations and strengths

This research concentrated on SFMI as a case study, as it was only possible to have a small sample and to involve only one family support organisation, thus the results derived from this research cannot be easily generalised to other family support organisations, or even to SFMI as a whole. Hence the study could be further strengthened if similar research was done with other family support organisations both in Auckland (Northland, North Shore and Manukau) and elsewhere in New Zealand, thus building the project to a larger scale. The quantitative distinctions made in the study (apart from the chi-squared test of similarity of the expected and actual sample) were not statistically tested, as the sample was too small for such testing. This again places restrictions on the extent to which results from this research can be generalised.

Another limitation of the project is that of the 100 invitations made, only 18 participants responded, all of whom were recruited, including two couples. The group did largely have the diversity intended of the study, and largely matched the diversity of the clients of SFMI. A acceptance rate of 18% would be considered good for a mail out questionnaire, and thus is probably reasonable for an invitation to an interview. Since the invitation came from the SFMI President, acceptance should have been relatively free of influence from SFMI fieldwork staff, none of whom would have been aware of who was invited. A key question is why 82 people refused to engage with the research and what might have the outcome had they engaged? We can safely assume that busy lives account for many of the refusals, and that issues of privacy and stigma were also prevalent and that neither of these factors would influence the outcome of the research. There is no strong reason to suspect that people dissatisfied with SFMI would consistently choose not to engage with the research.

Finally, for limitations, this research is carried out for the purpose of meeting the dissertation requirements of the Unitec degree of Master of Social Practice, which naturally placed heavy restrictions on the size, and scope of the study.

The key strength of the study is that it provides in-depth qualitative information of how a diverse range of caregivers respond to family/whānau mental health support services that have been running in New Zealand, essentially with little evaluation beyond in-house satisfaction measures, for more than a decade. Further, this qualitative data triangulates well with quantitative data of the study with regard to outcomes, and with the literature with regard to family/whānau experience of supporting a person with mental illness and family/whānau support needs. When these factors are coupled with the almost overwhelming level of positive support for SFMI's work by the participants in this study, then the argument that this is work that has considerable benefit must be taken seriously.

5.3 Recommendations to Mental Health Family Support Organisations

The recommendations made by the participants were not extensive or reflective of wide concern. They do relate to the core concerns of family support work. SFMI probably can do things to increase its profile in the community and strengthen its relationships with providers so that families and whānau make early contact, get early referral and do not spend vital months, and sometimes years, without support and information. The desire to have information and support groups that are focussed on diagnoses other than schizophrenia and better coverage of issues of dual diagnosis can also be addressed. A further exploration of the information and training needs (including website and library) of non-parent clients and non-European clients may be another useful task for SFMI

Some issues raised reflected gaps in funding. Support for children who have relatives or friends with mental illness is an area of contention known to SFMI, partly because of the difficulty in getting funding for this work. Other areas of concern raised about the adequacy of SFMI's resources – a worry about staff burnout and the quality of family counselling rooms – also emphasise funding issues.

This data was collected in 2009 and it is possible that SFMI has already addressed some of these issues. The weaker approval for the website suggests one avenue for improvement.

Looking at the website in 2011 (SFMI, 2010), the home page has a large advertisement for *Kids Club* a service clearly directed at children which looks like fun as well as a place where children can find out what they need to know about mental illness. There is also a link to the SFMI sponsored *Network Mosaic* whose role is 'connecting services in the Northern Region to promote best practice for working with young people whose family/whānau experience mental health and/or addiction issues'. (Network Mosaic, 2010). This site is badly out of date with the *New Events* section advertising 2010 events, suggesting room for improvement.

Also on the SFMI website is extensive information under the *Information* heading about a wide range of mental illnesses, perhaps addressing some of the concerns raised about access to information about mental illnesses other than schizophrenia. The same coverage of diagnosis does not apply to the *Research* section of the website, where of the diagnoses only Schizophrenia features prominently. There is also an extensive listing of service providers, so that families should be able to access the information they need. Using *Mental Health* as a search term for New Zealand pages, Google finds either the national organisation or SFMI Auckland three times in the top ten listings, suggesting that information on family support services is not hard to find.

The listing of support groups names one diagnosis specific group that is not schizophrenia (for borderline personality disorder), two culturally contexted support groups, one for parents of children with mental illness and another eight geographically focussed support groups. So there may be a need for more diagnosis-focussed support groups, sessions with support groups or diagnosis specific education and training. The suggestion from one participant to build a family forum into the website for family members who are unable to attend group sessions is well worth considering.

