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# **Mental Health Service Provision for the People of Cambridge**

*Are services facilitating recovery?*

*A thesis submitted in fulfilment of the  
requirements for the degree of  
Master of Social Sciences in Psychology  
at The University of Waikato*

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# Abstract

The purpose of the present research was to investigate consumer perspectives of mental health service provision in Cambridge and whether services were helpful in facilitating recovery. Cambridge is a small township in the Waikato region, approximately twenty-five kilometers south-east of Hamilton. The study aimed to: gain an understanding of consumers' interpretations of recovery; identify consumer perspectives of service delivery in Cambridge; assess whether services in Cambridge are working from a recovery ethos; and determine how consumers' think service delivery could be improved. Interviews with 14 consumers of mental health services were completed. The key findings of this study suggest that the mental health needs of Cambridge consumer's were not being met. More specifically, consumers' who had severe or mild mental illness were reasonably happy with service delivery. However, consumers whose mental illness impacted their life considerably, yet their symptoms were not deemed severe enough to access public services, identified significant discrepancies between service provision and recovery facilitation.

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# CHAPTER ONE

## Introduction

### Overview

The purpose of Chapter One is to provide an orientation to the present research. Part One of the introduction investigates the background to the research topic, including how the research topic was selected, an introduction to the town of Cambridge, an overview of the mental health services available in Cambridge, and an explanation of consumer participation. This is followed by an explanation of the researcher's position, gives a description of the present research, and concludes with relevant definitions used within the thesis. Part Two of the introduction presents a review of the literature relating to recovery approach to mental health care, then outlines how the current mental health services in New Zealand and how they have changed over the past few decades, and finally discusses potential barriers to appropriate mental health care for individuals with mental health needs.

### Part One: Thesis Orientation

#### A. Background to research

The researcher is a 24 year old woman who has lived in Cambridge, Waikato, for the past 18 years. Her interest in the provision of mental health services in Cambridge has stemmed from personal experience as a volunteer in a social service non-government organisation (NGO), based in Cambridge. When she first became involved with this NGO she conducted a small-scale research project aimed at identifying providers' perspectives of the efficacy of mental health service delivery to Cambridge people. Key informant interviews were conducted and the findings acknowledged that there were some gaps in service provision, particularly around geographical location of services, often long (six week) waiting times before consumers could access affordable services, and the lack of coordination between services providers which impacted effective referrals.

From this research it became evident that providers had particular opinions on ways in which the efficacy of Cambridge services could be improved. However, it was also necessary to ascertain the consumers' perspectives of service delivery in order to gain a broad understanding of mental health service provision in Cambridge, hence the present research. The present research has been financially supported by Trust Waikato, The University of Waikato, and the Vic Davis Memorial Trust.

### **A word about Cambridge**

The context of this research is the community of Cambridge. Cambridge is a town situated in the Waipa district, which is in the centre of the Waikato region, approximately twenty five kilometers south-east of Hamilton. At the 2006 census, Cambridge had a recorded population of approximately 16,000 people. The Waikato River runs through the centre of Cambridge, separating the town into two distinct areas; Cambridge Township and Leamington. For the purpose of this thesis Cambridge Township and Leamington will be combined under the name 'Cambridge' unless otherwise stated.

Cambridge is branded 'the Town of Trees and Champions', and has been described as a majestic tree lined town with an English-style atmosphere. The 'Champions' element is portrayed through the media as having two features; one is relating the equine industry, both horse racing and breeding, which brings a great deal of fame to Cambridge; and the other incorporates successful sporting achievements of people who live in the town (e.g., a number of Commonwealth and Olympic medalist are based in Cambridge).

While the connection Cambridge has with the equine industry is a prominent feature the benefits of the industry (i.e., employment and financial gain) lie with a small group of people and do not benefit the community as a whole. There is no one dominant employment type in Cambridge, however, the Waipa district and the wider Waikato region have a significant number of dairy farms which provide work opportunities.

The majority of the Cambridge population is New Zealand European, with approximately 84% of Cambridge Township identifying as European (on average

7.5% Maori), and Leamington 80% are European and approximately 13% identify as Maori (Statistics New Zealand, 2006).

### **Cambridge mental health services**

There are a number of agencies providing mental health services or related services within the Cambridge region. These include the Cambridge-Hamilton branch of the Community Mental Health team based in Hamilton at Adult Mental Health Services (AMHS) who travel to Cambridge to visit some clients, the Cambridge Community House, a non-government organisation providing a range of services, and a number of private counseling/psychology practices and/or individuals. Crisis services are provided by the Crisis Assessment Team which operates out of AMHS in Hamilton. Inpatient mental health services are located in Hamilton. There are also support groups such as Alcoholics Anonymous and ALANON (a support group for families and friends of problem drinkers) active in Cambridge. There are a wide range of services available in Hamilton that Cambridge people are able to access, however the majority of them do not provide any Cambridge based service. When discussing services for the people of Cambridge all the services that consumers have accessed, whether in Cambridge or Hamilton, have been considered.

### **Consumer opinions on service delivery**

The experience of people who live with mental illness has traditionally been associated with loss of freedom, choice, decision-making, and with persons becoming passive recipients of expert advice (Schiff, 2004). In the past twenty years, the recovery movement has developed (discussed in the review of the literature) which has led to a shift towards empowering consumers of mental health services by encouraging them to, among other things, get involved in the development, implementation and evaluation of mental health services (Ministry of Health, 1995). In this regard O'Hagan (1995) addressed the question of "what do consumers really want?" by outlining that consumers want: to have the power to order the services they choose and close the services they do not like; the skills and resources to run their own services; and services and opportunities that meet their needs, recognize their competence and suit their values.<sup>i</sup> Essentially the

process of consulting consumers should lead to the development of services which are more responsive to the needs of the service users and an accurate reflection of what consumers need to aid the recovery process.

Practically, this approach should help services to “get it right the first time”, rather than providing services which are either unhelpful or unwanted (Ministry of Health, 1995). Encouraging providers to include consumers in both the planning and day to day running of organisations can be a difficult process, as involving consumers’ conflicts with the traditional professionally governed mental health system that many providers are accustomed to. Genuinely seeking the opinion of service users is one step in consumer participation, which also involves consumers; gaining employment in services, being treated as equals in the workplace, and having completely or partially consumer run services. Research that collaborates with consumers, by either working alongside one another as researchers or by focusing the research topic on consumer experiences and perspectives, can be beneficial by promoting certain aspects of, or making appropriate changes to, current system functioning (Lammers & Happell, 2003).

## **B. Researcher’s position**

This project is influenced by the researchers position as a clinical psychology student, with the understanding that recovery from mental illness is possible and that the services available (professional or peer driven) to consumers who are on the recovery journey can influence their recovery process. The main focus of clinical psychologists, working within the mental health field, is to provide scientifically based assessment and treatment for people who experience mental illness. Even though clinical psychology is the area of her training the researcher is also interested in wider issues surrounding mental illness, such as community wide factors contributing to the development and maintenance of disorders (which incorporates service provision).

It is widely acknowledged by clinical psychologists and others working within the field of mental health, that mental illness does not occur in isolation, rather it impacts and is impacted by social, cultural, spiritual and relational factors. An effective mental health service structure requires that it encompasses these four factors (social, cultural, spiritual and relational) to ensure that it

communicates the importance of a holistic approach to mental health, as described by Mason Durie (1998) in his ‘Te Whare Tapa Wha’ model. This model is significant not only because it looks holistically at health, but also because it approaches mental health from a cultural standpoint, from the position of Māori. This is discussed in more detail below under the heading ‘Recovery approach in a New Zealand context’.

### **C. Definitions**

Traditionally people who experienced mental illness and accessed mental health services were given the title of “Patient” which suggested the direct link between mental health and the medical paradigm. During the period of deinstitutionalization and the shift to a recovery approach, the title of “Consumer/Service User” became more favourable and will be used throughout this document, referring to someone who has previously, or is currently, accessing mental health services. With mental health service use there are many variations (voluntary/involuntary, length of use, type of service, intensity of mental illness); however a service user can be someone who has accessed any type of service for any length of time. Generally service users are those who have accessed specialist mental health services, although some people consider themselves service users and have only accessed services from primary health settings (Mental Health Commission (MHC), 2002)

For the purpose of this thesis, mental health services provided through Community Mental Health teams which function as a branch of Waikato District Health Board (DHB) will be referred to as ‘psychiatric services’. These services are available for people who both experience severe mental illness and are perceived by DHB staff as requiring their services.

Services which are provided either by private organisations, non-government organisations (NGO’s) or primary services, which usually aim to serve people with mild to moderate mental illness, will be referred to as ‘other mental health services’, unless otherwise stated.

Care that people receive from mental health inpatient units within hospital settings will be referred to as inpatient services.

## **Part Two: Review of the Literature**

### **Overview**

The section will begin by providing an explanation of the recovery approach which is an underlying philosophy in the current New Zealand mental health system, as well as internationally (MHC, 1998). Services with a recovery focus are a relatively new development; therefore historical approaches to mental health care will be discussed, including the process of deinstitutionalization. The current structure of mental health care will be outlined followed by an examination of the factors which influence mental health service utilization as identified by previous research.

### **A. Recovery approach**

The concept of recovery is essential to New Zealand's mental health system. New Zealand adopted a recovery approach to mental illness, as stated in the document 'Blueprint for Mental Health Services in New Zealand – How Things Need to Be' (MHC, 1998), which outlines that recovery principles are the foundational values and ideals of service delivery. To understand the importance of, the reasoning behind, and the practical implications of the recovery model the following four questions will be discussed further: 1) what is the recovery approach? 2) where has it come from? 3) what does it look like in practice? and 4) how can the recovery approach be specifically applied to a New Zealand population?

### **What is the recovery approach?**

To understand the recovery approach, one must first grasp an insight into the concept of recovery. Over the past fifty years there has been a shift in understanding of the nature and prognosis of mental illness with a shift away from the traditionally held belief that mental illness was incurable. The concept of recovery has developed, which supports the notion that people with mental illness can recover from mental illness and have the right to shared decision making regarding their treatment to allow them to function in a way that produces healthy, meaningful and independent lives (Deegan, 1996). A prominent figure in the recovery literature, William Anthony, discussed that recovery when related to physical illness and disability is a common concept, however this does not appear to have naturally extended to mental illness (Anthony, 1993). Recovery from

physical illness the individual can, but is not required to, have total symptom relief or a complete restoration of bodily function to be in recovery or to have recovered. There is some confusion regarding the definition of and terminology surrounding recovery, as some people believe that recovery refers to no symptoms while others believe symptoms can be present during the journey of recovery (Davidson & Roe, 2007). Recovery literature suggests that a combination of both definitions is possible, as elimination of the symptoms mental illness is possible, although if symptoms do persist consumers can still have a fulfilling and meaningful life (Davidson & Roe, 2007). People can recover (physically and mentally) by learning new ways of dealing with their changed situation and by finding new meaning in their lives (Anthony, 1993). The concept of recovery from mental illness is described by Anthony (1993, p. 21) as:

*A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life, even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.*

The New Zealand Mental Health Commission defines recovery as the ability to “live well in the presence or absence of one’s mental illness”, and have developed policies to ensure that all mental health services in New Zealand are centered on the principles of recovery (MHC, 1998, p. 1).

Recovery is considered to be a process, which focuses on the journey and does not have a set destination (Jacobsen & Curtis, 2000). This is a particularly important idea as recovery is a unique experience that can be, and generally is, different for each individual; therefore, recovery cannot be defined by a specific set of guidelines (Anthony, 1993). A central feature to the concept of recovery is that consumers develop hope that a positive future is possible as the Mental Health Commission (1998, p. 15) explain that “the loss of hope kills recovery”. The Ministry of Health (2008) identify that recovery is about learning to deal with mental illness, but also includes learning to cope with the losses which are associated with it. Although recovery is an individual experience there are some central values of recovery that clarify the concept of recovery. Young and Ensing, (1999) studied consumer perspectives of recovery and outlined the following common themes of recovery, consumers’ must: accept the illness; develop the

motivation to change; and find a source of hope to change. These three themes are generally associated with the beginning stages of the recovery process, which has been labeled as difficult to initiate, but a necessary turning point (Ochocka, Nelson & Janzen, 2005). Consumers identified that at times it required an outsider (family member or friend) to encourage them to seek help before they would accept their un-wellness and begin this recovery process (Ochocka, Nelson and Janzen (2005). Having a sense of hope that recovery was possible was closely associated with having faith in God or a higher power, which served as a comfort especially during times of crisis (Turner-Crowson & Wallcraft, 2002).

The recovery approach is associated with consumers' taking responsibility, alongside their family and friends, for their own recovery, rather than it being entirely driven by professionals (Jacobsen & Curtis, 2000). Ochocka, Nelson and Janzen (2005) identified that consumers have an increase in self-confidence, self-belief and sense of pride when they experience self-empowerment which involves taking control over their own situation and having the power to make decisions. Having a basic level of functioning is seen as an important stage in recovery, as it enable consumers to live independently, connect with other people and be involved in pleasurable activities. The recovery approach asserts that consumers' overall quality of life is improved through their journey especially as consumers' are encouraged to set goals and strive for goal achievement to promote purpose and meaning in their lives (Turner-Crowson & Wallcraft, 2002).

### **Where has the recovery approach come from?**

Throughout history there have been consumer-survivors who have spoken out against the oppressive nature of psychiatric institutions and argued for the promotion of consumer rights (Schiff, 2004). However, this movement did not gain traction until the 1970s when small groups of past patients, initially based in the United States, rallied together to speak out about the unjust treatment people diagnosed with mental illness receive. This is often referred to as the survivor movement. Many people, who were once service users, explored the restrictive nature of psychiatric institutions which was a contributing factor to deinstitutionalization (which will be more fully discussed later in the section on historical mental health care). One would assume that these groups would have

gained confidence from the changes made around the same time in regards to societal understandings of civil rights, with the black, gay and women liberations gaining momentum and publicity (Schiff, 2004). The groups which developed in opposition to institutional care criticized the system for being so focused on treating symptoms that it ignored the holistic nature of mental illness, and did not teach people how to manage the impact of their illness in their everyday lives (Lapsley, Nikora & Black, 2002).

Following the closure of psychiatric institutions and entering the era of community care, the recovery approach focused on empowering consumers to take control of their own recovery journey's (Young & Ensing, 1999). This involved the development of self-help groups, and promoted that it was the consumer's right to choose the services they wanted to access and when they wanted to access them (Lunt, 2004; Mancini et al., 2005). During this time the expert role that professionals once had was continually challenged, and consumer's experiences became central to understanding illness and how to promote recovery.

Finally, changes began to occur at political and training levels, with the focus of government documents and psychiatric training being on the recovery approach. The recovery approach was first formally documented in New Zealand in 1998 (MHC, 1998) and recovery principles have since become that basis of national mental health documents. If services are operating from a recovery approach there should be common elements between them that are recognizable as recovery focused.

### **What does the recovery approach look like in practice?**

Several elements of recovery oriented services have been outlined in both consumer and organisational literature. Consumer perspectives of effective service providers have shown that consumers want providers who are empathetic, who develop a strong relationship with service users, and those who go the extra mile to support consumers (Borg & Kristiansen, 2004). The Mental Health Commission (2010) described recovery-oriented services as ones that had organisational structures and attitudes which support services users to regain their quality of life, by empowering consumers and by encouraging the involvement of

family in the treatment process. New Zealand has specific services guidelines that have been developed by the Mental Health Commission to provide a means of measuring service performance. These guidelines are as follows, (MHC, 1998, p. 16-18):

- *Recovery happens when mental health services reflect the Treaty of Waitangi: partnership between the Crown and iwi, positive Māori participation, and active protection by the Crown of Māori interests*
- *Recovery happens when mental health services enable people to find the right help at the right time, for as long as they need it*
- *Recovery happens when mental health services give people the best help available, whoever they are and wherever they are*
- *Recovery happens when mental health services provide for people in the context of their lives, not just their illness*
- *Recovery happens when mental health services protect service users' rights and treat them with respect and equality*
- *Recovery happens when mental health services are staffed by people who are compassionate and competent to assist people in their recovery*
- *Recovery happens when mental health services enable people with mental illness to take on competent roles*
- *Recovery happens when mental health services can prevent people from using them unnecessarily or from staying with them for too long*
- *Recovery happens when mental health services can look outward and assist people to find and use other community services, supports and resources*

While the above are some of the guidelines outlined by the Mental Health Commission for assessing the effectiveness of mental health services providers

there are other aspects which are important for the facilitation of recovery. An important theme in recovery literature is that consumers can recover from mental illness without the intervention of professionals. Consumers hold the key to recovery, and can choose to access professional support or to find other means to recover, such as self-help groups, family or friends (Anthony, 1993).

Recovery is a deeply human experience; therefore it is of no surprise that a key part of recovery and a recovery oriented service is having someone to walk alongside the consumer during the recovery journey, as an encourager and supporter (Deegan, 2003). Since personal relationships and interaction with others is important in the recovery journey, Anthony (1993) suggested that service providers should have increased training in developing an empathetic persona, to ensure that their interpersonal skills are facilitative of recovery. Another factor of recovery which has been discussed is the discovery and development of purpose (e.g., a hobby or a new occupational target). Mental health services, in pursuit of encouraging service users to develop purpose, need to treat service users holistically to ensure that they can gain control over a range of aspects of their lives. Holistic mental health care recognizes that mental illness is not only a result of biological determinants, but also incorporates well being in the areas of spirituality, physical health and personal relationships (Broom, Nicholls & Deed, 2010; Durie, 1998). Models such as Te Whare Tapa Wha (Durie, 1998), which is discussed below, incorporate holistic approaches that address a range of features impacting overall mental well-being. When looking at mental health services from a holistic viewpoint, it is important to note that one service is not expected to provide for all of the needs of the individual consumer, however, there is an expectation that service providers will have an understanding of the range of factors impacting mental illness. The Mental Health Commission identified core features of recovery oriented service providers, some of which explain that service providers must enable service users to access appropriate community services, which requires the service provider to have apt knowledge of, and the ability to link consumers up with, the services available within the community (O'Hagan, 2001).

There are two features which will be discussed in more detail as they are significant features of recovery oriented service provision. These are consumer participation and services run by service users.

### ***Consumer Participation***

A significant factor of the recovery approach is that professionals need to accept the knowledge and wisdom service users have gained during their journey with mental illness. Professionals' acceptance of this knowledge and wisdom is evident when consumers are encouraged to be actively participating in services already developed and/or setting up new services if required (MHC, 2002). A central theme is the importance of trust, between service users and professionals. Service users need to know that psychiatric services can be trusted, as collaborating between the client and service providers is effective when on the journey of recovery. The Blueprint states that "recovery happens when mental health services protect service users' rights and treat them with respect and equality" and "recovery happens when mental health services enable people with mental illness to take on competent roles" (MHC, 1998, p. 17). Consumer participation is an element of recovery, therefore for organisations to be working from a recovery approach there are expectations of service-user participation in decision making.

There are three main categories that discuss different levels of consumer participation which have been set out by the Mental Health Commission (2002). The first category, which has been the most common approach in traditional mental health care, describes an organisation where service users are not included in decision-making or program planning. The result of this is an organisation which may be abusive and neglectful, as they may not be fully informed of consumer needs and may assert total control over consumers. The second is when consumers have limited involvement in decision-making processes, which is referred to as paternalism (where the professional behaves as if they know best) and tokenism (service users are consulted but no value is placed on their contribution). The third category is when decisions are made jointly which results in partnership between consumer and provider. This is an important factor as consumers and professionals have valuable knowledge and expertise to offer one another.

However, mental health services have traditionally discouraged consumer participation; therefore organisations need to take steps to actively promote service user involvement. Service users have identified that to promote participation they themselves need training, preparation and adequate resources.

This includes information being presented to service users in a language that they can understand, advice and training on meeting protocols, clear guidelines of their roles and responsibilities and appropriate opportunities to participate in meetings such as access to appropriate clothing, transport, childcare and financial remuneration (MHC, 2002). Service users also need an environment which builds self-confidence and trust, reduces stigma and discrimination, and is inclusive in order to be comfortable to participate (MHC, 2002).

### ***Service-user Run Services***

Service users' by definition have personal experience in accessing mental health services, and as a result of this they can make considerable contributions to mental health services (Doughty & Tse, 2005). Service providers who are also service users are perceived as more sensitive to client needs, and there is a promotion of hope and an aspect of positive role-modeling which occurs (Walsh, 1996). Self-help groups, which are run by service users and can include professional input, have been correlated with a reduction in psychiatric symptoms, hospitalization and medication dependence (Dadich, 2009). Self help/support groups have the following components: shared experience of mental illness which develops into unique insight; the group determines their own activities; the most effective way to be helped is to give help; support is reciprocal; the focus is not on pathology but rather on inner strength; support is free and not financially driven; support is provided by social interaction; the group is not dependent on professional help, rather they can manage by themselves with the wisdom gained from experience (Dadich, 2009).

Lawn, Smith and Hunter (2008) studied the use of peer support groups to reduce re-admission to, and to promote early admission from, hospital, finding that people who experience mental illness (and are living well) can provide valuable support for other people with mental illness. There was concern that peer support groups would be used inappropriately, for example group members calling peers late at night, however this did not occur (Lawn et al., 2008). Curtis (2003) identified that support groups can serve to encourage behaviour which maintains mental illness, such as self-harming. There is a danger in promoting support group participation if the support group environment has potential to exacerbate symptoms. An essential element of the development of the support groups was having a manager who could liaise between service users and service

providers and who could provide support and advocacy for group members (Lawn et al., 2008). It is important to remember that many of these factors are influenced by each other and cannot be considered in isolation; however they will be discussed below in more detail.

### **Recovery approach in a New Zealand context**

New Zealand has specific factors which are important to consider when discussing recovery, one of which is the culturally appropriateness of services. Based on the history of New Zealand and the signing of the Treaty of Waitangi, New Zealand's foundational document, health is considered to be *taonga* which translates to mean a treasure (Ministry of Health, 2002). Based on this concept the mental health system, like all health services in New Zealand, must be focused on providing services which are sensitive to Maori (Ministry of Health, 1997). The Treaty of Waitangi has a number of key principles (which cannot all be discussed due to the scope of this research), however well-known ones which relate to mental health care are; partnership (with Maori and Pakeha both participating equally in all aspects of mental health service delivery), participation (emphasizes Maori involvement in all levels of health planning and delivery), active protection (where the crown must be proactive in health promotion and prevention to ensure that Maori and non-Maori can enjoy the same level of health) (Ministry of Health, 2002; Durie, 2001). Addressing issues surrounding the Treaty of Waitangi are important as there are clear discrepancies between Maori and non-Maori in mental health results. Based on the findings of Te Rau Hinengaro, the New Zealand Mental Health Survey, Maori have higher rates of mental illness compared to non-Maori, and amongst Maori those who are young (aged 16-24) have the highest rate of mental illness (Oakley Browne, Wells & Scott, 2006). Baxter (2008) identified that access to primary care for Maori was a barrier, as Maori were 1.6 times more likely than non-Maori to report not seeing a GP when required.

As described earlier key elements of the recovery approach are, valuing consumer knowledge and choice, empowering consumers, and engendering hope. In order for services in New Zealand to provide services which are in line with recovery principles, cultural appropriateness is an essential element which must be considered. Services which are culturally appropriate respect and promote

Maori conceptualizations of mental illness, and embrace these models when developing assessment and treatment methods. One holistic Maori model of mental health is Te Whare Tapa Wha, which uses the analogy of a four-sided house to describe the need for wellbeing in all of the following areas; physical body (tinana), the mind (hinengaro), the family and community (whanau) and the spirit (wairua) (Durie, 1998). Durie (1999) identified ways in which to improve Maori mental health, one of which was to increase the quality and quantity of Maori mental health services so that Maori could more easily access culturally appropriate services and benefit from them. More specifically Durie (1999) suggests that a greater emphasis on primary care reduces reliance on specialist services and allows more involvement from family and the community will be of overall benefit for Maori. Durie (1999) also recommends that further development of Maori health services which can incorporate mental health care in their service provision. A specific focus of services aimed at meeting the needs of Maori youth, aged 15-29 was recommended as this age group is most at risk of developing mental illness (Oakley Browne et al., 2006). Durie (1999) concludes by identifying the importance of having services which are centered on Maori frameworks and understandings of health and ill-health, alongside increasing the number of Maori health professionals, who are grossly underrepresented in mental health fields.