We have seen in s4.7.1 how those participants with six or less contacts perceive themselves as having less access information than those with a longer history of contact. What may help here, with regard to the issues of focus on diagnosis, carer role and culture, is that more attention be given to how the website, library, training and support groups are presented attractively to each of these audiences. Staff training may also be needed to increase the scope of information and advice that staff feel comfortable in providing.

Two of the top rated four services, counselling and telephone support, are clearly much needed, but not necessarily well funded services, Added to this, services for children of adults affected by severe mental illness, and the maintenance and development of the library and website are not specifically funded or only partially funded. The counselling offered by SFMI would not be recognised as such by the New Zealand Association of Counsellors, and SFMI could not afford to offer much in the way of professional counselling services, despite there being a real need for this for family/whānau members, particularly in the early stages of adapting to the changes brought on by mental illness.

The expense of counselling is a significant additional burden to families and whānau already under huge stress, so it needs be free or very low cost. Providing an accredited counselling service would require significant additional funding and the right model for delivery of such a service would need to be explored. For example, is it a service that SFMI would provide or would it be sub-contracted to a counselling service?

The level and continuity of funding is major issue for any non-government organisation. With the current recessionary economic environment the government will seek ways to reduce costs in mental health by pushing greater responsibility onto families and communities – getting more for less. At the same time, funding for family support services such as SFMI is under threat from:

- government policies that seek greater integration of services
- competition arising from development of family support services within major mental health providers
- fragmentation of SFMI regional services due to a collapse in SFMI's national office in 2009
- lack of a strong cost-benefit analysis to justify the funding of current family support services

There are other family support organisations in New Zealand, and major mental health NGOs and iwi organisations that incorporate family/whānau support within their services. However the combined SFMI branches constitute by far the largest family/whānau service provider in mental health with offices located across the nation.

So the key recommendation relates to funding. The gaps in funding relate to four core service elements. These are a highly accessible, informative, interactive and up to date website; a great telephone information and support service; a counselling service that can provide in depth counselling when needed, and a funky support service for children of parents with a mental illness. These services all need better funding, but where that funding should come from and should go to is a matter of debate. Professional counselling may not be an in-house service and the longer term may see many SFMI branches amalgamated into other much larger providers, significantly reducing administrative overheads. What do we do less of to fund new services? Such ideas are compelling when resources are short.

5.4 Conclusion

About one third of the cost of mental health care is borne by people with a mental illness and their families (SANE, 2001). A 2006 New Zealand survey (M-TAG, 2006), put the cost of care that the family incurs at $350 per week or $18,200 per year, or over $21,000 in 2011. Keeping families and whānau involved obviously stops this cost, and possibly much more, from being passed onto the state, so it makes good economic sense to keep families involved by providing supportive services. The question I left unanswered in the last paragraph was *is it important that SFMI continues to have the major role in providing such services, when others might be able to do the same in a more integrated fashion*?

The results of this study not only show appreciation for SFMI's work but a real affection for the staff (many of whom are or have carers themselves) and a concern for the welfare of the organisation. SFMI's board is elected from the mostly family members of the organisation, and the total focus of the organisation is to ensure that families and whānau can readily do the support work that is needed to help themselves, and thus their relatives and friends with a mental illness, in the recovery journey. While large Auckland mental health NGOs, such as Pathways, Richmond Fellowship, Challenge Trust, Affinity and others, run services to engage clients' family/whānau in the treatment and recovery process, they are not set up as family/whānau advocacy/support organisations. These mental health providers can (and should) take on the family support role, but this will be either isolated work of individuals or an extra responsibility built into everyone's job description and easily forgotten when under pressure from the organisation's much wider objectives.

Through satisfaction surveys, family/whānau board members, support groups (including cultural support groups), training sessions, presentations, regional advocacy groups and local and national conferences, SFMI is very much in touch with the experience of families and whānau and changing tides of their expectations. This complex information can be the source of innovation, so that while other organisations may be able to replicate aspects of what SFMI does, they cannot create it in the first place. In maintaining that innovative edge, maintaining a close relationship with other SFMI branches and other family organisations, and finding a useful way of coordinating at a national level, will be important. At this level there is a need to have a powerful family advocacy voice that is not compromised by funding issues or constrained by the weight of service provision, and is recognised as speaking authoritatively on behalf of families and whānau.

The future will be a delicate balance of what services and roles to hold onto and what to let go. If families and whānau deeply appreciate what SFMI is doing, how can this be sustained, improved and exported to other organisations and other places in New Zealand? At the centre of this question is the role of research. How can research tell us what works and what does not, and how do we report the good news (even the bad news is good, because at least we know what not to do)? I hope that in a small way this dissertation will help SFMI chart its direction in these uncertain times.

APPENDIX 1- INFORMATION SHEET

Information for participants

How people who have a relative or friend with mental illness are supported by the Auckland Branch of Supporting Families in Mental Illness.

My name is Alabi Adeosun and I am a second year Master of Social Practice student at Unitec. Part of my degree programme involves doing a research project. My research topic looks at how people who have a relative or friend with mental illness are supported by the Auckland Branch of Supporting Families in Mental illness.

What I am doing

I want to find out the effects serious mental illness of a relative or friend has on the families and whānau. This research is to examine and critically evaluate the effectiveness of support being provided by Auckland Branch of Supporting Families in Mental Illness (SFMI) to families and whānau of people who have a relative or friend with Serious Mental Illness. You will be helping me to understand what is relevant and important for families and how SFMI can further help families and whānau of people with a relative or friend with serious mental illness. The interview questions have been approved by SFMI.

What it will mean for you

I want to interview you and talk about:

- What effects does the mental illness of your relative or friend have on you?
- How did you get to know SFMI, and your experience at the first encounter?
- What you have found most helpful in your dealing with the organization?
- Your opinion regarding the services, and your contribution?

At the end of the interview I would like to complete a short list of tick box questions that will provide a summary of your views. You will be given a copy of the transcript which you may alter should you wish to do so.

I would like it if you could meet with me for about 45 minutes to talk about these kinds of things. I will come to you. I will tape the interviews and will be transcribing them (typing the conversation out) later. All features that could identify you will be removed and the tapes used will be erased once the transcription is done.

Confidentiality and consent
No one apart from the researcher will know who is being interviewed.
No one apart from the researcher will know the name of staff that has been supporting the participant.
No staff or participant name and uniquely identifying features will be used in this research.

If you agree to participate, you will be asked to sign a consent form. This does not stop you from changing your mind if you wish to withdraw from the project. However, because of our schedule, any withdrawals must be done within 2 weeks after you have received the transcript of your interview.

Your name and information that may identify you will be kept completely confidential.

All information collected from you will be stored on a password protected file and only you, the researcher, and my supervisor will have access to this information.

Contacts
Please contact me if you need more information about the project.

Alabi Adeosun. Phone: 027 6791112. Email: monialab@yahoo.co.uk

At any time if you have any concerns about the research project you can contact my supervisor:

My supervisor is: David Haigh. Phone: 09 3795538. Email: sideline@.co.nz

REC REGISTRATION NUMBER: (2009-996)
This study has been approved by the UNITEC Research Ethics Committee from (date) to (date). If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 7248). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

APPENDIX 2 - CONSENT FORM

Participant consent form

How people who have a relative or friend with mental illness are supported by the Auckland branch of supporting families in mental illness.

This consent form is an agreement between researcher and participants.

Participants will have individual interviews with researcher about how well people who have a relative or friend with mental illness are supported by the Auckland branch of Supporting Families in Mental Illness.

At the end of the interview I will complete a short list of tick box questions that will provide a summary of my views.

I have had the research project explained to me and I have read and understand the information sheet given to me.

I understand that I don't have to be part of this if I don't want to and I may withdraw up to two weeks following my reception of the transcripts of my interview.

I understand that everything I say is confidential and none of the information I give will identify me and that the only persons who will know what I have said will be the researchers and their supervisor. I also understand that all the information that I give will be stored securely on a computer at Unitec for a period of 5 years.

I understand that my discussion with the researcher will be taped and transcribed, and that the tape will be wiped following transcription.

I understand that I can see the finished research document.

I have had time to consider everything and I give my consent to be a part of this project.