While the focus of the present research is not broad enough to elaborate further on the concepts of cultural mental wellbeing, it is important to ensure that services are culturally appropriate in order to ensure that they are working within a recovery ethos. The Mental Health Services Research Consortium (1994, p. 60) identified that appropriate services would have: a kaupapa Maori focus; whanau and community involvement, a holistic approach; strong connections with other services; and Maori health workers involved at all levels.

## **Summary**

Many philosophical changes have taken place in relation to the basic understanding of mental illness and the ability of the mentally ill to recover. Traditional views were that mental illness was incurable, and that the mentally ill were dangerous, however the notion of recovery has developed which supports the ability of people with mental illness to live healthy, meaningful and

independent lives regardless of symptom amelioration. Recovery values are foundational to the New Zealand Mental Health System and are acknowledged in national documents as the basis effective mental health care. Key tenets of the recovery approach include the development of hope, personal responsibility, developing purpose and the promotion of consumer involvement. Two significant concepts of recovery oriented service delivery are consumer participation and the development of service-user run services. In order to promote recovery there are issues specific to New Zealand such as, an acceptance of the importance of including Maori models of mental health and the involvement of Maori at all levels of service provision. In order for services to be providing the best possible care for consumers they are required to operate from a recovery approach, in both daily functioning and underlying organisational principles.

## **B. Health Care System in New Zealand**

### **Historical Context**

Following the pattern of many other countries around the globe, New Zealand's mental health system underwent a significant restructure, involving a move away from institutional care and towards a more community based approach. The traditional approach of mental health care was institutional care where people who were experiencing mental illness were admitted into lunatic asylums (later renamed psychiatric hospitals) (Joseph & Kearns, 1996). With parallels to the prison system, psychiatric patients were seen as a threat to public safety and became a state responsibility (Gauld, 2009). New Zealand's psychiatric hospital population peaked in 1944, with 8261 residents in total, with the ratio of five to every thousand New Zealanders in inpatient psychiatric care (Joseph & Kearns, 1996). Shortly after this time, changes began to occur internationally which led to a dramatic shift in the emphasis of mental health care, moving away from institutions towards community care, a process known as deinstitutionalization. The international changes of the 1960s and 1970s occurred slowly in New Zealand with significant changes occurring in the 1980s.

Deinstitutionalization is the moving of patients from psychiatric hospitals to community based care programs for the majority of their treatment, with the aim of only admitting them to inpatient care if they are in a crisis or are acutely unwell (Deane, Huziff & Beaumont, 1995). Driving forces behind this change of structure were a combination of the following: the introduction of antipsychotic medications, an increased awareness of human rights among people with mental illness and their families, the development of psychosocial and rehabilitation services and the financial cost of psychiatric inpatient care and other mental health services (Chamberlain, Rapp, Ridgway, Lee & Boezio, 1999). The closure of psychiatric hospitals was significantly impacted by the changing opinions of both medical professionals and the general public, such as a decrease in the traditional belief that “people with mental illness are dangerous and need to be locked away” and increased understanding that “people with mental illness are more than their illness” and “psychiatric hospitals may cause more harm than good” (Dew & Kirkman, 2002). These changes in opinion were largely due to the advance of the consumer movement which emphasized the right for mental health consumers’ to live as normal lives as possible, free from the isolation and stigmatization that institutions created (Brunton, 2001). Following increased discussions about consumer rights, it became apparent that mental institutions were not meeting the needs of people with psychiatric disability and that the community setting may be more effective for this population (Young & Ensing, 1999).

There is substantial literature discussing the process and effectiveness of deinstitutionalization. For example, Gerrand (2005) provided an overview of the mental health reforms in Victoria, Australia, and concluded that effective deinstitutionalization involves: ensuring community based services are developed and functioning before hospitals are closed; giving priority to people with severe mental illness; providing residential and inpatient care as well as community services; ensuring services are easily accessible (e.g., practical physical location and the time range that services are available); and ensuring that there is access to housing, social networks and employment. The closing down of psychiatric institutions in New Zealand occurred with some criticism as suggestions were made that this country followed suit of the United States and England but did not have the community based structures to support the influx of ex-patients (Dew & Kirkman, 2002). As a result of speedy hospital closure the government did not have policies prepared for the new mental health structure (Hall, 1988). This

started community-based mental health care off on a back foot and has resulted in chronic underfunding ever since (Hall, 1988). Dew and Kirkman (2002) raise the question of whether deinstitutionalization occurred in an attempt to provide more humane and empowering services in community settings for people with mental illness, or whether it was a cost-cutting strategy aimed at providing similar care at less expense.

### **Current Service Delivery**

Following the closure of psychiatric hospitals and the development of community based care; the New Zealand health system underwent significant restructuring before reaching the current system. A summary of the health reforms will be discussed in the following section, followed by an overview of the current mental health system.

#### ***Summary of the health reforms***

The election of the fourth Labour government in 1984 saw the beginning of major changes in the health system. Traditional health care in New Zealand was organized under a Nationalised System with 30 hospital boards that provided subsidized GP visits and free hospital care funded by the Department of Health (Morgan & Simmons, 2009). From 1975 onwards a gradual change began which involved the 30 hospital boards being changed to 14 Area Health Boards (AHB) in an effort to extend the focus from simply running the hospital to the planning of prevention and primary care. Like many of the reforms Labour implemented in the public arena they focused on introducing idealized corporate approaches (Deane, Huziff & Beaumont, 1995). The health system was included in the corporatization and was made more 'business-like' by focusing on corporate management roles and by measuring AHB effectiveness in terms of goal attainment (Morgan & Simmons, 2009).

Another significant reform occurred in 1993, which was implemented by the National government and was concerned with developing a provider/purchaser split. The plan was to cultivate a competitive culture between providers to improve efficiency by creating four Regional Health Authorities (RHA) which were in charge of purchasing the best treatment from whatever service was best able to provide it. The 14 AHBs were changed to 23 Crown Health Enterprises

(CHE) which competed against each other to gain funding from the RHA. This increased competition between public, private and voluntary organisations whittled away the cooperation between different providers and the sharing of ideas and resources ceased (Morgan & Simmons, 2009).

When Labour was elected in again in 2000 another health reform occurred, this time abolishing the CHEs and RHAs (which had changed to Health Funding Authority at the end of Nationals term) and replaced them with 21 District Health Boards (DHB) and the development of Primary Health Organisations (PHO) (Morgan & Simmons, 2009). The development of PHOs was intended to have a noteworthy impact on preventing disease, by encouraging people to attend GPs rather than waiting for conditions to worsen. However, as there is a cost associated with seeing a General Practitioner (GP), people still chose to access hospital emergency departments for complaints that could have been prevented from an earlier GP visit, as the hospital was a free service.

### ***Structure of mental health care***

It is estimated that 5% of New Zealanders experience severe mental illness and 17% have mild to moderate mental health problems (Oakley Browne et al., 2006). The New Zealand public health system is designed to provide for people with severe mental illness (MHC, 2005), which leaves a significant amount of people with mild to moderate mental health problems dependent on primary health settings or left to their own devices. The MHC identified that there is a need to provide services for people who do not fall under the 3% severity criteria in order to prevent mental illness, with a focus on services for children and adolescents (MHC, 1998b).

### **District Health Boards**

At present the District Health Board (DHB) system which has been in effect since the year 2000 is still in place. In terms of mental health services, the DHB system provides secondary care for the top 3% of people with severe mental illness (MHC, 1998), for people with drug and alcohol addiction, and for those who require inpatient care.

The DHB is responsible for caring for people who are acutely unwell or are experiencing mental health crises by focusing on “rapid response, assessment, stabilization, ensuring safety, and reduction of the risk of harm” (MHC, 1998, p.

31). They do this through the use of crisis services, which provide services for all age groups at any time during the day, seven days a week. Consumers access this service by calling a free-phone number and explaining their situation to the service provider. The action which takes place following the phone call depends on the severity of the caller, but can include respite (community based 'time out' for consumers), or inpatient care which is provided within the hospital setting.

Inpatient care is provided for people who are either acutely unwell, experiencing a crisis in which they are unsafe to be within the community, or in need of close supervision to manage medication regimes (MHC, 1998). There is commonly a high turnover of staff in inpatient wards, as the work is demanding (patients are high-risk and require intense support) and there is limited prestige in working within inpatient services with staff relating their role more to custodians than therapists (Sensky & Scott, 1995). A study which assessed service users' perspectives of emergency services identified that the minority of participants responded positively about inpatient care, as most responses were in regards to the noise, lack of privacy and institutional atmosphere, all of which were hindrances to recovery (Sayce, Christie, Slade & Cobb, 1995). In this study most participants did not see inpatient units as safe places, they disliked being disconnected from the community and there were both positive and negative remarks towards the efficacy of inpatient care (Sayce et al., 1995). Participants also identified admission to inpatient care as problematic when the police were involved, as being detained in police custody until they were moved to hospital was a negative experience for consumers (Sayce et al., 1995).

### **Primary Health Care**

Primary health care aims to reduce some of the barriers of access to care and is based on the Primary Health Care Strategy which was released in 2001 (King, 2001). Primary care relates to professional health care which is received in the community usually from the GP, primary care nurse or other health professional (Jatrana & Crampton, 2009). Primary mental health care is a term that refers to assessing, treating and when required ongoing management of people with mental health problems/addiction in the primary care setting (Dowell, Garrett, Collings, McBain, McKinlay & Stanley, 2009). Primary health services, in contrast to hospital services, are not necessarily free for patients, which can produce barriers to accessing care (Adam, 2003).

In the attempt to reduce the barriers to accessing primary health, Primary Health Organisations (PHOs) were developed, with the role of providing DHB funding for primary care services. PHO's were set up and funded by the Government based on the amount of patients that are enrolled in a PHO service. While PHOs provide funding for primary health services, these services (such as GP's) also receive funds from patients paying a reduced service fee each time they attend an appointment, however the aim is to keep these copayments to a minimum. PHOs were developed to detect cases for treatment, improve access to care, integrate and liaise between services, and use specialist services for the enrolled population (Dowell et al., 2009, p. 2). Not all primary care services are involved with PHOs, as some professionals remain practicing independently of DHB funding.

GP's are physicians who work in primary health care settings and it is estimated that 50% to 70% of mental health conditions are managed exclusively by GP's (Dowell et al., 2009), and they are responsible for the majority of referrals to secondary mental health services (MHC, 2008). International studies continue to report that there is a lack of recognition of mental disorders from GPs, which has resulted in suggestions that GPs require further training and should use specific screening measures to detect mental illness (e.g., Pignone, Gaynes and Rushton, 2002). Screening measures are a beneficial approach for identifying mental illness, however unless they are administered to every client in primary care settings the administration of screening tools are dependent on professional discretion (Herman, 2001). It is likely that professionals will screen for mental illness among those who have a high risk of developing mental health problems, such as people with a history of mental illness or those who have experienced bereavement (Herman, 2001). However, there is still ambiguity as to the risk factors for developing mental illness, resulting in potentially overlooking the use of a screening measure for an individual who does not present as high risk but may have significant mental health concerns.

Primary health care is often the first port of call for people who have mental health concerns and it is focused on promotion, prevention, early intervention and ongoing treatment for mental health (Dowell et al., 2009, p. 1). Primary services are important for people who require specialist mental health services, as there is a general progression of medical care, accessed via GPs, leading to specialist care for those who require such care. In a sense primary

services are a doorway to specialist services and consequently require accurate diagnosis of mental health conditions in order to refer at appropriate times (Dowell et al., 2009). Early access to services, followed by appropriate treatment, is important in the prevention of mental illness and the reduction of the effects of mental illness and addiction (Mental Health Commission, 2010). In order for early detection to occur and be beneficial, there must be a connection between the different service providers. These connections are between different primary care providers to ensure that there is a full understanding of all the factors impacting the consumer's situation, as well as between primary and secondary services if there is a need for referring on for further assessment and/or treatment (Herman, 2001).

The cost associated with primary mental health care has been discussed as an issue which can affect access for some people. New Zealand research has found that of the people who attend general practice services, up to 40% delay the consultation as a result of the cost (Dixon, Watt, Thompson, Lewis, Crane & Burgess, 1994). It is important to note that mental health concerns are complex and take time to deal with; therefore repeated consultations, which involves repeated attendance fees, are often required (Dowell et al., 2009). The Mental Health Services Research Consortium (1994) identified that there may be a perverse incentive for consumers to defer seeking treatment from primary services as they incur a financial cost, and instead attend secondary services (public mental health services or inpatient care) which are free of charge.

GP's are major contributors to primary health care, although there are other organisations which function to make up the primary sector. Non-government organisations (NGO's) are vital mental health services as they provide a wide range of services which meet the needs of diverse New Zealand communities. NGOs receive approximately 30% what the Government spends on mental health and addiction and are diverse in type and structure (MHC, 2010). Some NGO's are small consumer-run drop in centers, functioning on a minimal budget, while others are large in size and employ a substantial number of staff (Ministry of Health, 2009). The development of NGO's and their ability to compete for contracts from funders has lead to the diversification of service provision (Walmisely, 2003).

## **Politics of Service Provision**

Deinstitutionalization not only served the purpose of caring for those with mental illness in a more appropriate and humane manner, but it also provided a means of cutting the high costs of running psychiatric institutions (Chamberlain et al., 1999). The reducing of government expenses has appeared to be an important driving factor behind the health reforms in New Zealand. These reforms, and closure of psychiatric institutions, occurred at a similar time as the corporatization of many other sectors, and was reflective of the emerging neoliberal philosophies. Neo-liberal values emphasize minimal government involvement, and focus on efficiency, accountability and financial management (Kearns & Joseph, 2000). The underlying beliefs of the market approach to health is that competition for funding will improve the quality of care provided at the same time as reducing the cost (Cummings & Mays, 2002). Neo-liberalism was an underlying philosophy of the changes which occurred in the New Zealand health system, focusing on economic advancement and minimized involvement in health by the Government. Critiques of neo-liberal models suggest that these approaches produce compartmentalized service delivery especially evident in the health sector (Davis & Ashton, 2001).

Changing mental health care structure radically changed the delivery of services as a result of the development of a purchaser/provider division, which separated the funding and the provision of mental health services (Barnett & Barnett, 1997). This division cultivated a competitive environment in which services were competing with one another for the same funding and/or contracts (Kearns & Joseph, 2000). The development of competition is suggested to provide three main benefits: it forces providers to deliver services which consumers want and at a cost which is appropriate; it forces services to find the most efficient way to deliver services; and it provides a reason for services to be innovative in their delivery to make them both identifiable and attractive to consumers (Dranove, 1993). There are often strings attached to competition, such as when mental health services gain contracts to provide funding, they are bound by the specifics of the agreement as to what services they are able to provide (Dew & Kirkman, 2002). If consumers' do not meet the criteria for the contracts which service providers hold there is a possibility that they will be declined access to the service and end up receiving minimal, if any, support (Dew & Kirkman,

2002). The Mental Health Services Research Consortium (1994) highlighted the negative effect repeated assessments can have on consumers, which is often associated with service providers referring consumers on to different services, as a result of their narrow service scope. The Consortium (1994) also identified that consumers may experience pressure to selectively describe or exaggerate their symptoms in order to meet the appropriate entry criteria. While there are some critiques of contracting, the development of this funding method has increased variability of services, allowing organisations, which did not previously provide services, to gain contracts and provide care in their own style (for example, ‘for Maori, by Maori’ services) (Ashton, Cumming & McLean, 2004).

### **Summary**

New Zealand’s health system has undergone significant changes in the way that mental health services are provided. Following international trends the process of deinstitutionalization began to occur in the 1980’s and resulted in the closure of psychiatric hospitals. Care for mentally ill persons was transferred into the community as a more humane and cost effective approach. After repeated structural changes, the current system developed, with DHB’s as the public provider of health services, and with a significant emphasis on primary care, being provided via PHO’s, other primary care services and NGO’s. Primary care is focused on the early detection and subsequently the prevention of mental illness. Changes in the health system have been influenced by neo-liberal and free market policies, which have accentuated the importance of services provided in a financial efficient manner, with minimal government involvement. These changes have resulted in organisations competing for health funding, and focusing services on contract criteria in order to secure financial support.

### **C. Factors influencing recovery**

Mental health care in New Zealand and internationally has been criticized from many angles over the past fifty years. Institutional care was seen as inhumane and removed patient’s freedom and individuality. The process of deinstitutionalization transferred the care of mentally ill individuals into a community setting, which was also criticized, as there appeared to be a lack of

structure and resources (Gauld, 2003). In reviewing the literature on mental health services, it appears that although community based care is seen as optimum for people with mental health concerns there are some common barriers to effective care and therefore recovery. The following sections will discuss individual, societal and organisational factors which have been identified as barriers in previous literature both in New Zealand and internationally.

### **Individual factors**

There are individual factors which play a significant role in the provision of mental health services, which need to be considered when assessing the overall effectiveness of service delivery and individuals' ability to progress towards recovery. Perese (2007) identified that in order to move people with mental illness into the process of recovery, it is essential to address their basic needs first such as housing, transportation, health care, finances, personal safety, social connectedness, employment, a sense of self identity and purpose. The Ministry of Health (1997) identified similar areas of need, however concluded that the provision of these services are not necessarily the responsibility of the health system although health professionals must make appropriate referrals to other agencies to address these issues for consumers. While there is an expectation that other community services will provide services

### ***Social support***

Having a connection with other people, who have experienced mental illness or not, is an important aspect of recovery as it develops hope that a purposeful and satisfying life is achievable (Mancini et al., 2005). Elements of recovery as previously discussed include the development of relationships, and involvement in communities as factors which facilitate recovery. Mancini et al. (2005) identified that people with mental health concerns find that social relationships with family/friends, professionals, and other service users are all effective in promoting recovery. People who experience mental illness, especially severe mental illness, are frequently missing relationships with other people (Perese, 2007), and therefore their mental health and recovery journey is impacted negatively. People with mental illness have a tendency to participate in activities that are solitary, some of which can be linked to the financial costs often associated with socializing (Perese, 2007). Loneliness and isolation have been found to be a

common problem among people with mental illness as they frequently have difficulty forging strong interpersonal relationships (Borge, Martinsen & Ruud, 1999). In a study by Whitley, Harris, Fallot and Wolfson Berley (2008) it was found that when people are involved in recovery communities, such as support groups or other social networks there is an increase in social skills, and coping strategies which result in a healthy mental state.

### ***Sense of purpose***

Participating in meaningful activities was found by Mancini, Hardiman and Lawson, (2005) as a significant factor promoting recovery as it gave consumers' an opportunity to learn new information about themselves and others. Dale Walsh (1996), a consumer-survivor who is active in teaching recovery principles to service providers, identified the development of new meaning and new purpose as essential for assisting recovery. When consumers gained a new purpose for their lives they described the process as developing hope, as it provided something to strive for and to aim for which was outside of their illness (Schiff, 2004). Being involved in meaningful activities can include employment, social interaction and developing new skills. Meaningful activities provide daily routines, a sense of structure, and greater opportunities for consumers to experience positive outcomes such as gaining confidence, having a sense of purpose and contributing to society (Mancini et al., 2005). As this is an important factor in facilitating recovery, the absence of purposeful activities acts as a barrier to overcoming mental illness. There are societal aspects to consumers' experiencing a loss of purpose, as discrimination towards people with mental illness can reduce the opportunity for employment, social interaction and meaningful activities (Walsh, 1996). Associated with increasing a sense of purpose which is frequently portrayed in the literature is consumers' experiences of finding meaning by becoming familiar with spirituality (Turner-Crowson & Wallcraft, 2002). Consumers report that having something outside of themselves to depend upon created an inner strength and motivation that was deeper than they had previously experienced (Ochocka, Nelson & Janzen, 2005).

### ***Resources***

A lack of essential resources can have a negative effect on consumers' mental health and their journey of recovery. The main resource issues discussed in the literature were financial, incorporating unemployment, and housing.

## Financial

Employment provides the individual with financial resources but the benefits of employment are more than just financial gain, they also involve access to social interaction, both of which can significantly impact on psychological well being. Unemployment increases the risk of mental illness as well as physical health problems and suicide rates (Collings & Ellis, 1997). Employment provides the individual with financial resources, which can be essential in recovery. Social support, as described earlier, is often dependent on having spare money to participate in entertainment activities. Access to a range of services is impacted by financial standing, as public services can have long waiting lists which can be avoided by individuals who are able to pay to attend a private service.

Wilton (2004) explains that people who have insufficient money, goods or means to support themselves are unable to meet their basic needs and miss opportunities to participate in educational, leisure and social activities. There have been consistent findings that identify a correlation between low socioeconomic status and a poorer standard of mental health (Costello, Compton, Keeler & Angold, 2003). Jatrana and Crampton (2009) found in their study of access to primary care in New Zealand that people frequently deferred accessing primary care services as a result of the cost per visit.

## Housing

Finances play a significant role in daily living arrangements, such as suitable housing and transportation to access services, and a lack of these are closely associated to mental illness. As Freeman, Malone and Hunt (2004) identified in an Australian study, appropriate accommodation is an essential requirement for the successful treatment of people with mental illness. New Zealand findings indicate that there is a relationship between housing and mental illness, as people who experience mental illness are more likely to experience inadequate housing (Barwick, 1992).

## ***Medication***

The introduction of effective medications for people with mental illness was an instrumental factor in the process of deinstitutionalization, as medication often allows consumers to better manage their illness (Chamberlain et al., 1999). Consumers have also reported that medication is an essential element to

facilitating and maintaining their progress of recovery, however the side effects of medication have been identified as a significant barrier to recovery (Mancini et al., 2005). Side effects can be physical (e.g., fatigue or weight fluctuations), emotional and/or cognitive, with some consumers finding that they make more progress when medication is ceased (Mancini et al., 2005).

## **Societal factors**

### ***Attitudes***

The development of discrimination originates from stereotypes that people hold regarding people with mental illness, and these stereotypes are the result of interpretations people make of observable behaviours (Corrigan & Kleinlein, 2005). For example, stereotypes, and therefore discrimination, may result from people witnessing psychiatric symptoms (e.g., talking to self aloud), social skills deficits (e.g., poor eye contact, body language), peculiarities in appearance (e.g., personal hygiene) and from labeling people (e.g., a diagnosis or association with mental health professionals can result in labeling) (Corrigan, 2000; Corrigan & Kleinlein, 2005). Stereotypes common for people with mental illness are that they are dangerous, irresponsible, unpredictable and unlikely to recover (Watson & Corrigan, 2005). Corrigan and Kleinlein (2005) conclude that people with mental illness suffer greatly from stigma, which comes from both public and personal attitudes.

### **Public**

New Zealand research has identified that the general public have a consistently negative perception of people who experience mental illness (Dew & Kirkman, 2002). A study of public attitudes in New Zealand concluded that the public have minimal knowledge about mental illness and are more likely to attribute violent and unpredictable character traits to people who experience mental illness (Patten, 1992). Public attitudes can significantly impact upon an individual's acceptance of their mental health concerns which can delay self-referrals and access to support (Ministry of Health, 1996). Negative public attitudes towards the

mentally ill can result in a loss of opportunities to seek employment and adequate housing (Corrigan & Kleinlein, 2005).

Public attitudes of mental illness and of consumers are largely dependent on negative stereotypes of people with mental illness, which is often portrayed via the media (Dew & Kirkman, 2002). Media portrayals of people with mental illness are generally sensationalized, for example, people who are mentally ill commit crimes their mental illness is often emphasized in the media (Mullen, 1991). The Mental Health Commission (2000) identified that it is more common to have articles released in media arenas that are negative, rather than positive, towards people with mental illness. Using the media can be an effective tool to provide a means for challenging negative stereotypes (particularly surrounding consumer dangerousness, responsibility for their illness, incompetence and beliefs that consumers are irresponsible (Watson & Corrigan, 2005) and for generally educating the public about mental illness (Jacobsen & Curtis, 2000). Negative public attitudes towards mental illness can reduce the rate of consumers' accessing mental health services, as can individual attitudes towards illness (Sareen, Jagedo, Cox, Clara, ten Have, Belik, de Graaf & Stein, 2007).

### Personal

People who experience mental illness are often aware of the public attitudes and stereotypes surrounding the illness, which can result in lowered self-esteem if consumers accept the negative beliefs and stereotypes (Corrigan & Kleinlein, 2005). Stigma as described by Peterson and Barnes (2009) includes people with mental illness thinking something which will not change is wrong with them, and that as a result of this difference they are less worthy than other people without the same level of entitlement. Many of these beliefs are fed by negative experiences with service providers, through loss of employment as a result of mental illness, through stereotypes and public attitudes, and traditional societal beliefs that mental illness is incurable and is the fault of the person experiencing it (Peterson & Barnes, 2009). Walsh (1996) explains that experiencing stigma creates barriers to recovery, which removes hope for the future.

Other personal attitudes also impact individuals with mental illness, especially by affecting their patterns of accessing help from service providers. Attitudinal factors, such as consumers' attitudes towards mental illness and its

treatment, have been found to be instrumental in delaying help-seeking (Thompson, Hunt & Issakidis, 2004). Common consumer responses that United States-based researchers Sareen et al. (2007, p. 361-362) identified were consumers' desire to "solve the problem on my own" and "I thought that the problem would get better by itself". Thompson et al. (2004) agreed from an Australian study that attitudinal factors were the most significant barrier to help seeking, and that consumers reported that help seeking on average was delayed for 8 years from the initial onset of symptoms. Another Australian study assessed factors influencing help-seeking in rural townships, and identified that the most common reason was feeling embarrassed for needing to seek assistance for mental health complaints, which was impacted by stigma and discrimination surrounding mental illness (Wrigley, Jackson, Judd & Komiti, 2005).

### Challenging attitudes

Peterson and Barnes (2009, p. 26-27) describe certain steps that are important in challenging stigma which will be briefly outlined:

- Celebrate the differences between people
- Have recovery-oriented service providers
- Develop support groups to enable consumers to be leaders, and to promote positive role models
- Empower consumers as this improves self esteem, and affirm their human rights and ability to contribute
- Challenge attitudes and behaviours of discrimination whenever possible.

### ***Rural society***

Although Cambridge is considered a semi-urban township, there are elements of the rural health literature which are particularly relevant for Cambridge people. A study which evaluated mental health services in Australia identified that people who do not live within cities are disadvantaged by the lack of appropriate specialist mental health services within a close proximity (Hickie & Groom, 2002). A New Zealand perspective identified that access to health care in rural settings can be problematic for people who have limited resources (finances or transport), who are elderly or who belong to marginalized groups (Panelli, Gallagher & Kearns, 2006). Panelli et al. (2006) identified that the distance rural

people often need to travel can be a disadvantage to them, as it impacts on their time, flexibility to leave work, and their ability to meet the costs of travelling.

### **Organisational factors**

As explained earlier consumers are able to recover without the intervention of mental health services; however, if consumers choose to use services there are a number of organisational issues which can impact the recovery process.

Shepherd, Boardman and Slade (2008) outlined challenges which can face organisations when attempting to implement a recovery framework, concluding that the most difficult challenge is to translate the recovery ideas into concrete changes in everyday functioning.

### ***Access***

Access to mental health services are impacted by a variety of factors, many of which have been discussed earlier under different headings (such as geographical factors in rural areas, and financial factors). The availability, suitability, eligibility, and knowledge of mental illness and what services are available all impact access to mental health services.

The availability of services is a term which encompasses the types of services a consumer is able to access in a particular area as well as the ease in which they gain access to those services. Availability is initially determined by the services which are developed in an area, or which a consumer has appropriate transport to access (Panelli et al., 2006). The hours services are open can also play a role in the accessibility of services. The types of services which are available are affected by the funding arrangements of the organisation. For example, the introduction of contracts between funding organisations and service providers limits providers as to the services they can offer, as these services must meet the specifications of their funding contracts (Dew & Kirkman, 2002).

To promote equal access to services for all individuals, services must be appropriate to a range of different cultures, genders, and ages. The need for suitable services plays an important role in the overall accessibility of services, as services should meet the needs of consumers.

Similarly to issues surrounding availability, the function of funding plays a role in the access of services based on eligibility. Services are awarded funding for a specific group of people, and organisations are not able to work with people outside their contractual boundaries. As a result, consumers can fail to meet the organisations criteria, and therefore not receive any help at all (Dew & Kirkman, 2002). Eligibility to access psychiatric services is limited by the entrance criteria of the top 3% of cases of severe mental illness. As discussed under the health system heading, this leaves people with mild or moderate mental illness depending on other services to meet their mental health needs. Sayce et al., (1995) found that consumers were often turned away from acute mental health services because they were not 'ill enough', however this resulted in them becoming worse and either getting no treatment or being admitted involuntarily due to being a safety risk. Respondents thought it would be more appropriate to receive treatment earlier on in the process so that they would require less intensive and shorter treatment than if they waited until their illness was very severe (Sayce et al., 1995).

Two important factors in accessing services is having adequate information about the types of services that are available and having an overall understanding about mental illness. A discussion paper on primary mental health care (Department of Health, 1993) highlighted that a lack of knowledge about services, and of what these services provided, reduced the consumers' fundamental right of 'choice', which served as a barrier to accessing services. This document also identified that mental illness is consistently under recognized by GP's, as a result of their lack of knowledge of mental illness symptoms, prognosis and treatment plans, and also appointments which are deficient in length which then reduces GP's ability to identify mental health problems (Department of Health, 1993).

Overall, these four factors impact the accessibility of mental health services for consumers' and their families.

### ***Service coordination***

Coordination of services promotes recovery as it allows for the most appropriate service-utilization by consumers and is the best way of meeting the range of needs presented in a diverse population (Anthony, 2000). New Zealand has had a history of poorly-coordinated mental health services following the closure of

psychiatric hospitals as identified by a number of reviews of service provision (National Mental Health Consortium, 1989). Mason, Johnston and Crowe (1996, p. 100) stated that:

*...all services, including crisis support, assessment, treatment and continuing support are fragmented and under resourced, both in skills and size. Co-ordination, in many services, is non-existent.*

In a study of stakeholder perceptions of the effectiveness of mental health services, McClellan and Warren (1995) identified service coordination, and different organisations working together, as a significant weakness of current service provision. The main reason for this was the result of competition between services for funding, which was perceived as undermining organisations' ability to work together (McClellan & Warren, 1995).

Some people need greater support than they can receive in a primary care setting. For example, they may receive a limited number of treatments in primary settings but require more intense therapy as provided by psychiatric services. It was found that there was a lack of connection between primary and secondary services (Fitzgerald, Galyer & Ryan, 2009). There is also a need for primary care clinicians to up skill to have accurate case identification and knowledge of when to refer on to another service. Hickie and Groom (2002) found from studies in Australia that there is a requirement for GPs to be better supported by their mental health specialist colleagues who work in secondary services in an attempt to maintain links between primary and secondary mental health services. For services to be recovery focused there is a requirement for services to function well with other services and to use allocated resources efficiently (MHC, 2010).

## **Summary**

Effective service provision has been found to be influenced by a variety of individual, societal and organisational factors. Individual factors such as social support, purpose and available resources can be barriers to effective care and therefore recovery from mental illness. Similarly geographical location and societal attitudes, which are often developed through media portrayals, often impact upon the efficacy of care. Factors associated with organisational impacts on recovery are the overall access to care, understood by assessing the

availability, suitability, eligibility and knowledge of services, and also the level of coordination between service providers.

## **Chapter Summary**

Following a period of mental health care in New Zealand characterized by medical dominance and institutional care, a new philosophy of care has developed based on the recovery principles. Recovery-oriented care is empowering to consumers and their families, encouraging them to take responsibility for their own recovery, and providing them with the choices and skills to make informed decisions about their well-being. New Zealand services are expected to be functioning from a recovery approach, based on the Ministry of Health's (1998) document describing the importance of the underlying principles of recovery for mental health service provision. Shepherd et al. (2008) identified that while recovery principles are valuable, the real challenge is to translate the recovery philosophies into tangible changes in mental health service provision. A range of individual, societal and organisational barriers which were identified as potentially impacting services ability to provide effective mental health care that promotes recovery.

## **F. Rationale for the present research**

Based on the literature, it is reasonable to question the extent to which the services are facilitating the process of recovery, especially in light of the potential barriers to effective mental health service provision. Information on accessing services for people in rural settings is of particular interest as Cambridge is a small town which is dependent on Hamilton for the majority of secondary mental health service provision. Recovery philosophies clearly assert the importance of including consumers' in the development and implementation of services. Seeking consumers' valuable perspectives and encouraging consumers' to share their experiences and knowledge is an important element of the recovery model.

# CHAPTER TWO

## Method

### Overview

This chapter will outline the present study and describe the process by which this research was undertaken. Firstly this chapter describes what the aim of this research was and why this was an important topic to investigate. A research plan is outlined to explain how the aim was addressed, followed by an explanation of the benefits of using qualitative research methods for this type of research. The type of participants and method of recruitment is described. The research procedure and the interview guide are outlined, and a description of, and justification for, the methods which were used for data analysis concludes the chapter.

### A. Research aim

The aim of the research is to ascertain consumer perspectives on mental health service provision in Cambridge, and to identify how these services affected consumers' recovery journeys. Consumers of mental health services are valuable commentators on mental illness, recovery and effective service provision (Anthony, 1993). Since the establishment of the recovery focus in mental health care, both in New Zealand and internationally, consultation with consumers has become an essential element of service development and delivery (Mental Health Commission, 1998). For this reason consumers of mental health services were the participants in this study, providing a firsthand account of the type mental health services that worked/did not work in facilitating and continuing the recovery process, and consumers' interpretations of why this may be the case.

### B. Research plan

The research plan for this study is set out in Table 2. The first column shows the four main research topics, which make up the interview guide and direct the focus of the study. The second column identifies the type of information which will transpire as a result of the information gathered from the research topics.

<b>Research topics</b>	<b>Outcomes of research</b>
Concepts of mental illness and recovery from mental illness, and what is required for recovery.	Identify the meaning of mental illness and recovery and an outline of the needs and expectations of service users.
Experiences of using mental health services	Assessment of effectiveness of services in relation to the recovery model. Identify strengths and weaknesses of service delivery.
Other services which could be made available to aid the recovery process.	Improvements in mental health service provision for the Cambridge community.

*Table 2.* Research plan for identifying consumer perspectives of mental health services for the people of Cambridge.

### **C. Ethical considerations**

A proposal and ethical application was submitted and approved by the University of Waikato Psychology Research and Ethics Committee, as well as the Ministry of Health's Health and Disability (Northern Y) Ethics Committee. I identified a number of potential ethical issues while developing the research plan, and the main issues were:

- Protection of the participants' identity: All identifying characteristics were removed from interview transcripts and participants were given pseudonyms to be used in presenting the research findings.
- Need for informed consent and informed decision making: Participants were given a letter and information sheet when they contacted the researcher showing an interest in the research which outlined the study, the researcher and the rights they would have if they chose to participate (for letter see Appendix A, for information sheet see Appendix B). This

information was reiterated at the beginning of the interview before the consent form was signed (for consent form see Appendix C)

- Research must respect Maori: A cultural advisor was used throughout the research process, who acted as ‘a sounding board’ for the researcher to double check that all behaviours were culturally appropriate for the local people. The research also received support from a Maori advisory panel.
- The welfare of participants is paramount: It was identified that reflecting back on experiences of mental un-wellness and their journey of recovery could be emotional for participants. For this reason, during the recruitment phase, service providers were asked to refrain from sending out letters of invitation to participate in the research, to clients whom they perceived as too unwell to be able to cope with the interview process. Participants were also sent a letter with their interview transcripts, a week after interviewing, which included a list of local social services should they need support in dealing with any issues which arose from the interview.
- Access to the research findings should be made available to participants: At the conclusion of the interviews participants were asked whether they would like a summary of the research findings. Copies of the report findings will be made available to local social service providers for consumers to access, and also for the knowledge and development of their workforce.

## **D. Recruitment**

Prior to the beginning of the recruitment phase ethics approval for the research was gained from both The University of Waikato Ethics Committee and the Ministry of Health’s Northern Y Regional Ethics Committee. Following ethics approval recruitment occurred in three stages which will be discussed in this section. These were: networking with service providers to gain organisational support; sending letters to participants via their current mental health professionals and distributing posters to gain involvement from participants who were not currently involved with services; participants contacting the researcher and displaying a desire to participate, followed by a screening process; and

finally, the researcher providing participants with further information about the project and arranging a meeting time for interviewing.

### **Networking**

Stage one of recruitment involved networking with service providers in both Hamilton and Cambridge. The aim of networking was to be able to recruit Cambridge based participants who were currently using, or had historically used, a range of mental health services to enable comparisons to be made from the findings between the different services. These organisations were contacted via telephone, where the researcher briefly explained the research and inquired as to whether a meeting could be arranged to provide further information.

The majority of providers who were contacted through the initial telephone conversations agreed to meet with the researcher, with the exception of two doctor's clinics who did not return any of the researcher's calls. This provided the opportunity for the researcher to meet with two medical centers in Cambridge, one NGO, and the Waikato District Health Board community out-patient service which is based in Hamilton. Each of these meetings outlined the research aims and objectives, the recruitment process, and explained that ethics approval had been gained from appropriate committees. It was explained to these providers that their role in the research was either to send letters out to, or talk directly to, clients on the researcher's behalf to invite them to participate in the research. The providers were given a letter which outlined their potential involvement (see Appendix D), which explicitly explained that once the letters had been sent to, or a discussion had occurred with, participants there was no further involvement required from providers. Providers were given a copy of all the information which would be sent to potential participants as well as an outline of what was involved in the interview process, this included: participant invitation letter, information sheet, consent forms, an interview guide (see Appendix E), and post-interview letters (see Appendix F) which were sent to participants with their transcripts.

During this recruitment meeting a discussion occurred with service providers as to specific areas they perceived as valuable to cover during interviewing. Service providers perspectives were taken into account when developing the interview guide (discussed in detail later in the chapter).

## **Accessing potential participants**

Stage two of the recruitment process was completed in two ways; a) by providers sending letters to, or asking, clients if they would be interested in participating, or b) by consumers' responding to posters which were displayed on public notice-boards in a variety of Cambridge locations. In either case interested participants were asked to contact the researcher. Following this contact, potential participants were given information about the project and then they had the choice to decide if they were interested in participating.

The first approach was via health professionals who were given letters to send to participants (see Appendix one), along with prepaid, self-addressed envelopes for participants to post an expression of interest to the researcher if they wanted to participate or gain further information. Posting the response part of the letter to the researcher was one way participants could express an interest in the research, however, they could also respond via email, telephone or text message if they preferred. The letters explained the research, introduced the researcher, gave a description of the ethics committees which had approved the research, and outlined what was to be expected if taking part in the process, which explained to potential participants that if they wanted to participate in the research by completing an interview they would receive a \$15 grocery voucher to thank them for their time and knowledge. The letters also explained to the participants how they had been selected to be invited to participate, and that their decision to participate or not would not be disclosed to the health professional that sent them the letter, nor would it impact on the services they were receiving. Letters were signed by the researcher and also by the health professional who sent it on behalf of the researcher.

The second approach was aimed at accessing participants who were not seeing health professionals for their mental health concerns. This was achieved by displaying posters in various locations (e.g., community notice-boards at The Warehouse, New World supermarket, Countdown supermarket, the public library, waiting rooms of medical centers and community centers, and in church foyers). These posters explained the research topic, participant requirements (e.g., over 18 years of age, past or present users of mental health services, living in the Cambridge areas) and gave the researchers contact details (telephone, email and cell-phone details were provided) on a tear-off strip.

## **Connecting with identified participants**

As explained above, participants were given the option of how they wanted to respond to the invitation to participate in the research project through a range of communication methods (letter, telephone, email or cell-phone/text messaging). Once participants contacted the researcher via one of these methods, the researcher made contact with them and enquired as to whether they would like further information about the project in written form or as a meeting with the researcher. At this stage participants were screened, ensuring that they met the research participant criteria (outlined below). If participants met the research criteria subsequent interviews were scheduled.

## **Screening criteria**

Participants were required to be:

- past or present users of mental health services (defined in chapter one)
- over 18 years of age
- currently living in Cambridge or surrounding districts (within approximately 12km of Cambridge township) and
- able to participate in an interview, which required participants to speak English.

During recruitment, service providers were asked to exclude clients who they thought were too unwell to participate in an interview, or if the interview process would have a significant negative impact on their mental health. Screening for age, living in Cambridge, and ability to speak English were completed when participants contacted the researcher to express an interest in participating. The screen for whether an interview would be detrimental to participants mental well-being was not available for those participant's who responded after seeing a poster. To accommodate this, the names of local counsellors, crisis services and psychologists were given to all participants at the end of the interview in case the research process had caused them distress.

## **Factors impacting recruitment**

As previously discussed, the researcher worked in a voluntary capacity at a local NGO and had a conversation with the staff members about other organisations that they thought may be interested in helping with the initial recruitment phase. Cambridge is a relatively small town, and the majority of mental health and/or social service providers within the area are aware of the other providers, even if it is only by name. The researcher supposed that the association with this NGO was beneficial for gaining the support of other organisations, as they appeared to be more willing to cooperate knowing that there were other reputable organisations involved in the research process.

## **E. Research participants**

There were fourteen participants in total who completed interviews for this research project. Of these participants, four contacted via letters sent to them from their mental health professionals at the DHB community based out-patient service, four were from letters sent by other mental health services based in Cambridge, two were from letters sent by GPs, and four participants were as responses from the poster displays.

## **Description of participant groups**

Participants were asked information regarding their age, gender, nationality, diagnosis and the types of services they had accessed in order to make comparisons between their responses. The following table outlines participants, who have been given pseudonyms, and information about them. In summary, there were five male and nine female participants who ranged in age from 22-69 years. All participants identified as being of European descent, two of which were from the United Kingdom, one from Australia, one from the United States of America, and the final ten from New Zealand.

Name	Gender	Age	Nationality	Services accessed - past	Services accessed - present	Diagnosis
Adam	Male	33	New Zealand/ Pakeha	Private Counsellor (Hamilton), Psychiatric service		Cyclothymia
Betty	Female	69	United States of America/ New Zealand	Psychotherapist in America, support group in New Zealand, very briefly		Dissociative Identity Disorder and Depression
Craig	Male	49	United Kingdom/ New Zealand	Drug and Alcohol Counsellor	Drug and Alcohol Counsellor	Substance Dependence, Post Traumatic Stress Disorder
Diane	Female	55	New Zealand/ Pakeha	Psychiatric service, in another town, General Practitioner	Psychiatric service, Counsellor,	Borderline Personality Disorder, Depression, Anxiety
Emma	Female	32	New Zealand/ Pakeha	Counselling	Counselling, support groups	Depression
Faith	Female	50	New Zealand/ Pakeha	Crisis Assessment Team	Psychiatric service, Public Alcohol and Drug service	Borderline Personality Disorder and Substance Abuse
Gail	Female	23	New Zealand/ Pakeha	General Practitioner, Counsellor	Psychiatric service	Major Depression, Borderline Personality Disorder, and Bipolar Disorder
Heather	Female	49	United Kingdom/ New Zealand	Counsellor	Psychiatric service, Counsellor,	Bipolar Disorder
Isabelle	Female	49	New Zealand/ Pakeha	Psychiatric service, private Psychologist, private Psychiatrist, Counsellors,	Private Psychiatrist, Private Counsellor	Dysthymia
Jack	Male	40	New Zealand/ European	Supported employment	Psychiatric service, supported employment	Paranoid Schizophrenia
Kevin	Male	39	New Zealand/ Pakeha	Counsellor, GP, Psychiatrist	Psychiatric service	Bipolar Disorder
Louise	Female	22	Australian	Psychiatric service, hospitalisation, support groups	Counselling	Borderline Personality Disorder

Maggie	Female	37	New Zealand/ Pakeha	Psychiatric service, Hospitalisation, Community Alcohol and Drug Service, Pain Clinic.	Counselling, Public Alcohol and Drug service	Post Natal Depression and Substance Dependence
Neil	Male	47	New Zealand/ Pakeha	Alcoholics Anonymous Group, Counselling	Drug and Alcohol Counsellor	Substance Abuse (historical), Depression

*Table 1.* Demographic description of participants.

## **F. Research method**

Qualitative methods of inquiry were used to gather information for this research project. Qualitative methods provide the scope for detailed research on a specific topic, generally by gathering in depth data from a small sample of participants (Patton, 2002). In qualitative research methods participants can be purposefully selected based on their experience in the area of inquiry (Patton, 2002). As discussed in Chapter One, gaining consumer opinions on service delivery is an effective way of gain insight into service provision and to gain an accurate reflection of what assists the journey of recovery from mental illness (Ministry of Health, 1995). This research project focused specifically on consumers' experiences of using mental health services, and drew upon their knowledge for ways in which their recovery from mental illness could be enhanced; therefore purposeful sampling was appropriate for this research.

As the researcher had not experienced mental illness and therefore was not personally aware of the issues surrounding mental health service provision, using a research technique which allowed for a complex exploration of the area of interest was important. Using semi-structured interviews is a method that allows for investigation based on participants' knowledge, where questions can be tailored to participants' responses and areas of interest can be investigated which the researcher had not anticipated would be important (Banister, Burman, Parker, Taylor & Tindall, 1994).

Conducting face to face interviews allows for the researcher to develop a relationship with the participants during the early stages of the interview, which can cultivate an atmosphere of trust (King, 1996). Sharing experiences of mental illness, and reflecting back on past events, which may include painful memories,

can put participants in a vulnerable position and may lead to further traumatizing them (King, 1996). For populations such those who have experienced mental illness, sharing experiences may be additionally difficult as mental illness has been found to be associated with high levels of stigmatization which can develop a sense of unworthiness, and reduced self confidence (Corrigan & Kleinlein, 2005). For these reasons face to face interviews were appropriate as it allowed participants to speak to the researcher in a trusting environment and allowed for the researcher to be sensitive to how the interview was impacting the participant, especially when discussing sensitive topics. Being sensitive to participants' needs is also a valid reason for using an interview guide, to allow the researcher to order questions in a way that best suits the participants' presentation.

In qualitative research one way of determining when interviews can be terminated is when the point of data saturation is reached. Data saturation is the point when the collection and coding of supplementary information yields no new information (Henwood & Pidgeon, 2006).

### **Interview guide**

An interview guide provided the basic format of the interviews, which consisted of a list of topics that were explored during interviews. The topics of interest to the researcher were developed prior to interviews, however when using an interview guide there is freedom for the researcher to decide the sequence, and depth, of questioning for each topic (Patton, 2002). The interview guide was developed in consultation with a range of service providers during the initial recruitment phase, supervisors from the department of psychology at Waikato University and in response to a review of literature about; service delivery, the New Zealand mental health system and the concept of recovery from mental illness.

A combination of open and closed questioning was employed in this research project. Open-ended questioning was used as it is an effective method of enabling the researcher to see the world through the eyes of the participant (Patton, 2002), which was particularly important in this project as the researcher did not have experience in using mental health services. Open-ended questions allow participants to give answers that are important and relevant to their own experiences. Within the interview guide certain questions were asked of all

participants to allow specific information to be identified (e.g., what services have you used? What does recovery from mental illness mean to you?). By using some closed questions (e.g., age, gender, diagnosis, cultural affiliation, and length of time using services) specific data could be gathered to allow comparisons to be made between participants from different circumstances.

One benefit of using an interview guide, rather than a structured interview schedule is the flexible approach to interviewing it provides, allowing participants to determine the flow of the dialogue. Interview guides produce a systematic explanation of the participant's individual experiences and perspectives, while using a relaxed, conversational style of interviewing (Patton, 2002). Patton (2002) describes a weakness of using an interview guide as a schedule as being that responses will not be able to be compared as reliably as those with a more structured schedule, as the interviewer may have asked some questions differently and elicited altered responses. It is also possible that salient topics may have been overlooked in the development of the interview guide which could result in the absence of potentially interesting findings. The researcher minimised the likelihood of salient topics being ignored by exploring areas which participants brought up during interviews, especially if issues were raised that had not been considered during the planning stages of the project.

Interviews commenced with an introduction, followed by four areas of enquiry and then a conclusion. The introduction involved building rapport between interviewer and participant, familiarizing the participant with the scope of the research project and emphasizing the rights of the participant throughout the research process.

Part One focused on the participants demographic information that was relevant to the topic such as, age, gender, ethnicity, diagnosis, and types of services accessed. These were described by the interviewer as important in order to gather information that allows comparisons to be made between participants who had different personal situations. Questions asked of participants in this section were: their age, cultural or ethnic group they affiliate with, do they have a diagnosis and if yes when did they receive that, their social support networks, length of time living in Cambridge, and the past or present services they have used.

There was flexibility in the order of Parts Two, Three and Four which were asked in a sequence which suited the flow of conversation. Each part had

some key questions to cover, and further information was elicited on topics which were either of interest to the researcher or points that the participant emphasised.