Participant Signature: …….. Date: ……

Project Researcher: ……. Date: ……

UREC REGISTRATION NUMBER: (2009-996)
This study has been approved by the UNITEC Research Ethics Committee from (date) to (date). If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 7248). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome

APPENDIX 3 – INTERVIEW SCHEDULE AND QUESTIONNAIRE

Interview Questions

1. When did mental illness become an issue in your family/with your friend and what happened then? (History of the mental health issue, effect on wider whānau/family, what help was sought/received and when?)

2. What happened in your first appointment with the Supporting Families? (reasons for getting in contacting, how you get to know about SF, what did you think SF would be able to do, what type of appointment and where (phone, face-to-face, at office, at home, etc) what happened in the first encounter? What were the outcomes? How did you feel about it?)

3. What happened after the first appointment? (what other appointments were made, how many contacts (face-to-face, phone), how long with SF, SF services used (support group, peer support, library, etc), referrals, planning, supported with professionals, family meetings, what worked and what didn't work, were your hopes or expectations met?)

4. What might have enhanced the service that you received?

Looking back how valuable (1=excellent, 2=very good, 3=good, 4=poor, 5=not available, 6=not offered, 7=not wanted, 8=not applicable, 9=not sure, don't know) were the following service/s of SF Auckland.

5. Provision of or access to:
   a. Information about mental illness
   b. Information about mental health services
   c. Seminars, lectures, discussion groups on mental illness and mental health services
   d. Training in how to manage the consequences of mental illness in a family or whānau member
   e. Participation in family or whānau support groups - sharing of experiences, the developing mutual support systems, and/or gaining the strength and skills that enabled you to cope
   f. Participation in family or whānau support networks - the sharing of experiences, the development of mutual support systems, and/or gaining the strength and skills that enabled you to cope
   g. Opportunities to comment on or promote policies around the involvement of family and whānau in recovery processes within the mental health field.

6. Provision of
   a. Telephone support from an SF staff member
   b. Face-to-face support from an SF staff member
   c. Direct support from an SF staff member when meeting with a mental health professional
   d. SF library services
   e. SF website information services

7. Demographics: The obvious ones will be ticked during the interview or from data required to select the participants e.g. gender, culture, while others will be verified; age, occupation, length of time since engaging with service, type of relationship with client, etc.

APPENDIX 4 -SFMI BOARD APPROVAL LETTER

Dear Sir / Madam,

Invitation to be part of a Research Project

The Committee of Supporting Families in Mental Illness Auckland (SFMI) have approved a small independent research project which is an evaluation of the support services to families and whānau of people with a mental illness that are available through SFMI.

Mr Alabi Adeosun, a research student who is doing his Masters of Social Practice thesis at Unitec, would like to interview 16 people who are users of SFMI services - some short term and some long term. These interviews will take no more than 45 minutes and will be conducted at your home or a place that is convenient for you. More information about the research is in the attached Information Sheet.

If you are happy to support the research you may call Alabi on his phone 09-2560-991 or 0276-791-112 and make an appointment for interview. Alabi can also be contacted by email – monialab@yahoo.co.uk.

This research will help SFMI to identify what we are doing well and the gaps we might have in our services. Your support will help us improve services and provide justification for continued funding in these difficult times. Our fieldworkers can also be available to assist you in the interview if you would like their support – please just ask.

Thank you

Yours sincerely

Max Lloyd
Chairman
SF Auckland Branch.

SFMI Auckland PO Box 78-122 Grey Lynn Auckland New Zealand.
Tel: 09 378 9134 Fax: 09 378 6783 Email: admin@sfauckland.org.nz Website: www.sfauckland.org.nz

APPENDIX 5 - APPLICATION FOR ETHICAL APPROVAL FOR A RESEARCH PROJECT – FORM A

Form A is for all research that involves or may involve potential for contentious or sensitive issues.

PLEASE REFER TO THE GUIDELINES ('2008 ETHICS POLICY & GUIDELINES H:\RESEARCH\ETHICS\2008 ETHICS APPLICATION FORMS & GUIDELINES\2008 ETHICS POLICY AND GUIDELINES.DOC AND THE GUIDELINES FOR THE USE OF FORM A OR FORM B (INSERT LINK)) BEFORE FILLING IN THIS FORM. RESEARCH CANNOT PROCEED UNTIL FORMAL APPROVAL FROM UREC HAS BEEN GIVEN IN WRITING.

(For office use only)

Ethics Committee Ref. No:		Date approved:	
Date received:		Period of approval:	

DECLARATION:

This application is a true and correct outline of the research project. I, the supervisor and/or the applicant, undertake to notify the Unitec Research Ethics Committee whenever there is any ethically relevant variation in the research process.