Part Two focused on services that participants had used while living in Cambridge, based either in Cambridge or surrounding areas. Some key questions which were asked were:

- What has been your experience with mental health services?
- When you needed to use services, did you know who to turn to for help?
- How did you find out about available services?
- Were the services available easy to access?
- Have specific services helped/not helped you?
- What do you think people with mental un-wellness need from services? Are all your needs being met?

Part Three explored participants' expectations of mental health services, identifying the services they expected to be available and any suggestions for improved service delivery. Key questions included:

- What are some essential services which need to be provided to help you get well? Why are these services so essential?
- In an "ideal world" what mental health, or other services, would you like to be available?
- How would these services assist you?

The concept of "recovery" is a guiding principle of mental health services in New Zealand, as discussed in chapter one. For this reason Part Four focused on recovery from mental illness; what the term meant to service users and what is required for recovery. The key areas of questioning were:

- What does recovery from mental illness mean to you?
- What helps or hinders your recovery?
- What are your recovery related needs? What do you think will help you recover?

Participants were asked at the conclusion of the interview if there was anything they wanted to talk about which had not already covered or anything they wanted to go back to.

## **G. Procedure**

Interviews were conducted over a three month period, from July to September 2010. Recruiting participants and the completing of interviews was terminated after the fourteenth interview as the point of data saturation was reached, where there was no new information being generated from interviews.

Once participants had received the research information and confirmed their desire to be involved, a time and meeting venue was arranged for the interview to take place. When organising a time for interviews to take place, the researcher explained that a room was available at the Cambridge Community House, a local service provider, and the option to meet there, or in another venue was given.

Interviews ranged from 30 minutes to 1 hour and 40 minutes in duration. Ten interviews were conducted in a hired room at the Cambridge Community House, and the remaining four interviews were in participants' homes. Two participants required interviews in their homes due to physical disabilities, one due to child care restraints and the remaining participant preferred to be at home rather than meeting at a service provider location.

At the beginning of the interviews participants were given a second copy of the participant information sheet (the first was sent in the beginning stages of recruitment), as well as a consent form which outlined their rights as participants (see Appendix C). At the time of the interview participants were asked if they were happy for the interview to be tape-recorded in order to transcribe the interviews verbatim, and a consent form was signed before interviewing began. All of the participants gave consent for interviews to be recorded, and all participants consented to the researcher taking notes.

At the beginning of the interviews each participant was given a \$15 voucher for New World supermarket to thank them for their time and to cover any costs associated with the interview.

At the end of each interview participants were asked whether there was any other information they would like to add, which had not been covered, or any questions they had of the researcher. This gave participants the freedom to disclose any further information they deemed relevant to the research topic, and to clarify any concerns they might have had. Participants were also asked if they would like a copy of their interview transcript to be posted to them to give them an opportunity to check what had been recorded. The participants were informed

that they were able to make changes to the transcript if they were not happy with the record which had been made, providing that they returned the transcript to the researcher with any changes (in a prepaid and self-addressed envelope provided by the researcher), within three weeks of them receiving the transcript.

Participants were informed that if the transcript was not received within the specified time frame the researcher would assume there were no changes to be made and would use the original transcript for analysis. All participants requested a copy of their transcripts and three returned their transcripts with requests for changes to be made.

Interviews were transcribed verbatim to ensure that an accurate report of the interview was attained. Notes which were taken by the researcher during interviews provided the researcher with a record of significant responses which accompanied certain areas of questioning. Transcripts were posted to participants the week following the interview and were accompanied by a letter to participants thanking them for their time and for being willing to share their knowledge. The letter acknowledged that reflecting back on the process of recovery from mental un-wellness and on service use may have been a difficult process and it was emphasized that the researcher hoped the interview process had not negatively impacted them. The list of local service providers, which were given to participants at the conclusion of their interviews, was also included and the researcher encouraged participants to speak to either a professional, or a support person about any concerns they had. The contact details for the University Ethics Committee was provided and participants were reminded that it was their right to complain about the researcher or any aspect of the research process.

## **H. Data analysis**

### **Qualitative data analysis**

Inductive analysis and thematic analysis were the primary methods used in analysing the data. Inductive analysis is a process of allowing patterns and themes in the data to emerge rather than deciding, prior to data collection and/or analysis, what the important dimensions will be (Patton, 2002). The development of categories occurs with inductive analysis only after participants have shared

their experiences, rather than trying to fit participants' answers into predetermined groups. Once data was gathered the method of thematic analysis was used to recognize, evaluate and describe patterns and themes in the data (Braun & Clarke, 2006; Boyatzis, 2002).

### **Developing structure**

Putting the information gathered from participant interviews into categories provides a structure for understanding the topic of interest.

Interviews were transcribed verbatim and any identifying characteristics were removed to protect participants' identities. The research supervisor examined some transcripts and gave feedback on whether the data gathered was pointed in the direction of answering the research questions. The researcher read and re-read each transcript to ensure a detailed understanding of the interview content. Interviews were examined line by line and the researcher underlined any words or phrases that were repeated or that captured interesting ideas or key issues (Braun & Clarke, 2006). Underlined words were given codes, which were written in the margin, and collated at the end of each interview. From these codes potential theme groups were identified, based on patterns and concepts which were strongly and/or frequently expressed in the transcript. Each transcript was compared to the others to determine if similar themes had emerged. Participants were grouped during data analysis based on their age, gender, ethnicity, diagnosis, and types of services accessed, to determine whether there were any significant differences between groups.

Braun and Clarke (2006) recommend the use of visual representations, such as hierarchy maps, of themes to reduce the raw data into manageable portions and to identify main overarching themes; therefore themes were mapped out as seen in the diagrams presented in Chapter Three.

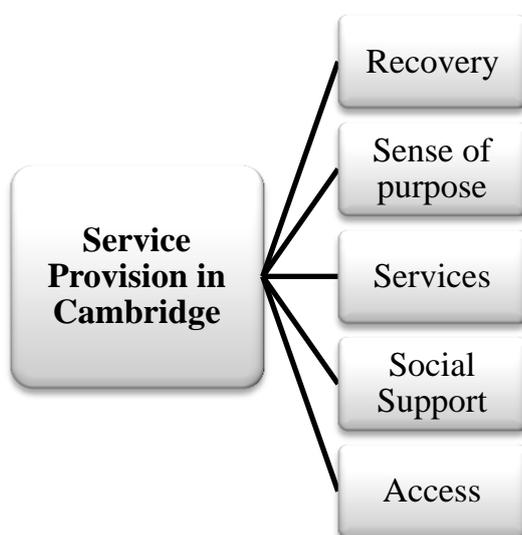
# CHAPTER THREE

## Findings

As a result of the interviews conducted, five themes emerged which expressed Cambridge based consumers' experiences of recovery from mental illness and their perceptions of mental health service provision in Cambridge. These five themes are: recovery, sense of purpose, services, social support and access. This chapter will be organized by systematically expanding on each of these themes followed by a summary of the overall theme.

### Overview

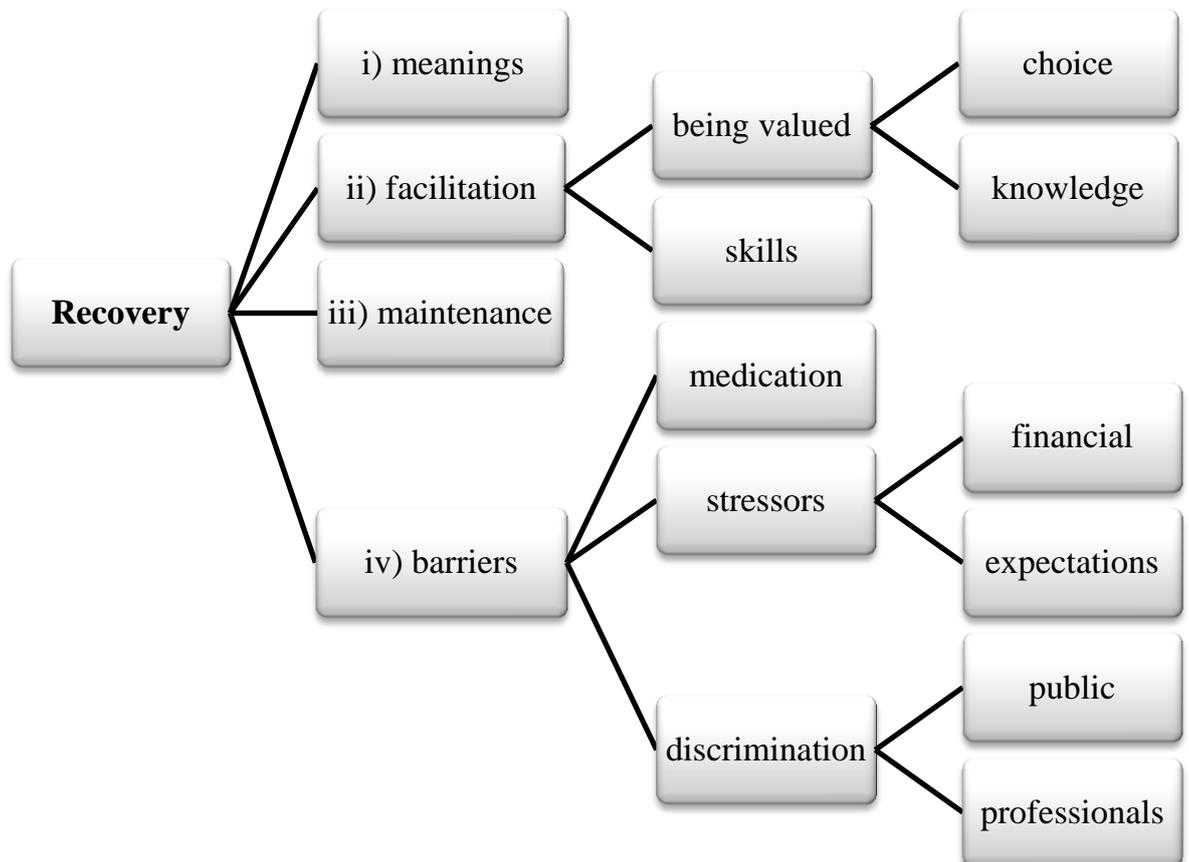
The following diagram identifies the five main themes which emerged from consumers' responses. The overall research topic was focused on service provision in Cambridge, and all these themes relate to this. Each theme will be elaborated on in following sections.



*Figure 1.* Overview of the themes from the current research.

## A. Recovery

The following diagram identifies the key ideas associated with the theme of recovery. The meanings connected with recovery, factors which facilitated recovery, requirements to maintain recovery and barriers which prohibited recovery varied between consumers, however the following trends were evident.



*Figure 2.* Overview of the main topics from the recovery theme

### i) Meanings

Participants gave a variety of explanations for what recovery meant for them, which ranged from a completely biological perspective to more social interpretations of their mental illness. Some of their explanations of what recovery from mental illness meant were:

*Kevin: Not until we find a genetic answer to this will I be able to get any better...You don't recover, you learn to manage.*

*Isabelle: For some people that means they are all better and don't need medication, but for some of us we will always need medication and probably always needs some other intervention. The word is wrong, if you recover from measles, you never get them again...if I am in recovery from mental illness, does that mean it is suppose to be gone?*

*Adam: Back to the point where you can function again in your work and leisure, basically a wholeness of life...being able to do day to day stuff, that's what recovery is about.*

*Betty: Feeling a sense of inside empowerment which allows me to feel safe in the world.*

*Faith: Being able to make my kids feel proud of me again...not wanting to die every day. Or maybe just being able to go out and mingle with people like I used to...and maybe being happy.*

*Neil: Recovery is about personal growth, about achieving new levels of freedom from the baggage in one's head.*

There were three respondents, Isabelle, Kevin and Maggie, who put significant emphasis on the biological component of mental illness, concluding that they would require medication/support long term to stay well. These three people had been using mental health services for the longest period of time and had experienced numerous cyclic episodes of being mentally unwell, followed by a time of wellness, followed again by being mentally unwell.

A noticeable idea that emerged was the desire to find enjoyment, to appreciate the small things in life and to gain a sense of overall happiness. However one respondent explained that there is a difference between feeling better and recovery, as recovery is the process of reaching new personal levels through challenging oneself and learning new techniques to deal with difficulties.

*Neil: You can feel better and not be recovering at all. Old habits are hard to unlearn so people need long enough time in counselling to deal with all their issues.*

Regaining functioning and being able to perform at a level similar to that before mental illness was a common response; however this will be further discussed when the ‘Purpose’ theme is explored.

## **ii) Facilitation**

Two significant aspects of how recovery was facilitated were consumers being valued, by health professionals and the general public, and also the learning and development of skills which promoted recovery.

### ***Valued***

Consumers identified that the facilitation of their recovery journeys were positively impacted by their belief that they were valued by both health professionals and by members of the wider community. This sense of being valued can be discussed in two categories; choice and knowledge.

### **Choice**

One participant ardently questioned the assumption that people with mental illness want to change. He suggested that people may access services for reasons other than making specific changes; they may just want to have contact with people.

*Craig: what they [services] can offer in a lot of cases is just giving them [consumers] a place to go, and sometimes people are not going to change...they've relapsed and fucked up again, 'cause sometimes people come and organisations think they are looking for change but they have just come in to see people.*

Allowing consumers to choose what services they want to access, if any, and at what point in their lives, promotes recovery by confirming to consumers that their decisions and opinions are valued and worthy.

Connected to the idea of choosing to engage in services versus attend for socialising purposes is the relationship between social connection and recovery from mental illness which will be discussed in the ‘Social Support’ theme. Similarly the desire to have option in regards to which service one decides to

access requires a variety of services to promote choice which will be elaborated on in the 'Access' theme.

### Knowledge

A number of consumers who participated in this research project considered themselves well versed in understanding the delivery of mental health services as well as having significant insight into determinants and symptoms of mental illness. Consumers' portrayed that they would benefit from service providers recognising that they had knowledge about their illness and incorporating their perspectives into treatment plans. Providers need to listen when consumers are concerned about a symptom or side effect.

### **Skills**

A common theme in responses from consumers in regards to their recovery related needs was that they needed external help to get well and to stay well. Professionals who had skills in treating mental illness were seen as valuable, especially when they taught consumers skills they could use outside of the therapy setting.

*Betty: My therapist gave me tools – she taught me things that I could use for myself. That way I didn't need her all the time because I could just use what she taught me.*

*Kevin: My therapist taught me to "fake it till you make it" so that would help when I felt really down. I'd just pretend to enjoy things until I did enjoy them.*

*Adam: The psychologist gave me skills for ways of dealing with crisis, ways for me to show my wife that I was making an effort to get better.*

One consumer had been involved with sports coaching and likened recovery from mental illness to learning a sport. He believed that it was necessary to learn from professionals how to function properly, rather than try to manage alone and then getting it wrong.

*Neil: Just like when learning [a sport], people are encouraged to take lessons. It is easier to learn good habits than to un-learn bad habits. We can accept that philosophy in sport but not when it comes to mental health.*

Neil also discussed the importance of making a decision to get well and then putting in the required effort to gain the skills necessary for recovery.

*Neil: You can't just sit on the seat and warm your hands and think that is going to make you get well.*

The internal skills that individuals possess were another aspect of facilitating recovery. Internal strength, also known as resilience, was a personality characteristic which some consumers recognised as relevant to themselves.

*Louise: I know that I am strong, but some people just aren't. I wouldn't be here if I wasn't strong, so I don't know what happens to other people.*

The development of skills and effective coping strategies resulted in an increase in overall functioning, which is explored under the theme 'Purpose'. Some of this improved functioning is as a result of skills gained from learning from other peoples experiences which is part of the 'Social Support' theme.

### **iii) Maintenance**

In order to sustain the gains that individuals made during the recovery process, consumers indicated that there needed to be some form of continued check-ups from professionals. These check-ups would serve the purpose of ensuring that people are on the right track, of helping to notice any early warning signs of becoming unwell and to keep the consumer connected with the service should they need to return.

*Adam: it would have been good to have someone come and check up on us, just to make sure we were doing ok.*

*Betty: I need someone I can call or schedule an appointment every now and then so I can touch base...*

The freedom to have services which were aimed at the stage of recovery the consumer was at was considered to maintain the recovery gains. Consumers discussed the need for services to be available to them on a needs basis, which in their experience did not equate with services currently available.

*Isabelle: that's what so hard about the mental health system, you are either in or out, and there is no room in the middle to be just managing...and to be managing I may need to see someone once every two months.*

*Kevin: I know that my body goes in cycles...the way the health system is set up doesn't cater for people like that. You get better and then you're signed off the case load.*

#### **iv) Barriers**

A number of the themes discussed have elements which serve as barriers to consumers recovering from mental illness. However three barriers will be discussed here which are not covered in other sections. These are: medication, life stressors, and discrimination.

##### ***Medication***

While medication was seen as a positive factor by many consumers, they reported that a lack of understanding surrounding expectations of, length of time on, and side effects of medication as complicating factors for their recovery journey. Consumers' described that they received little information about the types of medication they would receive, nor was it explained to them the length of time they were expected to be on medication. The process of finding the right combination of medication was portrayed as a negative experience for many consumers.

*Adam: the doctor would...just pump it in [medication]. I felt like a slot machine.*

This negativity related to medication administered from both General Practitioners and from Psychiatrists; however Psychiatrists were described more negatively as there was often a lack of continuity with Psychiatrists especially within the public health system, this will be further discussed in 'Services'. Associated with regularly changing Psychiatrists was the regular changing of medication prescriptions and the side effects from different medications. One consumer experienced significant weight gain as a result of a change in

medication, and did not feel that her Psychiatrist acknowledged the impact weight gain was having on her overall mental health.

*Heather: My Psychiatrist isn't really worried about the 20kgs I've put on, she only cares about the Bipolar...I don't want to be overweight just to deal with the Bipolar.*

### ***Stressors***

Other life stressors that were raised by consumers are considered under this heading, the main ones being, financial stress and expectations put upon someone in the process of recovery.

#### Financial stress

The added burden of financial stress was emphasised by a number of consumers, in relation to the need for financial security to promote recovery as well as accessing financial support from services.

A lack of financial security negatively affected consumers' mental health as it was seen as a burden that they did not have control over. As will be discussed in the section on 'Purpose' being involved in activities that provide meaning and pleasure is helpful when recovering from mental illness. However, it was perceived by consumers that many of these activities required them to have excess money, which was not realistic for their current situation. Therefore, consumers interpreted that they missed opportunities to gain wellness because they could not afford it.

*Emma: you get really down because you know you need to get out of the house to stay well but it costs to put petrol in the car.*

Gaining financial support from the Government agency Work and Income New Zealand (WINZ) was perceived as a significant barrier because of negative past experiences as well as discrimination that consumers predicted, especially in relation to WINZ staff members refusing to provide them with support. One consumer joked that his mental health would take a downward turn whenever he accessed WINZ and another explaining that he felt he had to prove himself every time he went to WINZ, because they lacked understanding of what it was like for people with mental illness.

*Adam: you need a counsellor just to go to WINZ*

*Craig: that's what it's like with WINZ...everything you want you have to fight for it, well that's what it feels like anyway.*

The main consumers who discussed issues with WINZ were men, however women also talked of financial burdens but did not discuss perceived discrimination from services when accessing financial support.

### Expectations

Expectations from outsiders were deemed to produce stress among those who were journeying through recovery. The expectation that once someone was discharged from the mental health system they would be completely recovered and ready to participate fully in the activities they once did, concerned consumers. Consumers reported being afraid of claiming they are recovering, or of being discharged because it inferred that they could manage by themselves, and that there was a feeling of failure if they needed to re-enter the system.

*Diane :It's like, if you're on the road to recovery so you should be working and you should be doing well, and it's all those should's and expectations that I can't cope with...sometimes I would have a crisis to make sure that I wouldn't be discharged.*

*Isabelle: For me that's been the biggest barrier, and there is a certain amount of shame and stigma that comes from re-entering. Like you have failed, didn't make the grade.*

### ***Discrimination***

Discrimination was identified as a barrier to recovery from mental illness, and this included discrimination from the public as well as from professionals.

### Public

A lack of understanding of mental illness from family, friends and the general public contributed to consumers perceiving that they were discriminated against. In keeping with the typical 'she'll be right' New Zealand attitude, consumers reported that family and friends would often tell them to 'toughen up' and 'just get over it' when discussing mental health concerns. In relation to this attitude Isabelle described how stigma and discrimination impact mental illness;

*Isabelle: I think it's that you don't talk about it, don't share it, hide behind a mask*

Consumers reported being embarrassed to attend services which were in public settings as they feared that someone they know may see them. The majority of consumers responded positively to the advertising on television with New Zealand celebrities such as John Kirwan, believing that the advertising had made people more aware of mental illness and how anybody can experience it.

*Betty: It's good to see education for people that...you can still be a 'real man' even if you suffer from a mental illness.*

*Kevin: It's good to have someone with a high profile doing the advertising*

One consumer made the comment that although the advertisements were effective and it was good to use people with a high profile to raise awareness, the people on the television advertisements are not average people who experience mental illness. They promote people who have extraordinary lives, and Heather expressed that it makes it acceptable for those people to have mental illness because they have achieved amazing results, but the acceptance of mental illness does not seem to filter through to people who are not celebrities.

*Heather: He's [John Kirwan] got a lovely house, a lovely family, a beautiful wife to go back to, but he's not an ordinary person. The need to get real and show some real people...show the horrible side of bipolar.*

There does appear to be a fear from the general public, as perceived by consumers, that people with mental illness are dangerous, all the same and in response to this, participants reported that they would be discrete in revealing their diagnosis.

*Heather: Most people don't know about bipolar...everyone thinks that everyone is at the extreme...People need to be taught that I am not going to hurt anyone.*

*Betty: I was in an interview and my support worker said to me, whatever you do, don't tell them about your [diagnosis].*

*Diane: At work, I will have to wear short sleeves as it will be too hot but customers might see my scars and be scared and uncomfortable with my scars.*

*Louise: Where I work I don't want people to know that I have a mental illness, because they will treat me differently and they won't respect me as much.*

### Professionals

Consumers viewed discrimination from health professionals in two ways. Firstly, that service providers discriminated against them by not wanting them as their clients because they were high needs, and secondly, that discrimination came from a lack of education and appropriate language from the health professionals about mental illness, diagnoses, medication and treatment approaches.

*Isabelle: I had an old guy, very judgmental and spoke in medical speak. I felt like he was doing it to me, a real power imbalance. Even now when I read his report I feel so dysfunctional. My self-worth went from zero to negative zero.*

*Louise: When I got diagnosed it wasn't at all helpful. I didn't receive any information or education about the diagnosis, I had to go and do my own research.*

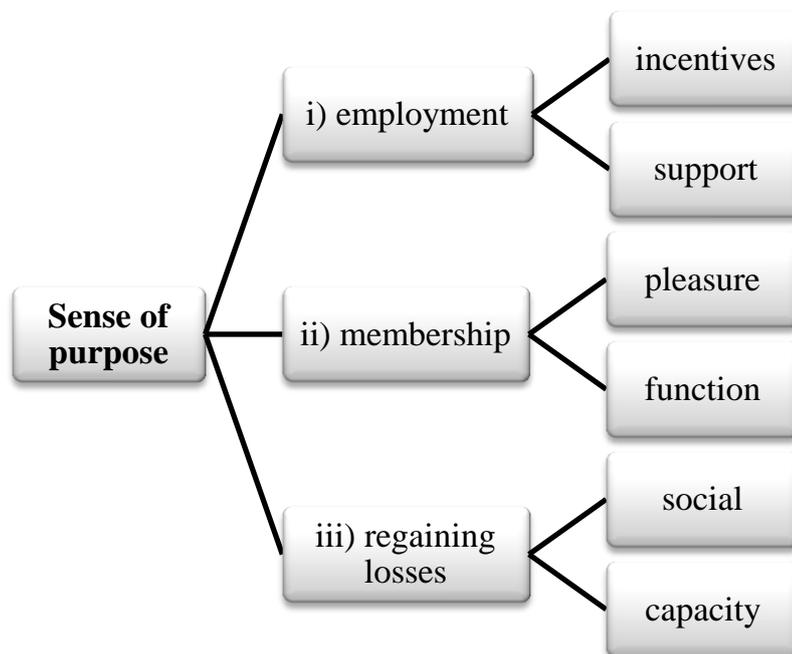
### Summary

Consumers identified that their experiences of recovery from mental illness can be varied, ranging from biologically based to socially constructed, and there are a number of factors which influence the facilitation and maintenance of recovery. When consumers are valued, by health professionals who encourage them to make choices for themselves and promote the importance and worth of consumer knowledge, recovery is facilitated. Recovery is also advanced when consumers learn/use skills, either from within themselves or learnt from professionals that can help their daily functioning. Recovery gains are, or would be, maintained by having regular check-ups with professionals and by having these services available to consumers on as needs basis. Barriers which were identified include side effects of, and limited education surrounding medication, stressors such as

finances and other people's expectations, and discrimination from the public and from health professionals.

## B. Sense of purpose

The theme of sense of purpose is linked to consumers' perceptions of recovery from mental illness. Sense of purpose in consumers' lives was developed by involvement in either employment or another form of group, which developed a sense of membership. The ability to regain some of the losses that occurred as a result of experiencing mental illness, such as overall capacity and social interaction was another factor which promoted a sense of purpose within consumers'. A sense of purpose was associated with an increase in self-esteem and self-worth which was essential for fostering recovery among consumers.



*Figure 3.* Overview of the main topics from the sense of purpose theme

## **i) Employment**

Consumers' identified that having work, either paid or unpaid was an important element in developing purpose and therefore promoting recovery. While employment/work provided consumers with financial and routine based incentives and social interaction, the focus was not solely on financial gain, allowing voluntary work to cultivate purpose.

### ***Incentives***

Financial pressure on consumers was a significant burden, impacting their ability to access services, socialise, and participate in fun activities. Gaining employment served to reduce financial pressure, therefore employment was associated with monetary incentives.

Another form of incentive for gaining work was the daily structure it provided. Having a routine was seen by consumers as a protective factor against mental illness, and was perceived as essential in maintaining their desired level of wellness.

*Emma: Having a job gets you out of the house and it's something to do. There is also the financial struggle, but having a job is not only about finances, it's about having a purpose too.*

*Diane: I need some sort of structure in my day, a routine. Then I can cope.*

One consumer described that part of her motivation to work was the way in which it removed her from temptation during the day. She reported that she was more likely to self harm or abuse substances if she was at home by herself, which was not possible if she had a job to attend.

Employment or voluntary work provided social interaction with staff and clients/customers, which consumers' could not always access outside of the work environment. As described earlier (in the 'Social Support' theme) social interaction was a significant component in promoting recovery, and reducing the levels of isolation that consumers' experienced.

## Support

Although consumers' perceived employment as important and somewhat necessary in developing purpose and promoting recovery, there was concern that they were unable to facilitate the process of gaining employment without extra support. A number of consumers had not been active in the workforce for a significant amount of time and reported some anxiety surrounding returning to work.

*Craig: I haven't worked properly for years...the biggest roadblock is how do I get back into the workforce? I guess I'm floundering a bit*

Support from organisations to reintegrate consumers' into the workforce was perceived as an important element of gaining employment and identified as a gap in available services in Cambridge. Kevin had experience with an organisation, based in Hamilton and organized by the psychiatric service he was involved with, whose role was to support him to regain employment by, among other things, searching for jobs, helping with curriculum vitae writing, and selecting appropriate clothing for interviews.

## **ii) Membership**

Another factor which developed purpose and facilitated recovery was membership in a group of some sort. Groups which consumers identified as helpful were sports groups, churches and other social groups. This theme incorporates some aspects which will be covered under 'Social Support'; however key ideas of pleasure and function will be discussed further.

### ***Pleasure***

Consumers reported that gaining pleasurable experiences was an important element in their recovery journey. Pleasure was discussed in two different ways; doing activities that one enjoys, and the happiness gained from group involvement.

Participating in an activity that produces pleasure was particularly evident when discussing involvement with sports and social groups. Some consumers explained that sport in itself was therapeutic because they were doing something that they enjoyed and gave them pleasure. However it was not only the sport that

was beneficial, but also belonging to a team and the sense of happiness which came from belonging to something. Another consumer explained that when she belonged to a group, there was an expectation on her to attend meetings and participate. She made it clear that she felt a sense of contentment from people caring and worrying about her, especially when people contacted her if she did not manage to attend a weekly meeting.

### ***Function***

Membership in different groups not only provided pleasure but it also served a function which helped to achieve an overall sense of purpose. Functions that membership provided for consumers in this research project included: a reason for consumers to get out of bed and begin their day; socialising; and the development of spirituality by being a member in a church group.

*Emma: I go to my craft groups...they are just fun social groups, it's nice to have people remember what is going on for me. They ask me about things that are going on in my life. They may not be close friends but they care.*

Having a routine and a daily plan which motivates consumers to structure their day is a beneficial aspect of group membership. As described earlier, in the Employment section, having a routine reduces tempting situations to abuse substances or self harm by removing the individual from their isolated house. Socialising has been discussed, in the Social Support section, but also relates to group involvement as many of the consumers' hobby/sports groups served a noticeable socialising function.

The final function that group membership incorporated, which was evident in many consumers' responses, was the development of spirituality. Involvement in a church group and 'finding God' was discussed by multiple consumers' as being essential to their recovery process. The meaning behind believing in a higher power was not closely examined; however it was clear that for many consumers this was an important element in recovering from mental illness.

### **iii) Regaining losses**

Consumers' believed that they had lost a variety of skills, capabilities and confidence as a result of experiencing mental illness. These losses are associated with relationships and consumers capacity to participate in the life they wish to live. Regaining some control over the interpreted losses provided a sense of purpose for consumers'.

#### ***Social***

Losses in social functioning are connected with friendships, romantic relationships and family relationships.

*Faith: I lost all my friends when I got unwell, and I really hurt all my family.*

Consumers' discussed being unhappy with their current relationships which they believed had been negatively impacted by their mental illness.

#### ***Capacity***

Losses in capacity relate to the way mental illness has played a role in reduced functioning in the areas of employment (which has been discussed previously), independence and achieving goals. Having the ability to recapture control over these areas of functioning was discussed as being positive for recovery.

*Diane: It isn't going back to my old lifestyle, its finding a new lifestyle that suits my capabilities. My capabilities have changed, I'm not functioning like I used to be.*

Being independent and achieving personal goals were two aspects of functioning which some consumers desired to have more influence over. For some consumers' this involved living independently which was, or was to be, achieved by moving towns or finding alternative accommodation.

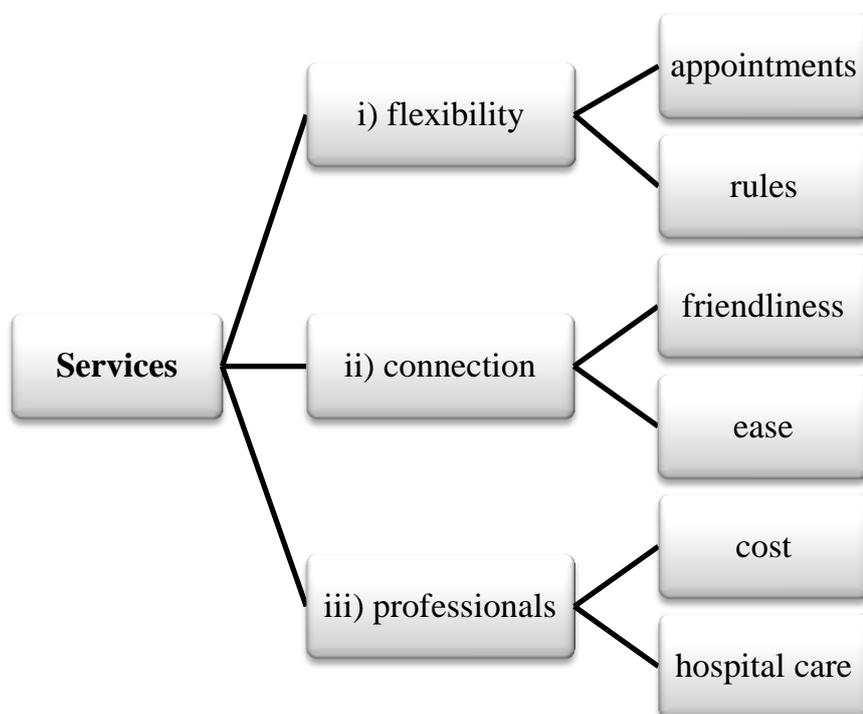
### **Summary**

Finding a sense of purpose and reason for one's life was a common theme presented by consumers. A sense of purpose was gained by consumers' having the opportunity to gain employment, which provided incentives relating to

finances, socialising and daily structure; however consumers' identified that they required support to reintegrate back into the workforce. Purpose was also achieved by being a member, either in a sports team, church group or other social group. Membership provided the opportunity for consumers to experience pleasurable activities and emotions, and also served the function of motivating consumers to participate in daily life, provided them a sense of belonging and enabled them to develop their spirituality. The final method of increasing purpose was in regaining control over the losses which had occurred as a result of experiencing mental illness. These losses were often encountered in relationships which were not meeting the expectation of the consumer and in reduced capability to work and live independently.

### C. Services

The 'Services' theme emerged from consumers responses to, and experiences of, mental health services in Cambridge. The following diagram identifies factors associated with this theme, especially significant were service flexibility, connection between services, and the role mental health professionals play in service delivery.



**Figure 4.** Overview of the main topics from the services theme

### **i) Flexibility**

Consumers identified that one does not know when a crisis is going to come, and cannot plan for it completely. Therefore it would be beneficial to have services that are flexible enough to accommodate individuals who do not fit into a regimented structure. Key ideas that surfaced were related to appointments and rules which govern organisations, which will both be expanded upon.

#### ***Appointments***

Consumers recognised that time spent with health professionals can be beneficial for their recovery from mental illness, especially in times when they are experiencing severe symptoms associated with their disorder. Accessing services which had long waiting lists (4-6 weeks) were a common trend among consumers who participated in this study. Some consumers had experienced services in Cambridge that allowed them to skip the waiting list in response to the severity of their presentation.

*Louise: I came to this one service, they had a wait list of six weeks. They were good though, they let me come in sooner as they could tell I needed to talk with someone.*

Other consumers had experienced services which did not alter the length of time on the waiting list and they thought that accessing the service would be pointless as the crisis would have passed.

*Kevin: So when you go low there isn't a red phone you can call and get the help you need. Quite often if you require a service by the time you wait you have got better and endured it all by yourself.*

Consumers also found it useful when a service remained flexible to allow an appointment to run overtime if required.

#### ***Rules***

Consumers raised the concern that when organisations focus too much on rules and regulations that a barrier is created, as Craig described it;

*Craig: It undoubtedly creates an 'us' and 'them'. I guess it's tolerance. If you walk into a place that is predominantly about rules and regulations, it doesn't lend itself to tolerance, it shows that the structure is more important than you.*

Consumers accepted that many organisations hold specific funding contracts which binds them in a sense, however the suggestion was made that the person accessing the service still needs to feel more important than the paperwork. From consumers' experiences, organisations that strongly stick to bureaucratic rules are not friendly places.

A desire was expressed that services address a range of issues that consumers present with instead of sticking tightly to their organisations rules. This was expressed when consumers complained about services refusing to help them in specific areas because there was another organisation which provided that service. Services were described as better when they would help the consumer with any problem, and only refer the consumer on if the issue was significantly outside their area of expertise.

*Craig: [specific service] is flexible...others are not...there is nothing worse than going somewhere and being told 'oh no this is the wrong place, you need to go there' then you get to the other place and they do the same.*

## **ii) Connection**

Having services which are connected and networking with one another makes accessing services an easier and more pleasant experience.

### ***Friendliness***

Consumers identified that services appeared to be friendlier when they knew their individual case. In order for this to happen there needs to be networking between different organisations so that all services working with a particular client are aware of the needs at the present time. Consumers perceived organisations knowing their case as them being friendly and caring, promoting a desire to access services and therefore promote recovery from illness.

After using mental health services for a significant period of time in a variety of situations, Adam explained that Cambridge has ‘*no sense of connection with facilities here...it feels nonexistent here*’.

### ***Ease***

Similarly to friendliness, consumers prefer organisations to share information about their case to make sure that accessing services is an easy process. The procedure of explaining the details of their case to every provider they encounter was perceived as a negative experience by consumers, which could be avoided by networking.

Networking can serve to maintain motivation for consumers to remain in services, as moving between providers with no connection can allow people to ‘fall through the cracks’.

*Neil: There was no communication between the GP and the [other mental health service provider]. If there was some dialogue between the two it would have been better at keeping me committed to therapy.*

Consumers also highlighted the difficulty of trying to make contact with services for support during a time of crisis or serious mental illness.

*Adam: my wife did all the phone calling for me, there was no way I was up to that.*

*Isabelle: When you're not well and not thinking straight you don't have the wherewithal to go and do the research and look stuff up.*

It was seen as the role of the GP who consumers were dealing with to facilitate the connections between service providers, however this will be discussed more in depth in the ‘Access’ theme.

### **iii) Professionals**

The role that professionals have in service delivery has been associated with two main factors for consumers, cost and inpatient care. The cost of professional care can serve as a hindrance to early access to services, while hospital care is associated with fear prior to being admitted but relief and safety while in hospital care.

## ***Cost***

Issues surrounding the cost of mental health services are associated with GPs, specialist mental health services and community based service providers. As a result of the high cost of seeing a GP, many consumers acknowledged that they would prefer to wait until they were desperate to see a doctor in order to save money.

*Louise: I ended up not being able to afford to go to my GP, so I waited for the emergency doctor. Problem is that they don't have your file and they don't know your case.*

It was not only GPs who were criticised for their high fees; counsellors, private psychologists and psychiatrists, and other mental health providers were also negatively appraised regarding their costs (per appointment fees) being a barrier to effective care.

*Neil: Money is not a problem for me...but I can understand that for people who are looking for where the next dollar is going to come from, then that can be a difficult thing for them to afford counselling.*

*Betty: I had a therapist lined up and I was really excited. But, it was a decision of do I pay the mortgage, eat or see my therapist. You can tell which one is going to go to the bottom of the list.*

The response some consumers had to the cost of mental health services, was to try and access services via the public health system to be able to get them free of charge.

*Isabelle: I needed to go down the public health line because we were financially in the crap.*

A more in depth assessment of access via secondary services is discussed in the 'Access' theme.

## ***Hospital Care***

The majority of respondents identified that before accessing hospital care they were anxious about the process and had often heard negative reports surrounding inpatient care. For those consumers who had been in hospital care for their mental illness, there was an overwhelmingly positive response to the overall

delivery of services. Hospitals were seen as a place to have time out, to be safe and to get medication stabilised.

*Faith: It's [hospital] good because it settles you, brings you back down. You feel safe and there's always someone you can talk to.*

*Diane: the hospital was good because I felt safe there, I didn't really want to go home. It was just a good respite time.*

One criticism consumers had of hospital care was the lack of consistency of staff members who dealt specifically with their case, especially psychiatrists.

Connected to the use of hospital care were crisis services, of which the majority of the consumers who participated in this research project had used. There was significant variability in consumers' experiences with crisis services provided via the Crisis Assessment Team (CAT), a publicly funded mental health service. Some consumers' positively recalled their experience with the CAT, explaining that it was beneficial to have someone to talk to in the crisis.

*Diane: ...from ringing the crisis team, just having that contact with another person, having someone say you are doing well and that you can cope. I makes me think, yeah I can cope.*

Others perceived that the CAT were unhelpful in their recovery journey as a result of their negative attitudes.

*Faith: Some people are scared of them [CAT] because they rough you up...and they can be really nasty.*

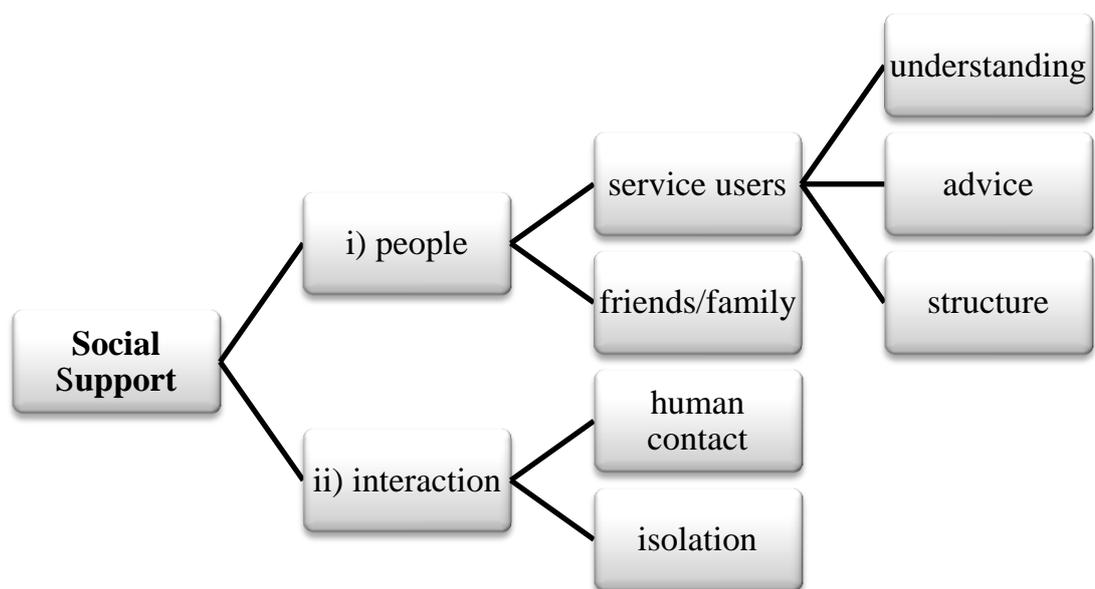
## **Summary**

Services significantly impacted consumers' experiences of mental illness and their journey towards recovery. Consumers identified that services were more supportive when they were flexible, both in terms of appointment length and the rules which govern the agency (e.g., waiting list times). Having a sense of connection between service providers was a recovery promoting feature, as consumers' found services that appeared to 'know their case' as more friendly and that when there was connection between service providers the referral process was easier. The cost associated with professional care was a barrier to service delivery

which often resulted in consumers delaying help-seeking or attempting to access services via publicly funded services. Hospital care was presented in a positive light by those who had experienced inpatient care; however fear was linked with inpatient care for people who had not experienced it.

## D. Social Support

The following section expands the ‘Social Support’ theme which emerged from consumers’ responses to the research. The main aspects of the theme are the supports received from people, both services users and friends/family, and the impact interaction with others can have on overall recovery promotion.



**Figure 5.** Overview of the main topics from the social support theme

The importance of having strong social support networks emerged as a theme from consumers. Social support relates to contact and meaningful relationships with peers, both services users and non-service users. The relationship that one has with peers satisfies a need for human contact, which reduces how isolated one feels and subsequently reduces the severity of mental illness symptoms. The relationships past or present services users have with one another provides a deeper level of understanding (developed from experience of mental illness) and allows for the sharing of advice and experiences. While consumers reported that

social support was an essential component to recovery they described that it was only one aspect and was not sufficient to promote recovery in isolation.

### **i) People**

A clear distinction was made between the support consumers' received from friends and family who had not been mentally unwell and the support they received from people who had experienced mental illness themselves.

#### ***Service users***

Support from past or present services users was identified as an important feature in recovery from mental illness as they provided understanding and advice from a firsthand perspective. A number of consumers' expressed opinions of how peer social supports could be enhanced within Cambridge, and outlined potential strengths and weaknesses of peer support services.

The most dominant suggestion for improving peer social supports was the use of support groups or drop in centers, where peers could socialise and learn from one another. The lack of peer services in Cambridge was evident with many consumers' responses, such as:

*Maggie: it would really help if people with mental health concerns in Cambridge could meet with one another.*

*Heather: The other thing I thought about was peer support groups – as far as I am aware there is nothing here in Cambridge.*

The two main reasons which consumers discussed for having peer support groups are outlined by the following quote:

*Adam: Having a support group for people with depression would have been helpful, to be able to talk to them about what has helped them, or just about what we are going through.*

Two essential components of peer support is that fellow consumers', past or present service users, can understand the situation better than those who have no personal experience, and also consumers' would like to have the opportunity to share knowledge with one another about effective strategies to promote recovery. These two ideas are discussed in more detail below.

## Understanding

Spending time with people who had had similar experiences provided an accepting and normalising environment for consumers to discuss some of their concerns. It appeared that there was emphasis placed on peers normalising consumers' experiences, as this reduced anxiety surrounding their feelings and symptom presentation.

*Emma: Someone who has been through the same situation, they can reassure you – that it's normal feelings. They understand you and can support you...If people don't know the situation they may tell me that what I'm feeling isn't normal, but it may be perfectly normal for the situation I am in.*

A consistent pattern of consumer responses was the frustration of explaining how they felt and trying to make other people understand their difficulties. Availability of consumer run services would eliminate this frustration as they described that they could spend time with people who completely understood their emotions and situation.

## Advice

Consumers described that by spending time with peers who were further along in their journey of recovery than they were, they could learn different approaches to dealing with their illness. This was a significant component in the desire for peer support groups to be run, to allow consumers' to discuss with one another how they attained/maintained wellness. Some consumers' were concerned that support groups would not serve the function of sharing advice between consumers' and would instead be a place to compare symptoms and situations, and have the opposite effect than intended.

*Heather: it has to be about learning too, you don't want it just to be a whining session, it has to be about things that people have found to help them.*

A number of consumers identified specific features of peer support groups which they thought were important for them to have optimal functioning, which leads to the discussion of how a peer support group would be structured.

### Structure

There was some difference in opinion as to the best time, location and overall structure of a peer support group. The most common suggestion was to have a peer support group meeting during the day, as this was a practical time for consumers to interact with others. As a result of their medication use, mornings were not seen as an appropriate time, however from mid morning to late afternoon consumers thought they would benefit from the social interaction a support group would provide. One consumer suggested that an evening would be the best time for a group to meet, as she found it hard to socialise in the evenings as she had no one to socialise with. She thought that the challenge of meeting at this time would promote recovery as it would help to train people to socialise again. Concern was raised by consumers who were in fulltime employment, as it would be difficult to attend support groups during the day.

*Heather: Perhaps it could be a daytime thing and then have events planned for the evenings. Like plan a meal... Just to get people doing things.*

Consumers reported that they wanted the support group to be located in a neutral environment that also had an element of privacy.

*Heather: I thought about a church but some people would exclude themselves, so probably just a hall...I don't think it would work in a café because you would be talking about things that you don't really want other people to overhear.*

The types of location varied between consumers, which was associated with what they perceived as being a support groups primary function. For those who wanted the opportunity to share knowledge and gain advice from other people's experiences, such as Heather (see above quote), a hall or private location appealed. However for consumers such as Isabelle, who wanted a support group as a means of interacting with other people purely for social reasons, a café or public social setting was encouraged.

*Isabelle: But then sometimes be able to go and go for a walk, go to a movie. Not just always sitting around talking about your problems. That would also be really beneficial, doing something fun together.*

A consumer run service in Hamilton, called Centre 401, was discussed by consumers as an example of what could work as a model in Cambridge. The setting of Centre 401 was seen as a positive environment for consumers to get together and spend time in one another's company, and a number of consumers in this research suggested a similar model in the form of a drop in centre. Positive aspects of drop in centers were somewhere to go and spend time with other people. Programs which were run through Centre 401 were also discussed by consumers, especially the peer support group called 'Psycoffogee'. 'Psycoffogee' is a support group where consumers meet in a café with a recognisable object on the table as a form of identification. Isabelle described how she found the anonymity of 'Psycoffogee' beneficial:

*Isabelle: no one else in the café needs to know that you are there for that purpose. I think that's really funky.*

Some ideas emerged surrounding whether to include professionals in support groups or if they should be run solely by consumers. The majority of consumers who discussed support groups recommended that there be some form of professional involvement, either in the beginning stages or as a guest speaker at meetings as a form of education for the group.

*Isabelle: I think it would be helpful at the initial set up stage to have a professional to organise it. It can be really stressful to go to something new, but if there is someone there who is helping to greet people and get it all started.*

One idea which emerged was the need for a mixture of consumers and either volunteers or professionals, as some consumers were concerned that spending too much time with other service users could be detrimental to their overall mental health.

*Faith: someone people say it's not good to hang around with other people who are sick because there are too many triggers. But a mixture of people with some volunteers would be better.*

*Betty: I went to one support group...if I wasn't depressed when I went in I sure was when I came out. The people just sit there and look so blankly...I can't take that.*

*Isabelle: But then I also see that it could be a bad experience that people would sit there and just talk about medication or almost compete with one another for who is feeling the worst.*

A number of consumers raised concerns that although they identified support groups as being good they did not think it would be suitable for them, and or for Cambridge. Cambridge is a small town and some consumers identified that there could be problems with a lack of confidentiality.