The information supplied below is to the best of my knowledge and belief accurate. I have read the current guidelines and policy for ethical approval for research projects involving human participants published by the Unitec Research Ethics Committee and clearly understand my obligations and the rights of participants, particularly in so far as obtaining freely-given informed consent is concerned.

Applicant name:	Adeosun, Alabi Ganiyu Tijani	18TH May, 2009
Applicant signature:		
Supervisor name (if applicable):	Geoff Bridgman,	18TH May, 2009
Supervisor signature:		
Head of School name:	Helen Gremillion	18TH May, 2009
Head of School signature:		

PROJECT/THESIS TITLE:

How people who have a relative or friend with mental illness are supported by the Auckland branch of Supporting Families in Mental Illness.

For student projects:

Conducted at which Tertiary Institution?	Unitec of New Zealand
Degree:	Master of Social Practice
Course number & name:	Dissertation.

ATTACHMENTS: Checklist

☒ Information sheet(s) ☐ Questionnaire(s)

☒ Consent form(s) ☒ Interview/focus group schedule(s)

Applications should be received by UREC **at least 10 working days prior** to the next advertised meeting. Every effort will then be made to resolve each application at that meeting.

GENERAL INFORMATION

1. PRINCIPAL RESEARCHER (APPLICANT) - STAFF OR STUDENT

Name:	Adeosun, Alabi Ganiyu Tijani
Address:	3-8, Cornwall Road. Mangere East, Auckland- 2022
School:	Health and Community Studies
Phone No:	**027-6791112**
Unitec Student ID:	**1336314**
e-Mail:	monialab@yahoo.co.uk

Brief statement of relevant qualifications and experience:

PG cert. Health Sciences, PG dip. Health Sciences. (Auck.Uni).
Work with Alcohol and Drugs rehabilitation / Mental Health service in the past three years.

2. PRINCIPAL SUPERVISOR (if applicable)

Name:	Dr. Geoff Bridgman
Address (Bldg & room number):	Room 5031, Building 510, Waitakere
School:	Department of Social Practice
Phone No:	8154321 EXT.5071

Brief statement of relevant qualifications and experience:

Dr. Geoff Bridgman is an experienced researcher in the area of mental health and the course coordinator for undergraduate and post-graduate research programmes in Social Practice at Unitec of New Zealand. He is a member of the Auckland Board of Supporting Families in Mental Illness and immediate past president of the National Organisation of Supporting Families in Mental Illness.

3. ASSOCIATE(S)/RESEARCH PARTNER(S)/ CO-SUPERVISOR(S)/ ADVISOR(S):

	1	2	3
Name:	Mr. David Haigh		
School:	Department of Social Practice		
Qualifications:	MA.		
Role in	Associate Supervisor		

Details of additional associates/research partners are attached ☐ Yes ☒ No

4. PROJECT DURATION:

Dates during which the research methods requiring this approval will be conducted (normally one year from date of approval; a maximum of three years can be requested, after which the researcher must seek an extension):

From:	May, 2009	**To:**	November, 2009

5. AIMS/OBJECTIVES OF THE PROJECT:

Describe in language that is, as far as possible, free from jargon and comprehensible to lay people.

This research is to examine and critically evaluate the effectiveness of support being provided by Auckland Branch of Supporting Families in Mental Illness to families and whänau of people who have a relative or friend with Serious Mental Illness

'People with serious mental illness are not ill in isolation. Their families, extended whänau and significant others, whatever they may think about the illness, cannot escape being affected by it. The lives of people with serious mental illness are inextricably involved with the lives of those they love and care for, and the lives of those who love and care about them.' Mental Health Commission, 1998, p3.

The following are the specifics objectives of this research:

- Confirm the extent of the challenges faced by whänau and families as a result of the mental illness of a relative or friend
- Analyse these challenges in relation to the contexts in which these occur
- Clearly evaluate the role and activities of SF in rendering services that make a difference in relieving these challenges and enhancing well-being of families and whänau
- Clearly evaluate the extent to which those services meet the mission and services of SF, and the expectations of service users, and
- Offer suggestions for new services or adaptations to services that will better meet the needs of families and whänau

6. VALUE AND BENEFITS OF THE PROJECT:

I expect that the outcome of this research will support:

- The families and whänau: This research will be helpful for this people to create a better awareness of services they need
- The Mental Health Service Providers and Funders: This research will provide local information about the kind of help that family and whänau require and, which hopefully will be able incorporated into individual packages of care for people with a mental illness.
- Supporting Families in Mental Illness (SF) will find this research useful in the development of their work in the community.