*Louise: Problem with Cambridge is that it is so small, and everyone seems to know everyone's business. If I went to a support group it would need to be really confidential.*

Another concern was that some consumers would not be able to cope with leaving the house to attend support groups. Some suggestions which were made were around the use of technology to promote contact between consumers without the stress surrounding group meetings. Technology in the form of internet support groups, or a buddy system set up using telephone calling were raised as potential options other than support groups.

One consumer raised an issue which related to the level of wellness within the group, and the detrimental impact individual people can have in a group setting if the group is not properly managed.

*Neil: You have to have the right people in the group, otherwise some people can make things bad for everyone else. How well the group functions can depend on the level of wellness within the group.*

A number of consumers, who were categorised in the severe mental illness range and under the public mental health service, disclosed that they would not attend support groups as they would find being with a large number of people too stressful.

*Betty: Oh a support group wouldn't work. That would be too unraveling, to tell all those people about myself.*

*Diane: The energy in the room is too much for me. Just too much for me to handle, I'm better in one on one or very small groups*

Overall, peer support was considered an important component of recovering from mental illness and there were a variety of structures that consumers identified as effective for facilitating social support from peers. Support from friends and family was also considered valuable by consumers.

### ***Friends/family***

For many consumers' friends and family made a significant impact on their journey of recovery, in either a positive way, a negative way, or as a combination of both. Some positive impacts that friends and family had on consumers were their practical support in accessing services, such as help with making appointments and providing transport, and their emotional support when required. Some consumers had lost contact with, or perceived a lack of emotional support and understanding from their friends and family, which was interpreted as negatively impacting on their recovery.

Accessing services is discussed in detail as a theme itself, however the involvement of friends and family in providing assistance to make access an easier process is discussed here. Out of the fourteen consumers who participated in this study, there were six who did not have access to a car or who were unable to drive. For some of these people family and/or friends were able to provide transport to and from appointments, however some consumers were unable to attend services as they had neither family nor friends who could assist them.

*Gail: Yeah my flat mates drive me in [to appointments], I don't have a car. They are really supportive.*

*Jack: My brother drives me around, I spend a lot of time with my brother.*

*Faith: My daughter went overseas so I borrowed my daughter's car, which was lucky otherwise I wouldn't have a car.*

Emotional support was described as an important element friends and family provided. A number of consumers commented that they had good social supports, but reflected that if they were not in such a fortunate situation they predicted that they would not have been as well as they were.

*Adam: Having someone that I can call at 3am if things are really bad, and knowing that they will come over, that's what helps me recover. Having that support keeps me going.*

Even when consumers did have families and friends around them, they did not always perceive that they were being emotionally supported to the level that they expected.

*Isabelle: Even if I try tell my husband how I feel, he has no idea. He makes some comment that he thinks is helpful and all it does is kicks you in the guts again...I have lots of people around me but not a lot of close friends that I can talk to.*

In response to the frustrations that some consumers found with the lack of understanding from family members, some thought that support groups could fill some of those gaps.

## **ii) Interaction**

A large factor in the theme of social support was the interaction that consumers had with other people, which reduced their overall level of isolation. The need for human contact was identified as an important concept in recovery, especially as technology has become more prevalent and therefore everyday dealings with other people have decreased. Isolation was found to have a significant impact on mental illness and was specifically related to self harm.

### ***Human Contact***

The lack of interaction on a daily basis with other people appeared to be a barrier to recovery for some consumers. Consumers' described that at times, they had minimal interpersonal contact and believed that this led to a feeling of being disconnected from society.

*Diane: It's the contact with another human being that's really important*

*Neil: If it wasn't for the support from my family and from my workplace I don't think I would have recovered as fast as I did.*

The structure of services was also discussed under this heading of human contact, in particular the recent focus on having technology based services, such as

services delivered via the telephone and internet. The consumers who talked about technological service delivery did not believe that it was enough to promote recovery; rather human contact was required in addition to internet or telephone services.

### ***Isolation***

For consumers in this research being isolated from other human interaction negatively impacted the recovery process. This isolation was as a result of the loss of employment, loss of relationships, and overall perceived disconnection within the community.

*Kevin: There is a real loss of community. How many people know their neighbours by name? It is not common anymore to know the people closest to you.*

Not having friends was also connected to being isolated. Some consumers identified that they believed that the level of isolation that they experienced was either connected to why they had a mental illness or was a barrier to their recovery from mental illness.

*Jack: I don't have any friends. I used to like being a loner but I changed my mind about that, I would like to have friends.*

*Isabelle: When things turn to custard I withdraw. I feel so unable or unworthy of reaching out to people, so there probably are people that I can reach out to, but that doesn't mean that I actually ask them.*

*Craig: that's a big part of the problem, I'm a...loner*

In some consumers responses it was evident that one of the outcomes of being lonely and isolated was an increase in their self harming behaviour. Diane discussed that at certain times of the day or week, when her loneliness peaks; she is more inclined to self harm as a coping mechanism for her emotion difficulties.

*Diane: Weekends are the hardest time, so that's when I over medicate ...That's the time you do things with your partner – that's what I've found the hardest, being by myself and not having anyone to do things with and talk to.*

Isolation can be altered by small changes in consumers' lives. Craig explained that it is the communication with people on a very low level which can oppose isolation such as seeing people in the street from a support group that you have attended.

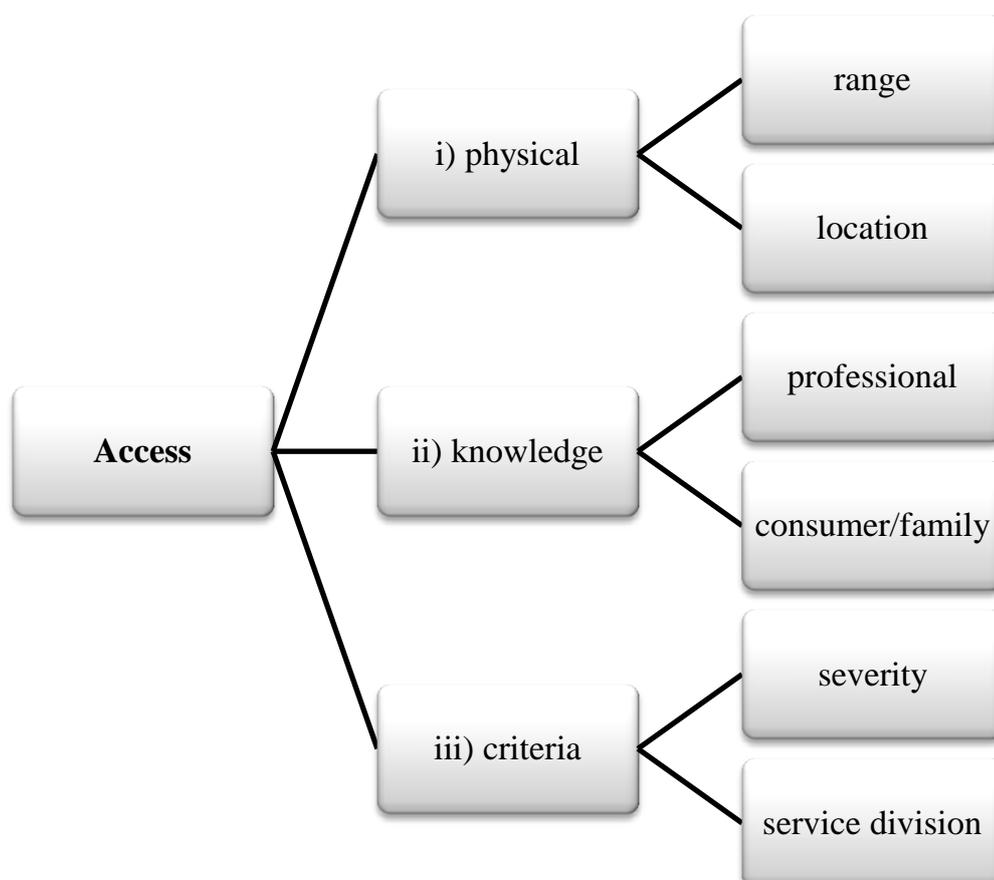
*Craig: well if you meet people in the group and then you walk down the street you can say hello to them on the street, just being able to nod to someone on the street can take the edge off a bad day.*

## **Summary**

Social support was identified as a feature which significantly impacts the journey of recovery from mental illness. Support from people, either fellow consumers or people who do not use the mental health system, emerged as an important factor for promoting recovery. Specific aspects which were effective about the support from consumers' peers were the advice that was shared from learned experience and the understanding, acceptance and normalising. The practical and emotional support friends and/or family provided served as a positive factor in the journey of recovery. Interaction with other people, whether service users or not was important for consumers, to reduce their isolation and also manage their illness.

## E. Access

The importance of consumers' having access to mental health services became apparent through participant responses from this research. Access is discussed in three main parts; physical access, knowledge of how to access, and the criteria which impacts access.



*Figure 6.* Overview of the main topics from the access theme

### i) Physical

Due to the size and location of Cambridge, there were physical limitations to accessing suitable services. These limitations are considered under two categories; range and location. Range refers to the availability of services, especially specialist services which are often required for people with mental illness. Location relates to where and how services are provided and discusses factors which may impact access based on location (such as transport availability).

### ***Range***

When discussing the range of services that consumers had access to there were a number of issues which arose, most of which were criticisms of current service provision. Overall the availability of all mental health services were reported as below the required standard. Consumers talked about the range of services being too small in Cambridge, as there was often only one organisation providing a specific service, and access to the service was generally impacted by a long waiting list. One particular type of service which was reported as being unavailable due to long waiting lists was the drug and alcohol services. Isabelle described the problem with drug and alcohol services as being due to the low level of contract funding allocated to organisations in Cambridge, which she did not believe was reflective of the population or needs of the local people. Isabelle had experience working in a provider organisation and had an understanding of the barriers from both a consumer and a provider perspective.

*Isabelle: The alcohol and other drug contract is only 0.5 FTE and this has been the same for 10 years, but the need has definitely increased. So you have to wait for a long time to get into see someone*

Similar to the drug and alcohol services, consumers expressed that there was generally a lack of quality specialists who were available to people in Cambridge. Some consumers who had accessed services in larger areas perceived that they would be settling for a clinician who did not meet their expectations if they were to use only the clinicians available in Cambridge. This related to specific characteristics of the clinicians (such as gender or age) as well as their qualifications and ability to work with certain clients.

*Adam: There was only one male counsellor in Cambridge, and I know him too well to go to him. Plus he was a new graduate. So I had to go to Hamilton.*

### ***Location***

The physical location of where services are situated had an impact on consumers and the interpretations of the services they had received. As described in the

social support section, many consumers use services in Hamilton and depend on family/friends to get them to and from appointments. One participant noticed a discrepancy between the services which are available in Te Awamutu, a similarly populated township the same distance from Hamilton as it is from Hamilton to Cambridge. This participant questioned why Te Awamutu are entitled to the range of services based in their own community whereas Cambridge is required to travel to Hamilton in order to gain the same range of services.

*Adam: They are the same distance from Hamilton, and basically the same population but Te Awamutu gets way more. It makes me want to change my address so I can get a whole lot more.*

Some consumers reported that they believed they would have progressed through the recovery journey at a faster pace if the majority of services they required were available within their own community.

An issue related to physical access, but not geographical location is the availability of services based on the opening hours. Consumer responses highlighted the importance of having access to services outside the normal work hours.

*Faith: You can't predict when you are gonna be feeling crappy...[services] are only 8.30-4.30, so I can only get crappy between those hours, and then the weekends and evenings there's nobody.*

Consumers' who worked full-time jobs also expressed that services outside of regular work hours would be beneficial for them.

## **ii) Knowledge**

Access was found to be significantly impacted by the amount of knowledge which both professionals and consumers/family members had about mental illness and the services available. A large part of professionals' knowledge refers to assessing when to refer clients on to more specialised mental health services, based on understanding the early warning signs of mental illness, as well as the knowledge of who to refer them on to.

### ***Professional***

Consumers had a general consensus that their General Practitioners (GPs) were supportive in prescribing medication, but when it came to understanding the features of mental illness and the needs of the mentally ill they provided very little support. Louise summed her perspective up by saying:

*Louise: GP's aren't specialists; their name says they are "general" practitioners, so they really don't know anything about mental health.*

Consumers believed that this lack of knowledge about mental health impacts doctors' ability to pick up on the early warning signs of someone becoming mentally unwell.

*Adam: The GP needs to know when to make a loud enough noise so the hospital system will listen.*

Missing these early warning signs results in people often being referred on to other services at a late stage, rather than gaining the extra support as soon as possible. Consumers perceived that there was an advantage of having a medical professional advocating for them, especially when trying to gain entry into the public mental health service.

### ***Consumer/family***

Knowledge that consumers' and/or family members had about the availability of mental health services was described as a factor that influenced access. A lack of knowing what services were available was a common trend among consumers, with many people expressing concern that they did not know where to go when they became unwell. In response to this lack of knowledge consumers often went to the GP, expecting them to inform them of what to do. However, as described earlier, consumers in general were disappointed with the apparent ignorance of GP's in relation to issues surrounding mental health.

Consumers who had been involved with mental health services for long periods of time expressed that they were aware of the places they could go for support and guidance. Consumers who had been involved especially with the public mental health service explained that they would be more able to deal with the system now, as they had previous experience and knew what to expect.

An increase in awareness of the early warning signs of mental illness for consumers and their families was portrayed as being beneficial.

*Isabelle: so you're family members need to be educated about what to look for. They don't get told about any of the warning signs or who they should call.*

### **iii) Criteria**

The importance that organisations place on consumers to meet specific criteria in order to access the service came to view as a significant barrier in accessing services. 'Criteria' was discussed in relation to both the level of severity of mental illness the consumer was experiencing and in terms of the way services have been divided. Public health services were more often discussed under the severity heading while service division often encompassed issues connected to NGO's and primary health care.

#### ***Severity***

The severity of mental illness that consumers experienced was perceived as something that significantly impacted their ability to gain entry into services appropriate to their recovery. The majority of consumers who discussed the issue of severity were referring to access of mental health services from the public health system. The public health system required consumers to experience severe mental illness before they were eligible for their services which consumers perceived as a barrier to appropriate care.

*Adam: It seems with the public system that they basically want you to go away and get worse. You have to get to a crisis point before anything happens.*

Entry pathways to public mental health services which consumers described included self-referrals, referrals from GP's or other organisations, by calling the CAT, or via inpatient admission. For consumers in this research inpatient admission followed a crisis, which was generally either an attempted suicide or a manic episode. Consumers who had been admitted to inpatient services, provided by Henry Rongamau Bennett Centre (HRBC), explained that their entry into public mental health services was straightforward, as public mental health service providers visited them in the ward and organised mental health support for them.

*Diane: I used services in Auckland...I had my first crisis down here, rang the crisis team, they got my notes from Auckland, put through a referral and then I got allocated a nurse...been pretty easy...I have slotted into the mental health system really easily.*

A common theme from all consumers, who had not had inpatient care and attempted to access public services, was the perception that they were not severe enough to gain support from the public health system.

A noticeable theme which emerged from some of the male participants was the need to exaggerate their symptoms to be accepted into the service. In general the male consumers expressed that the process of 'pleading their case' to gain access was an uncomfortable experience for them.

*Adam: I had to overstate my case in order to get accepted into the public service, which is not what I am about.*

From consumers who had received services from the public health system, a fear of the discharge process became apparent. The response to being afraid of discharge took two different forms. One was being aware of the support they had received from the public service and the need for discharge to occur, but being afraid of what supports, if any, would be in place following their discharge. The second response was to ensure that discharge did not occur, by remaining unwell to stay within the public system.

### ***Service Division***

The separation of services, and need to access a range of services provided by different organisations was seen as an issue when accessing mental health services. This was particularly relevant for services provided outside the public system, such as in NGO's and primary health settings. Service division referred to the way services within a town are split to provide different aspects of mental health care, such as different services for crisis care, drug and alcohol counselling, general counselling, couples counselling, and financial support and so on. Some aspects of service division have been explained previously, such as the importance of networking.

From consumers' responses it became evident that there was an understanding of the funding barriers which may result in divided services,

however accessing divided services was described as a negative experience for many. Influencing this negative experience was the need for consumers to explain their situation to a number of service providers, whereas the preference would be to explain their circumstances to only one service.

Consumers' reported being skeptical of the mental health system when there was significant service division, as they perceived that they were passed from one organisation to another. This transfer between organisations was perceived by some consumers as no-one caring about them.

*Louise: no service wanted to support me, they just kept saying that I had been discharged and referred back to my GP. It made me feel like nobody gave a shit.*

### **Summary**

Access to services was found to be dependent on a number of factors, physical access, knowledge of what is available and criteria for specific services. Physical access was impacted by the range and appropriateness of services which were locally available as well as factors influencing location, such as availability of transport. Knowledge of what is available had two elements, professional knowledge and consumer/family knowledge. Professionals were seen to be lacking in knowledge of what services are available and when the best time is to refer on to specialist services, while consumers believed they were ill-equipped to deal with the mental health system unless they had prior experience in accessing services. The criteria for accessing services were controlled by the severity of consumers' symptoms, with only those with severe mental illness being accepted into psychiatric services. Access to psychiatric services was a straightforward process for those who had been admitted into inpatient care; however for people who attempted to self-refer access was difficult. Those who were required to access other mental health services found the division in services difficult, as it required consumers to access services from a range of organisations rather than one overall service.

## **Chapter Summary**

There were five key themes which emerged from consumers responses about their experiences with mental health services while living in Cambridge. The theme of 'Recovery' incorporated consumers' understandings of the term recovery and explored factors which are important in the facilitation and maintenance recovery as well as specific barriers. Developing a 'Sense of purpose' was described as an important factor in facilitating recovery and involved gaining employment, becoming a member in a group and having an opportunity to regain some of the losses associated with mental illness. 'Services' were a key part of consumers recovery journeys with important features being the flexibility of service provision, the connection/coordination between service providers and the individual thoughts consumers had on professional care in hospital settings 'Social support' emerged as an important element of recovery facilitation and was connected with support from people, either other consumers or family and/or friends. The interaction with people was also an important aspect in this theme as human contact was essential in reducing isolation. Consumers discussed 'Access' as an important issue, specifically in relation to how physical factors, knowledge of services available and entry criteria impacted their ability to be involved with services. Overall, these themes identified key areas in which consumers considered service provision to be effective, consumers understandings of reasons why services were ineffective and suggestions for improvements in overall service delivery for the people of Cambridge

# CHAPTER FOUR

## Discussion

### Overview

This chapter discusses the implications of the research findings with respect to consumer perspectives of mental health services in Cambridge and how effective these services are in facilitating recovery. A summary of the major results, followed by a discussion of those results against the literature reviewed earlier is presented. This is followed by an examination of the limitations of this study and areas for future research.

### Key Findings

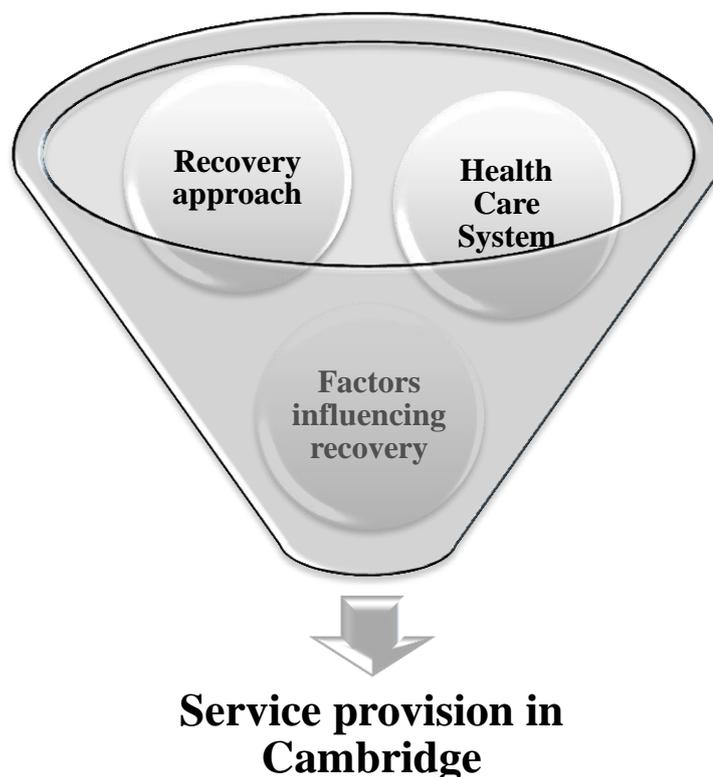
The results presented in the preceding chapter indicate that the current mental health services in Cambridge are not meeting all the needs of people on the journey of recovery from mental illness.

For consumers who had severe mental illness, met the admission criteria and were able to access public mental health services, the service delivery was mostly adequate with some suggestions of peer support services and further education surrounding mental illness which would aid their recovery. At the other end of the scale, consumers who experienced mild mental illness also suggested that peer support services would be the most beneficial addition to mental health services in Cambridge. However, for those who perceived that they were in the moderate-severe range of mental illness and unable to access public mental health services, there were a variety of barriers which impacted on effective service delivery and recovery promotion. The most salient issues for this group were: a greater emphasis on recovery principles from professionals including the promotion of consumer run services; the need for more affordable specialist mental health services based in Cambridge; a better referral process and more connection between service providers; the need for supported employment to

integrate consumers' back into the workforce; and an increase in knowledge of mental illness for consumers, their families and also for professionals involved with primary care.

## **Discussion of Findings**

The following diagram (Figure 7) illustrates the main ideas which consumers reported as impacting service provision in Cambridge, which will be discussed in relation to the existing literature. The three elements presented in the diagram, (recovery approach, system factors and individual factors) all combine to affect consumer's perspectives of overall service provision for the people of Cambridge. The use of a funnel diagram illustrates that all three aspects combine, and are connected with one another, to impact consumer's experiences of service delivery. There is no one feature which is more important and issues must be considered holistically, in connection with one another, in order to gain a full understanding of service provision.



*Figure 7.* Factors impacting mental health service provision for the people of Cambridge

Discussing whether the services which provide for people in Cambridge who experience mental illness are operating from a recovery ethos will be addressed first, as it is an overarching principle of mental health services in New Zealand, and will be compared to recovery movement literature. Secondly, health care system factors which impact on mental health care will be considered in relation to existing literature on the structure of mental health care and compared with consumers' responses. Third, the responses which reflect the impact of social factors will be compared to other studies, and finally, based on consumers' responses the overall provision of mental health services in Cambridge will be reviewed. Consumers' suggestions for improvements in service provision will be considered as well as the limitations of the current research.

## **A. Recovery approach**

The New Zealand mental health system is fundamentally focused on providing services in line with a recovery approach (MHC, 1998). The recovery approach emphasizes the importance of holistic, culturally appropriate mental health care, that empowers consumers' by treating them with equality, valuing their input and giving them choice and control over the services they access (Anthony, 1993; MHC, 1998). This approach promotes consumer involvement in the development and implementation of mental health services, and encourages consumers' to take on competent roles within services as well as in other areas of their lives (Jacobsen & Curtis, 2000). Essential to the recovery approach is that services need to instill hope in consumers' that recovery from mental illness is possible (Young & Ensing, 1999). Participants in the study recognized that elements of the recovery principles were being met by Cambridge services; however from their responses it has become evident that there is significant room for improvement. Consumers' perspectives of the concept of recovery will be discussed first, which will be followed by ways in which services are recovery focused, then concluding the section by explaining ways that services are not meeting recovery principles.

### **Meanings of recovery**

Recovery is defined by the Mental Health Commission (1998, p. 1) as "to live well in the presence or absence of one's mental illness". Participants in the

study all discussed their understanding of recovery, most of which was in keeping with previous literature on recovery (Anthony, 1993; Deegan, 1996) as well as the Mental Health Commission. Having a hope that life could be different, and recovery possible, was evident amongst consumers in this study and in previous literature (Anthony, 1993; Deegan, 2003; Ochocka et al., 2005). Participants described a desire to regaining some level of functioning, even if it were at a different level than prior to their illness, and to have a life that brought them happiness and fulfillment. There were three participants who believed that mental illness was mostly biological, and perceived that they would never recover because they would not be able to function without medication. It appeared that for these consumers, who did not recognize the possibility of recovery, their views of recovery were as a result of their dislike towards the label of 'recovery' rather than them disagreeing with the essential components of recovery philosophies. This was shown by these participants' revealing that although they did not see recovery as a possibility they still identified a desire to become well, aspirations for the future, a longing to return to a level of functioning that they could maintain in the presence of their illness, a hope to be able to support others to become well, and a yearning to find ways to manage their symptoms to have fulfilling relationships and an overall gratifying life - which were all consistent with the recovery literature (Anthony, 1993; Deegan, 1996).

### **Facilitators of recovery**

A response which emerged from five consumers responses was the development of spirituality which assisted their journey of recovery. The importance of spirituality on facilitating recovery has been documented by Turner-Crowson and Wallcraft (2002) as it aids the development of purpose among consumers. Ochocka et al's. (2002) findings are also consistent with consumers' responses as they explain that an inner strength, and increased motivation to recover, is developed from spirituality. Increased spirituality was also associated with the social support often gained from being a member of a church community, as described by consumers.

Membership, either within a church group, social group or sports team was commonly reported as being a necessity in recovery for the reason that pleasure was gained from membership as well as serving the function of increasing social

interaction (discussed under the heading ‘Individual factors’) and developing a daily routine. This finding is consistent with Young and Ensing’s (1999) findings that being involved in activities distracts the consumer from focusing on their illness and also provides an opportunity for positive social interactions and an overall sense of well-being.

Consumers in this research, as well as in other literature, found that developing a sense of purpose was an essential element of recovery, as it provided them motivation to recover, as well as enjoyment in daily life (Walsh, 1996). Having a purpose and meaning to one’s life also cultivates hope, by aiming for a goal and believing that a better situation is possible (Schiff, 2004). Employment was a significant factor in the development of purpose; however consumers discussed difficulty returning to the workforce, especially after a prolonged period of unemployment. Employment support will be discussed in detail below under the ‘Provision of mental health services in Cambridge’ section.

Ochocka et al., (2002) explain that when people become unwell, an important part of becoming well again is to accept that they have a new level of functioning and potentially different capacities compared to before their illness. Consumers consistently reported the difficulty connected with the losses associated with mental illness, which was acknowledged by the Ministry of Health (2008) as a significant issue. Consumers expressed a desire to regain the losses that they had experienced during illness but they accepted that their level of functioning may be different from what it was prior to their illness. Consumers desired to regain functioning in a range of different areas of their lives (e.g., employment, relationships, independence, and achieving individual goals) which Ochocka et al., (2005) also found to be important in moving forward after mental illness. Consumers who discussed regaining losses reported being self-reflective about their experiences, which is supported by Young and Ensing (1998) who identify that in order to regain what has been lost, to determine what is important to them, and to define realistic goals; the consumer must gain insight about themselves, their illness and their capabilities.

Taking the responses from consumers’ into consideration it is realistic to conclude that Cambridge service users’ concepts of recovery are in keeping with the recovery literature and with the New Zealand mental health system’s definition, however, misunderstandings of recovery terminology can serve as a barrier for some consumers.

## **Evidence of the recovery approach**

Recurrent positive responses about the services in Cambridge which describe recovery principles were the overall friendliness and caring attitudes of staff, the encouragement staff gave consumers to self-manage their illness, and for some the holistic nature of services.

Consumers reported the friendliness of some Cambridge services as a facilitator of recovery, which is in keeping with previous literature which discusses the importance of services providing emotional support for consumers (Deegan, 2003) and outlines the significance of service providers having high-quality interpersonal skills as well as being empathetic towards consumers and their families (Anthony, 1993). Consumers' discussed that services which displayed flexibility were perceived as friendlier and more helpful than services which stuck to the rules. This was exhibited by one NGO service altering the waiting list in response to a consumer who presented in significant distress, requiring an urgent appointment. Friendliness and helpfulness was associated with consumers being treated as equals, which is a facilitator of recovery according to recovery literature (Borg & Kristiansen, 2004; MHC, 1998). The evidence provided by consumers' shows that Cambridge services are meeting this component of a recovery ethos as a result of the positive descriptions consumers made of staff members attitudes who worked in Cambridge based organisations. Such positive feedback was not as prevalent for psychiatric services, as consumers reported that they received an unfriendly welcome from the public services they had accessed, especially crisis services, however all consumers' spoke very highly of the primary care worker (usually a mental health nurse) who was associated with their case.

Self-management of consumers' illness is a vital element of the recovery approach, as it values the knowledge of consumers and reduces barriers between professionals and consumers (Young & Ensing, 1999). O'Hagan (2001) outlines that professionals need to promote self-management by providing consumers with skills to encourage them to care for themselves. The mental health system especially in public health settings relies on consumers being able to identify if they are becoming unwell and take the necessary steps to regain wellness, which may involve re-entering the system. Consumers' highlighted that the most beneficial therapists were ones who placed emphasis on individuals learning skills

to promote self-management, which consumers' associated with becoming their own therapist (Anthony, 2000). The development of skills is a way in which services can promote self-management and avoid fostering a dependent relationship with consumers, as consumers must learn how to manage their symptoms in the absence of professionals (Slade, 2009). Fostering new skills can develop a sense of responsibility in consumers, encouraging them to develop self-determination to manage their illness which is also associated with increased self-esteem (Andersen, Oades & Caputi, 2003). All consumers reported that professionals they worked with encouraged self-management; however, the concept of self-management produced some concerns among consumers, which will be explored in more detail under ways in which services are not recovery focused.

A recurrent response among consumers who accessed psychiatric services was that the range of services and the availability of a multi-disciplinary team provided holistic care. Holistic care encompasses the many social, relational and environmental factors which impact mental illness, and does not treat symptoms in isolation (Broom et al., 2010). Psychiatric services linked between employment support services, arranged appropriate housing, and provided social and relationship skill development programs, all of which consumers found to be supportive. For consumers who were unable to access psychiatric services, there were common responses of the desire to have access to holistic care, however it was not currently occurring within other mental health services. Consumers identified that this may be as a result of the limited funding available and also as a result of the lack of linking between services, that service providers were unaware of the other community services which were available.

### **Evidence of the absence of the recovery approach**

Shepherd et al, (2008) identified that the most difficult feature of the recovery approach for organisations is translating the key principles into concrete changes. This appeared to be a difficulty in some organisations within Cambridge as consistent responses about the self management of illnesses, the lack of education, consumer involvement, and consumer choice identifies that there are some areas in which Cambridge services are not functioning within a recovery ethos.

As discussed earlier, self management of mental illness symptoms are associated with services working within a recovery ethos, as empowering consumers to manage without professional intervention is a key tenet of the recovery approach. However, consumers reported experiencing anxiety surrounding self-management and perceived that they were unable to identify when their symptoms were worsening and when they required extra support, as well as having uncertainty surrounding their ability to manage their illness by themselves. In line with Thompson et al's. (2004) findings, consumers' commonly delayed seeking help, as a result of being unaware of the severity of their symptoms and thinking that their symptoms would abate without professional intervention. Having support from family and friends who knew how to identify early signs of a deterioration of mental health was important, although consumers did not think their families had enough knowledge to effectively identify when they were becoming unwell.

Independent of whether early warning signs were identified or not, re-entering the mental health system was another problem when discussing self-management. Shame was identified as an emotion associated with re-entering the system after a period of wellness, as consumers' reported a sense of failure. Evidence from Dale Walsh (1996), who has experienced mental illness and is also a service provider, expressed a sense of shame and of failure when requiring re-admission to hospital following a period of self management. Re-entry was discussed by consumers in different ways. Three explained that re-entry was a smooth process as they were admitted to inpatient care in response to an attempted suicide. Easy access to inpatient services for people with severe mental illness was a goal of the Mental Health Commission (1998), therefore this is a positive finding for service providers. Two consumers with mild mental illness also experienced smooth re-entry as they did not have difficulty booking an appointment with a counselor. The final two consumers who discussed re-entry experienced obstacles when attempting to return to public services, as their symptoms were not considered severe enough to meet the entry criteria. This was interpreted by consumers as a reactive approach, rather than preventative, and they perceived that services expected them to become worse and then the service would provide care, rather than preventing symptoms from worsening. Recovery oriented services are services who accept that consumers' have significant knowledge about their illness, and value consumers' input into their recovery plan

(MHC, 1998). The findings regarding re-entering services are not in keeping with services working from a recovery ethos, nor are they in keeping with the preventative focus of primary health care services.

Treating consumers' with equality and respect is an essential feature in recovery oriented services, which can be expressed via the dissemination of knowledge surrounding mental health issues (Mancini et al., 2005). Participants in this study identified that they received very little information about their mental health diagnoses from services, especially evident when accessing support from a GP. No participant confidently responded that they had received adequate information regarding their diagnosis from any service provider, although some explained that initially their GP provided no information but they received some clarification from a counselor or mental health nurse. Most participants who accessed psychiatric services, who met the criteria for severe mental illness, reported that they did most of the research themselves in order to gain an understanding of their illness. One of the points in the guidelines for mental health services developed by the Mental Health Commission (1998, p. 16-18) states that, "recovery happens when mental health services protect service users' rights and treat them with respect and equality". Service users' have the right under the Health and Disability Commission to be informed by professionals of the information that is important for understanding their health or disability (Health and Disability Commissioner Act, 1994).

Other factors which consumers identified as not being in keeping with a recovery ethos were the lack of consumer involvement in service delivery, a lack of cultural services, and a disconnection between service providers both between primary and secondary services and within the primary care setting. These three points will be more fully discussed in the service provision and structural factors sections respectively.

## **Summary**

Key features of the meaning of recovery are having a sense of hope, a desire to regain some level of functioning, and to have a meaningful and fulfilling life. Important facilitators in the recovery process were having a sense of spirituality, being a member in a group, and having a sense of purpose for ones life. As the recovery approach is a key tenet of mental health services in New Zealand and

internationally it is important to assess whether services are functioning in a manner which is recovery-oriented. Consumers reported that the friendliness/helpfulness of services, encouragement of independence and the holistic nature of some services were recovery focused. On the other hand, the lack of education and consumer involvement, as well as reduced consumer choice was indicative of service delivery which was not facilitating recovery.

## **B. Health Care System**

The process of moving mental health care from psychiatric hospitals to community based settings, a process known as deinstitutionalization, significantly changed the mental health structure in New Zealand. Effective deinstitutionalization, as described by Gerrand (2005), requires that: effective community services are available; people with severe mental illness are well cared for; residential and inpatient services are available; services can be easily accessed; and that there is access to essential features such as housing, social interaction and employment. Critiques of deinstitutionalization have suggested that community services were neither well prepared, nor well funded, for the change to community based mental health care (Dew & Kirkman, 2002). There have been a number of system barriers identified, in both the research and previous literature, which reduce the effectiveness of mental health care in New Zealand and are not in keeping with Gerrand's (2005) effective deinstitutionalization requirements. There were three main areas identified under the heading of system barriers to care; access, funding, and primary health care, which all impacted the overall delivery of services.

### **Crisis services**

The DHB has a crisis service which deals with people who are at risk of harming themselves or others, and deals with consumers during crisis via telephone, by visiting their home, or by admitting them into the inpatient unit (MHC, 1998). Inpatient care is available for people who are acutely unwell, are unsafe to be within the community due to a mental health crisis, or need their medication to be stabilized (MHC, 1998). From consumer responses, there were two distinct impressions of inpatient care between consumers who had accessed

inpatient services and consumers who had not. Those who had been admitted to hospital for a period of time, to regain a stable level of wellness, perceived inpatient care as a positive experience, and were thankful for the safe environment. However, those who had not been admitted supposed that inpatient care would be a negative encounter and they displayed anxiety surrounding potential admission. Consumers responses who had experienced inpatient care was contradictory to previous findings by Sayce et al. (1995), who found that the hospital environment was a hindrance to recovery and that consumers did not believe hospitals were safe places for them to recover. Similarly Lapsley et al. (2002) found that New Zealand consumers had overall negative attitudes toward hospital care, however they found that people who stayed in hospital for shorter periods of time had more positive experiences. This may be an explanation for responses in the present study as all consumers had short stays in hospital in response to a crisis situation, in which Lapsley et al. (2002) also found consumers reporting hospitals as safe refuges for time out. Cambridge consumers did talk about being held in police custody until the hospital staff could care for them as a negative experience which was also found by Sayce et al, (1995).

A common response in relation to past literature was the high staff turn-over which consumers described as a negative experience (Sensky & Scott, 1995). One consumer in the present study recalled being in inpatient care and having a total of five psychiatrists deal with her over a period of a few months. She described repeating her situation to each psychiatrist and becoming frustrated with the lack of continuity.

## **Diagnosis**

Differences in experiences of mental health service provision in Cambridge were evident between diagnoses and as a result of specific diagnosis. The issue of acceptance into psychiatric services will be discussed below under access; therefore the differences that diagnoses make in promoting access will not be discussed again. One distinct trend which emerged was the fear of being discharged from services, and in response the development of intentional crises to avoid discharge. The idea of being afraid of the discharge process was fairly common among consumers' of psychiatric services as they were unsure what services were available within the community setting to support them. The

intentional self-harm for the direct purpose of remaining in the system and avoiding discharge was expressed by clients who were diagnosed with Borderline Personality Disorder (BPD), which may suggest that this response is influenced by the BPD diagnosis. Key features of BPD are intense and often erratic behavior, instability in mood, dependent and hostile relationships, and frequent states of crisis (Sadock & Sadock, 2007). For services to be recovery focused, as described earlier, there is an expectation that they will foster an attitude of independence among clients, encouraging them to manage their illness themselves (MHC, 1998). Consumers' who were involved with psychiatric services all discussed discharge as an inevitable process, suggesting that services are ensuring that consumers' are aware that acute mental health care is not designed as a long-term management strategy. This response reflects previous research which emphasizes the importance of having effective services for people with mild-moderate mental illness with coordination between primary and secondary services to ensure a smooth transition from acute to moderate care (Herman, 2001).

An aspect of diagnosis which consumers discussed was the impact of medication, and medication side effects, on their recovery journey. Consumers responded similarly to those in a study completed by Mancini et al, (2005), which identified facilitators and barriers to recovery, by mentioning that medication is important for their overall recovery and managing symptoms, but side effects can also be a barrier to recovery. One consumer discussed the side effect of weight gain as being a significant barrier to her recovery, and did not perceive that her psychiatrist was concerned about the impact medication was having on her weight gain. Both New Zealand and international literature has discussed the importance of treating mental illness holistically, however, from some consumers responses the holistic philosophy does not appear to be taking place in regards to medication side effects.

Another concern relating to a specific diagnosis was the lack of services for people with co-morbid mental illness and substance abuse/dependence. Addiction and mental illness are frequently linked in New Zealand with Adamson, Todd and Seligman (2006) finding that 74% of people attending a community alcohol and drug service also met the criteria for a mental disorder. Like with other mental illness diagnoses, access to services and support systems focused on addiction are beneficial for recovery. The paucity of addiction focused services in

Cambridge was discussed by consumers' who required such services, with only a recently started support group (Alcoholics Anonymous) and approximately six week long waiting lists for qualified drug and alcohol counselors. One consumer who had experience as a service provider explained that there was a need for an increase in funding for drug and alcohol services in Cambridge, as she did thought that the funding had not increased in proportion to the population's needs.

### **Access**

Accessible mental health services require services to be available within a close geographical proximity that are appropriate for the needs of the consumer. The eligibility criteria for services impacts access, as does the amount of knowledge consumers' and their families have about the services which are available.

In keeping with previous literature on availability of services, results show that the location of services significantly impacted consumers' ability to gain access as a result of their ability to meet the costs or practical requirements of travel (Panelli et al., 2006). For many consumers the distance to Hamilton was a barrier, generally due to financial factors such as no access to transport, or not enough money to fund transport (which will be discussed more fully under individual factors). Consumers' repeatedly reported negative experiences of being expected to attend appointments in Hamilton, either because the service they needed, or the service they chose, was not available in Cambridge. This was also a common feature in Hickie and Groom's (2002) findings, as people who do not live within cities were found to be disadvantaged by the lack of specialist services available to them. Providing consumers' choice as to the professional they work with promotes the process of empowering consumers, which is an essential component of facilitating and maintaining recovery (Lunt, 2004). Due to the small size of Cambridge and the limited range of services available (e.g., consumers reported a lack of psychologists, male professionals, and consumer run services and/or groups), consumers reported the need to travel to Hamilton for an appropriate range of services, but often did so reluctantly. Consumers who had gained access to psychiatric services expressed a desire for a satellite clinic to be set up in Cambridge to remove the stressors associated with accessing services based in Hamilton.

Another factor impacting access is the criteria which consumers need to meet in order to gain entry to some services. Entry criteria into publicly funded secondary mental health services in New Zealand is limited to people with severe mental illness, categorised as being in the top 3% of cases (MHC, 1998). This is in keeping the desire to ensure, that as a result of closing down psychiatric institutions, people with severe mental illness are cared for as best possible (Gerrand, 2005). However, as a result of the 3% criteria there is a significant number of people who have mild to moderate mental health concerns (Oakley Browne et al., 2006) who are forced to rely on primary health settings for mental health care or are left to develop their own strategies for coping. Consumers' reported that the entry requirement to gain access to psychiatric services developed significant barriers to effective care. Of the consumers who had attempted to gain entry into psychiatric services, and had either failed or it had taken a long period of time to gain entry, common responses of problems materialized. The Health Services Research Consortium (1994) identified that consumers feel under pressure to exaggerate their symptoms or focus specifically on describing certain symptoms in order to gain access to services. Consumers' reported feeling uncomfortable 'pleading their case' to psychiatric services as they perceived that they had to exaggerate their symptoms in order to meet the entry criteria. An interesting finding was that the consumers who reported being denied access to services as a significant problem were all men which raised questions surrounding the equality of service access between men and women (some female consumers discussed this as a minor issue). This is discussed in detail under the 'Gender' subheading of 'Individual factors'.

Another factor to take into consideration when discussing entry into secondary services is the method of entry. Of the consumers who had effectively accessed psychiatric services, the majority had done so via crisis services or admission to inpatient care during a crisis (including risk of harm to self or harm to others) or following an attempted suicide. Once these consumers had been admitted into inpatient care, they described the process of mental health services becoming involved as seamless, as they approached the consumer and made arrangements for care. Prior to their admission these consumers' symptoms were gradually worsening, however it was not until they were in crisis that they received mental health support. The Mental Health Commission (1998b) outlined that they had a desire to target at groups who were at risk of suicide in order to

improve the prevention of mental illness. Although there is a scarcity of research on the apparent ease of access during crisis, the apparent difficulty to gain access into specialist services, unless the severity of the consumer's illness has reached a crisis point does not appear to be in line with the ambition of mental illness prevention.

The final factor involved with access to mental health services is the requirement for consumers or family members to have knowledge of the available services in order to access them. Knowledge of services available has been found to be a barrier for people in the community in previous research, as a lack of awareness of services is a common trend (Department of Health, 1993). A finding from consumers was that there was a lack of awareness of services available from GP's who were responsible for referring them on to appropriate mental health services, which is consistent with previous literature suggesting that GP's lack knowledge which serves as a barrier to recovery (Pignone et al., 2002). This will be discussed further when primary health care is reviewed.

## **Funding**

Funding for services, influencing the type and accessibility of services, was another issue which arose from participants responses. Issues connected to funding, such as a lack of coordination between services, and the bounds in which services must work in order to meet their funding criteria are discussed.

Consumers' identified that there was a need for more publicly funded services based in Cambridge, especially from specialists such as psychiatrists and psychologists. Two participants had experienced being referred to a specialist service but were turned down as a result of the funding being 'used up'. The problem of under-funded services is discussed in the Mason report (1996) concluding that all services (crisis, assessment, treatment and continuing support) are lacking in resources (the number of staff that services can afford to employ as well as the quality of professionals) and coordination.

Not only are organisations limiting their cooperation with other services as a result of funding, they are also bound by the funding they receive. Many organisations receive contracts from government or other organisations to provide a specific service, which has found to have a mixed impact. Ashton et al, (2004) explained that contracting allows for greater variability in service delivery, as

services can develop to provide specific assistance to a sub-group, which was originally unavailable. However, from consumers' responses, there was a perceived lack of flexibility in the services organisations were willing to deliver, as consumers reported being told that they needed to attend a range of different services to meet their range of needs. Previous literature has explained that if consumers do not meet the criteria for the contracts service providers hold, then they can be denied entry into the service (Dew & Kirkman, 2002). This does not correspond well to previous discussions, in the recovery approach section, on holistic models of mental health care, which recognize the variability in service users needs and believe that compartmentalizing service delivery is not the most beneficial approach to health care.

### **Coordinated services**

A lack of coordination between services was found by consumers to be a barrier, as there was no sharing of knowledge or referring on to other more appropriate services, which was also identified by McClellan and Warren (1995) as a major weakness in current service delivery. The Minister of Health (2006) identifies that recovery will be enhanced when there are agencies working together in a way that provides coordinated support for people who are experiencing mental illness. The lack of coordination between primary and secondary services has been found in the New Zealand mental health system (Fitzgerald et al., 2009), and is also prevalent between organisations in primary settings. This issue was evident in this research as consumers discussed the limited networking between providers and a lack of knowledge from service providers of other organisations available which may provide a suitable service. The introduction of provider/purchaser philosophies in the health system brought about the development of competition, and the disintegration of cooperation, between service providers (Morgan & Simmons, 2009). Following the development of competitive funding, which was seen as the ideal in creating better market efficiency under neoliberal philosophies, Davis and Ashton (2001) suggest that while services may have become more efficient as a result of neoliberal values, they have become disconnected as a result, especially within the primary setting. Although there is a paucity of research on the underlying reasons for disconnection it may be as a result of organisations being unwilling to share

resources and knowledge with others as they are competing with each other for available funding, therefore sharing knowledge could be perceived as a threat to potential revenue.

The Health Services Research Consortium (1994) identified that repeated assessments are detrimental to the consumer's mental health, which emphasizes the importance of networking between services. Consumers revealed that it was difficult to explain their situation to numerous service providers, and would have preferred for services to share knowledge about the case with one another to avoid the need for this repeated disclosure.

### **Primary health care**

The final structural feature which influences service provision in Cambridge is primary care. Primary health care is a major focus of the New Zealand health system, which incorporates mental health care, and was developed as part of the Primary Health Care Strategy in 2001 (King, 2001). Primary mental health care aims to increase the early detection of mental illness to prevent mental illness from becoming more severe and increase appropriate referrals to specialist mental health services (Dowell et al., 2009). Primary care is an essential feature to consider in mental health care for consumers as Dowell et al. (2009) identified that approximately 50%-70% of mental health conditions are managed in primary health settings. Consumers' responses were in line with other findings which identified that there are problems associated with both access, and the referral process, in primary care (Pignone et al., 2002).

As primary care has a cost associated with it, consumers reported delaying attending consultations until their symptoms had worsened in order to reduce costs. This finding was supported by Dixon et al. (1994), who found that up to 40% of GP consultations are delayed because of the costs associated with accessing primary care. A perverse incentive to access free secondary services opposed to costly primary services has been documented by the Health Services Research Consortium (1994), yet consumers in this study did not discuss this motivation directly. Although there is a dearth of research in this area the financial incentive of secondary care may be connected to the pattern in accessing services via inpatient care (following an episode of self harm or a suicide attempt)

which was prevalent among consumers' with severe mental illness. Further research into this connection is required to investigate this more fully.

Another feature of primary care which hinders the recovery process, as described by consumers, is the lack of appropriate referrals following a consultation with a GP. Consumers reported that GP's lacked knowledge of mental illness, both by missing early warning signs of mental illness and also by failing to refer on to appropriate mental health services in a timely fashion. This finding was in line with those found by Pignone et al. (2002), who concluded that some GP's do not have adequate knowledge of mental illness and are not certain of when their patients require specialist care. Dowell et al. (2009) explain that primary care is the doorway to specialist services, so accurate diagnosis of mental health conditions is essential to ensure that people receive the most appropriate care. Consumers' suggested that GP's receive further training in identifying warning signs of mental illness to make certain that they are aware when to refer on, which is similar to Pignone et al.'s (2009) suggestion of further training and the use of specific screening measures for GP's. It is important to consider that there may still be barriers to referrals from GP's even with a screening measure, as who the GP asks to complete the measure will still be at their discretion (Herman, 2001).

In summary, structural factors which impacted service provision for consumers in Cambridge were issues surrounding access, funding, and primary health care. More specifically, access is dependent on available, appropriate services which consumers know about and can gain entry into, funding impacts the connection between service providers and can result in a detrimental lack of flexibility for services users, and finally primary care is associated with problems in referral procedures and the costs associated with care. Consumers' responses were generally in keeping with previous research suggesting that some of the barriers identified internationally and within New Zealand are having an effect on service delivery for the people of Cambridge.