Finally, this will contribute to literatures that are New Zealand oriented on this subject.

METHODOLOGY

7. TYPE OF PROJECT AND METHODS: (Mark the appropriate boxes)

Questionnaire	X☐
Focus Group	☐
Interview	☒
Experimental, Observational or Interventional Study	☐
Other (please specify)	Not Applicable

Will electronic media (e.g. e-Mail or the internet) be used for the collection of data from participants?

☐ **Yes** ☒ **No**

Please attach copies of relevant questionnaires, schedules, protocols and/or procedures.

8. SAMPLE & ANALYSIS DETAILS

a. How many participants will be involved in the research project? 16

b. From what groups are the participants to be drawn (e.g. general public, specific cultural groups, special interest groups, students, geographical groups, etc)?

c Participants will be drawn from the family/whānau who are currently engaging with SF (Auckland Branch), or have used the service within the last 2 years. I will recruit a purposive quota sample that roughly matches the diversity of clients that use SF Auckland's services.

Culture	Pākehā/European	Māori	Pacifica	Asians/other.	Totals
	10	2	2	2	16
male	2	1			3
female	8	5			13
schizophrenia	5	3			8
Other major mental illness	5	3			8
parents	8	4			12
other carers	2	2			4
1-3 face-to-face contacts	3	2			5
4-6 face-to-face contacts	4	2			6
more than 6 face-to-face contacts	3	2			5

c..What is the relationship between the participants and the researcher (friend, whānau/family, employee-employer, teacher-student, etc)?

None currently, although some may be connected through an acquaintance network.

d. What methods will be used to recruit participants? (Include information about koha, expenses, inducements)

A group of 30 participants will be randomly selected from SF Auckland's client list. Letters will be sent from the SF Auckland chair to the selected participants inviting them to participate. If categories of the proposed sample are not able to be filled, and further group will be randomly selected, and so on until the quotas are filled.

e. How did you determine your sample size?

The sample size is sufficient to report on the key outcomes identified. Considering the volume of work required for my dissertation, the sample size is adequate.

f. How will you analyse the data generated from the research project?

Thematic analysis will be carried out using Microsoft Word and Excel, and N-Vivo software. Themes will explore issues of satisfaction with a range of family support services, in relation to SF's vision and goals and given the context in which families and whänau find themselves - the dimensions of family burden due to mental illness; the relationship of the participant to the person with mental illness; the perceived quality of mental health services in relation to standards, and the other factors of culture, age, length of engagement, etc on which the sample has been constructed. The thematic analysis will use discourse analysis techniques (semiotic analysis, deconstruction) which will engage with issues that are central to families and whänau, while being sensitive to the roles and power of families. whänau, consumers, professionals, agencies and funders.

9. MAORI PARTICIPATION:

Could your research involve Māori participation, either by deliberate selection or by random sampling? Could it impact on Māori, or be of particular relevance to Māori?

☒ **Yes/perhaps** ☐ **No**

See HRC Guidelines for researchers on health research involving Māori (www.hrc.govt.nz)

If 'yes', please explain how your research process is consistent with the provisions of the Treaty of Waitangi. State what consultations and/or collaborations, and with which iwi/group, have or will be undertaken. What involvement does this group have in the project? How will the results be disseminated to the consulted group and participants at the end of the project?

Two of the 16 participants in this project will be Māori, and whilst this is not a kaupapa Māori research project, I have undertaken Treaty courses, my supervisors have extensive experience in cross-cultural research and I will seek advice as necessary from Dr. Helene Connor (Te Ati Awa, Programme Director Master's of Social Practice) regarding any issues relating to Māori participants in this research. I am myself from Nigeria and have some insight into the issue of colonisation and cultural oppression.

10. CULTURAL ISSUES:

Are members of a particular ethnic, societal or cultural group the principal participants or a sub-group of the research?

☒ **Yes** ☐ **No**

If 'yes', what consultations have been undertaken with appropriate parties?

The majority of SF service user group are predominantly parents, female and Pākehā. However two will be Pacific Island and two Asian. In my interview with participants, I shall approach this project with following standards in mind:

- Be respectful to my participants
- Organise all interviews in a professional manner
- Consider cultural sensitiveness, especially around English as second language participants.

11. MEDICAL RESEARCH OR RESEARCH INVOLVING HUMAN TISSUES OR BODY FLUIDS

Note that approval from an accredited Health and Disability Ethics Committee may be required, using their (or the national) application form (www.hrc.govt.nz). Please refer to this form and also contact the Research Office Administrator.

a. Does the research involve the collection or use of human tissues or body fluids?

☐ **Yes, Go to 12b** ☒ **No, Go to 12d**

b. If yes, what procedures will be used? Where and how will the material be stored?

Not Applicable

c. How will the material be disposed of (if applicable)?

Not Applicable

d. Does this research involve any invasive medical procedures, exposure to infection, the use of drugs, or constitute a clinical trial?

☐ **Yes, Go to 12e** ☒ **No, Go to 13**

E Describe the safeguards that will ensure against infection, damage, or risk to health.

Not Applicable

12. MEETING ETHICAL PRINCIPLES

UREC emphasises eight guiding ethical principles governing research and teaching activities using humans. These are:

- Informed and voluntary consent
- Respect for rights and confidentiality and preservation of anonymity
- Minimisation of harm
- Cultural and social sensitivity
- Limitation of deception
- Respect for intellectual and cultural property ownership
- Avoidance of conflict of interest
- Research design adequacy

EXPLAIN HOW THE RESEARCH PROJECT WILL ADDRESS ALL OF THE EIGHT ETHICAL PRINCIPLES AND WHAT STEPS WILL BE TAKEN TO ENSURE HARM MINIMISATION

Refer to Section 2, #3 'Minimisation of Harm' (insert link) in the Guidelines.

No physical or psychological harm is envisaged happening in this research. However it could be emotionally involving, hence following guideline will be observed during the interview process:

- Seek and obtain voluntary participation
- Be sensitive to possible distress of participants during the interview and avoid further questioning in areas that cause distress
- Carry out the interview in a conducive and relaxing environment
- Where emotional harm is possible, suggest counselling or support (e.g. SF Auckland) services that the participant might access.

DATA ACCESS

13. PROPOSED STORAGE AND ACCESS TO FILES AND DISPOSAL / STORAGE UPON CONCLUSION

Consent Forms

Note: Your consent forms must be retained for five (5) years before physical destruction.

a. Who will have access to the Consent Forms?

- Researcher
- Supervisors

b. How will you ensure that the Consent Forms are protected from unauthorised access? How and where will the consent forms be stored?

Store in locked cabinet at Unitec.

Data

Note: Your data must be retained for five (5) years before physical destruction.

c. Who will have access to the data?

- Researcher
- Supervisors

d. Are there plans for future use of the data beyond those already described? (The applicant's attention is drawn to the requirements of the Privacy Act 1993.)

The report will be available through the Unitec Library, and is the property of Unitec New Zealand.

e. How and where will the data be stored?

Store in locked cabinet at Unitec.

EXTERNAL CONNECTIONS

14. INVOLVEMENT WITH ANOTHER INSTITUTION/ORGANISATION

List the names of any organisations who are now or who will be involved in this research project, the type of involvement they have or are likely to have (e.g. funding [please state amount sought or received], co-researcher, venue for research, client), and indicate whether letters of support or approval from these organisations are attached.

Name of organisation	Type of involvement	Letter attached?
Supporting Families in Mental Illness. (SF) Auckland Branch	The clients of the organisation will be participants. A standard letter would be sent to potential participants from SF encouraging them to participate.	Yes.

b. ARE FUNDS BEING OBTAINED FOR THIS PROJECT?

☐ **Yes** ☒ **No**

Describe the investigator's, the host institution's, or a sponsoring agency's financial interest, if any, in the outcome of, or involvement in, the project.

Not Applicable.

15. RELATED APPLICATIONS

a. Have you ever made any related applications to other Ethics Committees?

☐ **Yes** ☒ **No**

b. If yes, have you enclosed copies of the applications and responses?

☐ **Yes** ☒ **No, Please explain**

Not Applicable

(Note that if you have already been granted Ethics approval by a University, Polytechnic, or Health and Disability Ethics Committee, you do not need further approval, but UREC must be sent a copy of the application and the approval.)

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