## **Summary**

A range of factors associated with the health care system in New Zealand were identified by consumers as impacting on their recovery journey. Crisis services were given mixed reviews, with first-line crisis workers receiving negative feedback from consumers, while hospital inpatient care was reflected on highly by

those who had accessed the service. Individual's diagnosis impacted their experiences either by common behaviours prevalent for the disorder or by a lack of services specifically aimed at the features of particular diagnosis (such as addiction services). Access to services was affected by having suitable services available to consumers, that were known about and that consumers were able to gain entry into. Some of the barriers to access were identified as a result of funding issues, such as the lack of coordination between providers which may be as a result of the competitive environment which has developed from contracted funding. The health care system provides care through primary mental health services, which are focused on identifying symptoms of mental illness early in order to prevent mental illness. However, there are financial barriers to primary health care, as attending GP appointments can be costly.

### **C. Social factors**

Overall perception of mental health service provision was influenced by factors which were specific to different individual consumers' and their current situation. Factors such as the availability of resources (such as transport, money, and housing), social support, gender, experiences of stigma, and their previous experiences with mental health services will be discussed, comparing research findings with previous literature.

### **Resources**

A lack of finances, transport, adequate housing and employment can be a barrier for recovery for people with mental illness (Perese, 2007). Consumers' identified that factors such as transportation, activity attendance, socializing opportunities, and gaining access to the types of services one might desire to use were all impacted by the availability of financial resources. A lack of financial resources is common among people who experienced mental illness (Costello et al., 2003) which can be as a result of reduced capacity to gain employment, sometimes for a significant length of time. Consumers' experienced difficulty accessing mental health services as a result of the distance they had to travel, as some did not have access to a car (or the financial capability to fund a car), and some had a car but could not easily afford petrol. For people who had limited transportation but had

strong social supports, this was not a significant barrier for accessing mental health services, however it did appear to limit their willingness to become involved in extra services outside their scheduled appointments. Consumers' identified that socializing was often associated with costs and subsequently they did not regularly attend, which was also identified by Wilton (2004) who discussed consumers reduced opportunity for educational, social and leisure activities as a result of the related costs.

One significant resource based individual factor which is described as influential on mental illness recovery and service provision is the availability of appropriate housing for consumers'. People with mental illness are consistently found to be living in inadequate housing (Barwick, 2002) and appropriate housing is essential for the successful treatment of people with mental illness (Freeman et al., 2004). In the current study there was only one consumer who indicated that housing was a concern, and this was not a dominant theme in her responding. The inability to access supported accommodation was problematic, however it was expected that this would have been a more prominent theme in Cambridge, as the only form of support accommodation (other than for the intellectually impaired) is in Hamilton.

There were a number of consumers that reported difficulty dealing with financial pressure, especially in regards to managing interactions with Work and Income New Zealand (WINZ). Consumers predicted that WINZ staff members would deny them their requests, generally due to consumer's perception that WINZ staff thought they should be working and not on benefits. There is limited research conducted on the impact WINZ interactions have on consumer's mental health, however consumers perceived discrimination may be as a result of the stigma associated with mental illness (as described below).

### **Social support**

Social relationships are important in fostering recovery among people with mental illness (Mancini et al., 2005), which was a common response from consumers in this study. One consumer responded that "*I'm a sociable loner...that's a big part of the problem*", and expressed that his isolation from people was a significant contributor to his mental illness. Perese (2007) identified that it is common practice for people with mental illness to participate in solitary activities and

frequently miss out on relationships with other people. Consumers explained that having interaction with people reduced their levels of perceived isolation and was a positive factor in promoting recovery. Isolation is a common problem for people with mental illness, as they have been found to have difficulty developing strong relationships (Borge et al., 1999). When consumers increased their levels of social support they received the opportunity to gain pleasurable experiences, and learn appropriate social interactions (Whitley et al., 2008).

Consumers in Cambridge perceived that a way to increase their social interaction would be through the formation of peer support groups, which is discussed below in 'Provision of mental health services in Cambridge'. Two consumers discussed using technology to connect with friends for social support, and the idea of accessing services online. Both of these consumers concluded that they would require additional support even when using technology to assist their recovery, as they described the human contact as essential.

Social support in the form of physical support was described as important in facilitating recovery, as family and friends assisted consumers with accessing services (e.g., by providing transport, or helping to make phone calls to find service providers).

Consumers identified that although social support was a positive factor, there were times where they perceived that the people around them had certain expectations about their recovery which were unhelpful. These expectations were based on the belief that friends and family anticipated that once the consumer was on the journey of recovery they would continue to improve and there would be no occurrences of relapses. Similarly to previous research, consumers identified that such expectations put pressure on them to maintain wellness, and if this did not occur they experienced shame admitting that there was a need to access services again (Lapsley et al., 2002)

## **Gender**

As briefly discussed earlier, in regards to access to services, consumers who disclosed attempting to access psychiatric services, and were denied access due to their severity level not being acute enough, were all men. For these men overstating their case in order to be taken seriously was expressed as a negative

experience. Adam (1997) states that there is a social expectation of men in New Zealand to be tough and not talk about their problems, which may have a significant impact on mental illness and service utilization. This research found that the refusal of entry into a service was perceived more negatively by males than it was for females. In a study on gender and personality factors which impact on help seeking, men were found to be more stoic than women, and to feel more personally discredited (personal stigma) as a result of mental illness (Judd, Komiti & Jackson, 2008). Although research on this is lacking, men and women may have been refused entry at similar rates however men perceived this as stigmatizing more than women, therefore reporting it as a more distressing event. There is a scarcity of research on reasons for males reduced access of services and whether there is discrimination based on gender into mental health services, the following suggestions are made as explanations worthy of future research.

Women access primary health and mental health services at a higher rate than men (McAvoy, Davis & Raymont, 1994). As women access services more readily, the consumers in this study may be more resilient to being denied access, as a result of being turned down on numerous occasions. In contrast, if men access services less frequently, their experience of refusal was potentially more significant as they were not accustomed to seeking out service support and therefore not used to being denied access. The differences in help-seeking between men and women can be evaluated in line with suicide attempts and rates for men and women. Research of suicide rates shows that men complete suicide more than women; however women attempt suicide more frequently than men (Disley, 1997). The present research found that admission to psychiatric services was most easily achieved by access via a crisis. The consumers who described this method of entry into services were four women and one man. Considering that women are more frequent help-seekers and attempt suicide more, and that access into mental health services is easiest during a crisis (or following an attempted suicide), the question of whether this disadvantages men from easy access into psychiatric services arises.

### **Experiences of stigma**

Dale Walsh (1996) explains that stigma and discrimination are key barriers to the healing process and are instrumental in making consumers feel isolated and

hopeless). Overall consumers concluded that, in keeping with Dew and Kirkman's (2002) statement, there were negative perceptions of people with mental illness especially evident in consumers' reluctance to reveal their diagnosis to other people (in situations such as job interviews or in social settings).

Consumers in the research identified with aspects of Peterson and Barnes (2009) description of self-stigma, by blaming themselves for their illness and considering themselves less worthy than other people (not wanting to tell others of their illness). Consumers reported feeling as if people thought they were dangerous and unable to cope with daily situations, which was supported by Watson and Corrigan's (2005) findings about common stereotypes of people who experience mental illness.

Stigma is often associated with stereotypes held by society (Dew and Kirkman, 2002), a common stereotype described by consumers related to the New Zealand attitude of 'she'll be right'. Two consumers significantly believed that this attitude contributed to a delay in help-seeking among those who experience mental illness, especially men. A common response, from the majority of consumers, was the positive impact the media campaigns were having on stigma and societies attitude in general towards mental illness. This is in keeping with findings from Fearn and Willey (2005) which assessed the effectiveness of the 'Like Minds Like Mine' campaign (which used the media to raise awareness of, and reduce discrimination towards, people with mental illness), as a reduction in negative attitudes towards those with mental illness was apparent before and after the campaign. The media has been found to perpetuate stigma associated with mental illness, as people with mental illness are often portrayed negatively in the media by sensationalizing mental illness and representing extremes of mental illness (Mullen, 1991). While there is a scarcity of research on the following points, two consumers described the media campaigns aiming to reduce stigma of mental illness as another form of sensationalism. This was as a result of the types of people chosen to feature in the campaigns, with consumers suggesting that these people were not what they would consider average New Zealanders, because they were highly successful individuals. These two consumers believed that using such prominent personalities was not as beneficial for reducing stigma, as it made mental illness acceptable for successful people but not for people who were more 'normal'.

## **Summary**

There are a number of social factors which impact consumers' experiences with mental health services. A lack of resources was a common theme, such as issues with financial and employment resources. Social support that was available for consumers was a positive factor in recovery facilitation, however if family/friends have expectations of the consumer that are perceived as unrealistic then there are potential problems. Support from consumers' peers was identified by all consumers as being essential, as this resulted in support and encouragement from people who understand them. Gender was a contributing factor to recovery facilitation as men reported higher levels of stigmatization from service providers than women. Stigma was described by consumers as negatively impacting their recovery journey, and the positive input media can have was discussed.

## **D. Provision of mental health services in Cambridge**

Based on the conclusions drawn in the previous three sections, consumers' do not believe that the service provisions in Cambridge are meeting their needs in order to promote recovery. This section will be structured by discussing overall responses of people with mild, moderate and severe mental illness. Suggestions that consumers' made in regards to changes which could be made to improve mental health service provision in Cambridge will then be outlined.

## **Overall responses**

Consumer's who were categorized as having severe mental illness and were able to access psychiatric services were generally happy with the comprehensive services they received. Overall, consumers' praised their mental health support team for the ease of access into the system, as many entered the service through inpatient services and also for straightforward access to appointments, with some consumers' being visited at home. Consumers' were concerned about being discharged from the psychiatric service as they were unsure as to whether suitable services would be available to support them in the community. A lack of social support was also a common response from people with severe mental illness, as they generally described their social situations as

isolated. Similarly consumers who had a more mild mental illness were happy with the services they had access to, which generally involved access to a counseling service on a fortnightly/monthly basis and they too desired a greater level of social interaction. However, consumers who had a mental illness that significantly impaired their life, but they did not meet the criteria to access public services were discontent with service provision. These people perceived that they required more intense services than counseling, which were the main services available in Cambridge, but could not access what they required in Cambridge. The group of people with moderate-severe mental illness strongly desired a greater level of social support, as many had accepted that they would not gain access to the services they desired and social support was perceived as an alternative option.

As discussed earlier in the three sections (recovery approach, health care system and factors influencing recovery) which impact service provision, there are a number of barriers to effective service delivery for the people of Cambridge. The following sections will discuss areas which consumers raised as suggestions of how services could be improved, which are compared to other research findings.

### **Increased knowledge**

One consumer reflected on the ease of accessing services especially based on knowledge of what is available. She recommended having a Webhealth Kiosk (one had been available at a local social service) in a more publicly accessible place such as the library, as this would promote people to use the information source. Webhealth Kiosks are free standing information sources which have access to a wide range of service providers and information about health related issues. The effectiveness of Webhealth Kiosks in improving access to Waikato primary health services was evaluated in a survey completed in 2010 from Kiosk users. Results showed that Kiosk user's regularly accessed information on mental health services as it was on average the 5<sup>th</sup> preferred search option. The survey found the following general themes: 41% of Kiosk user's identified as Maori and 33% New Zealand European; 67% were female; the most common income range was \$0-\$19,999 per annum; and 0-15 years and 15-20 years were the most common ages to use Kiosks by significant margins. Although this survey

identified that responding may not be accurate, there appears to be trends in Kiosk use from groups (e.g., Maori, youth and low income earners) who have previously been in a disadvantaged position in terms of accessing mental health services (Webhealth, 2010).

### **Peer providers**

A theme which emerged from the majority of participants was the desire for peer run services or support groups to enable consumers' to discuss their difficulties, and gain social support from other consumers. The importance of these services is stressed within the recovery literature (Deegan, 2003), and for this reason the notable absence of such services/groups in Cambridge is in opposition to the recovery values. Service-user run services or groups have been found to make significant contributions to mental health services as the consumers' who run them have personal experience in mental illness and accessing services (Doughty & Tse, 2005). If consumers are involved in service delivery (either within peer support groups or professional organisations) they are perceived as being more sensitive to clients needs, can provide assurance by normalizing experiences, and can serve as role models for other consumers – engendering hope that recovery is a realistic expectation (Mancini et al., 2005). Responses from this study indicate that consumers' would like some input from professionals to either help with establishing the group or as a means of education which has been found to be effective in previous research (Lawn et al., 2008). Previous research by Dadich (2009) indicates that service-user run services have the freedom to include professionals in their service delivery if they wish, however there is a focus on learning from the wisdom consumers' have gained through experience. Some consumers discussed the possibility for spending time with other people with mental illness as a negative experience, as there is potential for this to increase negative symptoms. These findings are consistent with concerns Curtis (2003) identified, which relates to the encouragement service users can receive to maintain their mental illness associated behaviours by spending time with other people who experience mental illness. Further research into this area would be beneficial, and as consumers suggested the groups dynamics may depend significantly on the level of wellness which is within the group. Overall, participation in a service-user run group has been found to be a

constructive activity as studies have found a correlation between involvement in service-user run/self-help groups and a reduction in psychiatric symptoms, hospitalisation and medication dependence (Dadich, 2009).

An interesting omission from responses was the involvement of consumers within mental health services. Literature has described the importance of consumers being involved in the development and operation of services to promote recovery (MHC, 2002), however this did not emerge from consumers responses. This may be evaluated more accurately if interviewing service providers in order to gain information about organisation procedures to ensure consumer participation is encouraged.

### **Employment support**

As described under social factors, employment is an important aspect in consumers' gaining a sense of purpose in their lives and increasing social interaction as well as financial resources. A common response that emerged from consumers' experiences was that returning to an employment situation is a difficult task, in which consumers' perceived a need for external support. Becker, Drake and Naughton (2005) highlight the importance of employment on recovery and explain that supported employment programs have proven to be successful in reintegrating people who experience mental illness back into the workforce. Key features of employment programs are that consumers have a choice about employment and can identify their preferred workplace, that there is connection between mental health and employment services, and that the support is ongoing as long as the consumer requires (Becker et al., 2005). This would be an area of development in Cambridge which would be beneficial especially in light of consumers' requests and the known connection between employment and recovery.

### **Self-management support**

A suggestion was made by seven of the fourteen consumers that regular check-ups from service providers would be beneficial in maintaining their journey of recovery, especially following being discharged from services. Early detection

of mental illness has been found to have a significant impact on the treatment of disorders (Herman, 2001). However, consumers did not regard themselves as capable of identifying when they were becoming unwell and in need of support as they found it difficult to differentiate between a low-patch and a relapse. This is consistent with Sareen et al.'s (2007) findings that consumers thought their problems would abate without professional help and therefore delayed help-seeking, although other findings in Sareen et al.'s study showed that consumers delayed help-seeking as they had a desire to manage symptoms by themselves which was not evident in the present research. The desire to manage symptoms without professional assistance can be connected with the stigma associated with re-entering the mental health system, as Walsh (1996) described feeling like a failure for becoming unwell again. The uncertainty of thinking symptoms would go away and consumers' experiences of being unsure when to access further help raises concerns regarding self-management of mental health. Consumers are expected to be able to refer back to services when they notice themselves becoming unwell, however if they are unable to do so, are there any services that will look out for them or will they need to experience a crisis to be re-connected with services? If there are no services supporting consumers during the time they are self-managing their illness, there appears to be a lack of preventative measures to avoid relapse. Consumers identified that in order to maintain the progress they had made; regular check-ups from professionals would be a beneficial service.

### **Location inequalities**

Two consumers fervently discussed the injustice of service delivery in Cambridge when compared to other towns of similar size, distance from Hamilton (Te Awamutu is 29 kilometers from Hamilton whereas Cambridge is 25 kilometers) and population characteristics. In particular Cambridge was compared with Te Awamutu, a town which is also in the Waipa region and is therefore governed by the same local council. Te Awamutu is of a comparable distance away from Hamilton yet has significantly different service delivery for mental health. Examples of these differences are that Te Awamutu has crisis services available, the psychiatric service has a clinic based in Te Awamutu (whereas Cambridge people are required to attend the Hamilton based service unless home visits are arranged), Maori specific services, youth services, and safe

housing such as women's refuge. Although there is a shortage of research comparing reasons for differences in service delivery between towns, an assumption can be made that the difference lies in the image of the town. As identified at the beginning of this document, Cambridge is known as the "Town of Trees and Champions", an image which does not relate well to the need for mental health services. It is possible that the image of Cambridge, as being clean and green, is a barrier within itself for consumers' as there is an assumption that there is not a large need for services within a town which is perceived to be upper class. One consumer, who had lived in a number of towns, explained that he enjoyed Cambridge because of the small town feel, and identified that he did not wish to live in a bustling city.

From consumers responses the inequalities would be improved by an increase in publicly funded specialist psychologists or psychiatrists based in Cambridge, even if only on a once weekly basis. Also, an increase in the availability of drug and alcohol counseling, as from one consumer's perspective, who had considerable knowledge in the service provider field, this was an area of need within Cambridge.

## **Summary**

Significant trends emerged based on the type of service that consumers had accessed. People who had mild mental illness and attended counseling and people with severe mental illness and were cared for by psychiatric services had similar responses that social support was the main request to improve service delivery. The significant group of consumers that required greater assistance than available in Cambridge but were not able to access psychiatric services perceive d significant gaps. Suggestions were made for increased knowledge for consumers and professionals of what services are available, an increase in service-user run services, support surrounding returning to employment and also with self-managing illness were raised. Inequalities which appeared to exist between Cambridge and another similar sized town were discussed.

## **E. Limitations**

In this research the lack of discussion surrounding culturally appropriate services is notable, which may be as a result of the absence of non-European research participants. Culturally appropriate services have been described in the literature as an essential feature of recovery focused mental health services; however these services are not available in Cambridge. It was of interest that no participants were of Maori descent, as based on the population of Cambridge it was expected that out of 14 participants at least 1 would have identified as Maori. As a result of having no Maori participants no comparisons could be made as to how Cambridge services are providing for people of Maori descent. During the recruitment phase of the research, there could have been a greater emphasis placed on accessing Maori participants, such as approaching Hamilton based Maori service providers (as they may be meeting the needs of Cambridge based people), and by using Maori language on the posters. As the cultural component of Cambridge based service delivery is absent from this research, this would be a useful area for future research to identify specific needs of Maori in Cambridge.

During the recruitment phase of the research service providers were approached to send letters on behalf of the researcher to potential participants (see Chapter Two). In an attempt to reduce harm to participants, the researcher requested that service providers did not send letters to service users who, in the provider's opinion, were too unwell to participate without their mental illness being exacerbated. Following this decision, the researcher discovered the findings of Ulivi, Reilly and Atkinson (2009) who studied mental health service users' views on access and consent for research. The results showed that service users' would prefer to have the opportunity to consent to participation in research without the prior screening of their mental health professionals (Ulivi, 2009). Service users' explained that if they believed that they were too unwell to participate they would decline the offer, but thought that they were entitled to the choice (Ulivi, 2009). The exclusion of participants in the present research may have resulted in valuable information being missed, as well as neglecting an opportunity for service users to gain empowerment (through making their own decision about participation).

Due to the scope of the research only participants over the age of 18 years were able to take part, as the focus was on mental health services for adults. It would be interesting to have information on child and adolescent services

and how these services facilitate recovery for children and young people living in Cambridge.

# CHAPTER FIVE

## Conclusion

This research set out to identify the extent to which mental health services were facilitating the process of recovery for people who were living in the town of Cambridge, in the Waikato region. Previous research, both in New Zealand and internationally, has identified that while community based care has potential to provide cost-effective and humane care for people experiencing mental illness, there are many barriers which can prevent effective care from transpiring. Specifically, there is research focusing on rural mental health service provision, which is relevant as Cambridge is a relatively small town which is dependent on Hamilton (a larger city 25 kilometers away) for the majority of secondary mental health service provision. In order to determine the state of service provision in Cambridge it was essential to seek consumers' opinions in order to learn from the valuable insights consumers' have gained their lived experience with mental illness.

A significant philosophical shift away from biological/incurable conceptualizations of mental illness occurred during the 1970's which influenced the process of deinstitutionalization and the development of recovery oriented services. Recovery values assert that people with mental illness are able to recover and are able to steer their own recovery. Definitions of recovery have been developed by the MHC (1998), and a focus of this research was to gain Cambridge consumer understandings of the meaning of 'recovery', to discover whether these definitions were in keeping with national guidelines. Consulting with consumers in the development and implementation of services is essential for recovery oriented services, as it provides a level of assurance that the services are operating in a way that is facilitative of recovery.

The research included conducting 14 semi-structured interviews with consumers whose mental illnesses ranged in severity from those who were acutely unwell to those who experienced mild mental illness. There were five male and nine female participants whose ages ranged from 22 to 69 years. All participants identified as being of European descent, two of which were from the United

Kingdom, one from Australia, one from the United States of America, and the final ten from New Zealand.

Findings from this research identified that the majority of consumers living in Cambridge have similar understandings of the concept of recovery to those presented in international literature (Anthony, 1993; Deegan, 2003), and in New Zealand mental health system policies (MHC, 1998). Consumers' meanings of recovery emphasized the importance of having hope that a fulfilling life was possible, either in the presence or absence of psychiatric symptoms. Recovery was portrayed as a personal journey, which required a sense of empowerment and a regaining of losses experienced through mental illness particularly in the areas of relationships, overall functioning and independence and was facilitated by the presence of having purpose, being involved sort of group membership and developing spirituality.

Consumers descriptions of service provision were compared to literature on the expectations of recovery oriented services, and positive and negative conclusions were drawn. Elements of service provision that were in line with recovery principles were: the friendliness of services identified by staff members attitudes and helpfulness towards consumers (Deegan, 2003); the emphasis placed on independence and self-management of consumers illness (Young & Ensing, 1999); and the holistic nature of psychiatric services as they provided skill development for managing symptoms, social skills training and employment support. Areas in which the recovery principles were not being met included the lack of: easy re-entry into mental health systems; knowledge sharing between provider and consumer; consumer involvement; and, connection between services within primary settings as well as between primary and secondary services. Consumers reported feeling disempowered by service providers neglecting to supply them with relevant information about their illness, as well as reduced opportunities for consumer involvement in the planning and decision making associated with their care, which were expected findings based on the literature (Mancini et al., 2005; MHC, 1998).

Specific factors which consumers perceived as impacting recovery from mental illness were health care system factors such as; access to services, the impact of funding, concerns surrounding primary care, and the experience of hospitalization, and other factors such as; the availability of resources and social support, specific diagnoses, and gender.

Access to services was described by consumers as a significant factor which impacted recovery and was influenced by having appropriate services available within close geographical proximity, that the consumer was eligible for and that they were informed of. Consumers desired a greater level of coordination between services in order to make transitioning between services easier and also to reduce the repetition of assessments which consumers described negatively. Hospital admissions were seen as positive experiences as it provided a safe place to recover from a period of being acutely unwell. Factors influencing recovery such as the availability of resources was a finding in this research consistent with previous research (Perese, 2007), as consumers identified that a lack of finances, transportation, and employment can be barriers to recovery.

In terms of overall service provision for people experiencing mental illness that live within Cambridge, clear trends emerged from consumers' responses based on the services they had accessed. Consumers who experienced mild mental illness and required fortnightly or monthly counseling appointments perceived that increased social support was all that was required to improve service provision in Cambridge. Similarly, consumers at the other end of the scale with severe mental illness, and who had gained entry into psychiatric services identified that psychiatric services provided comprehensive care and suggested social support as an important addition to service provision to ensure a smoother transition following discharge. However, people with mental illness that was either moderate or severe, but who were not able to access psychiatric services identified a range of problems with the provision of services and made some suggestions as to how to improve service delivery.

In light of these findings, and the barriers described which are especially evident for people with moderate-severe mental illness who are unable to access psychiatric services, there are clear barriers to service provision for people who experience mental illness in Cambridge, and therefore recovery facilitation is not at its optimal level. Consumers suggested that increased awareness of service available, through an information kiosk, the development of peer support groups, more publicly funded mental health specialists available to people with moderate mental illness, a satellite clinic for psychiatric services based in Cambridge and increased training for GP's to recognize early signs of mental illness would all be beneficial for facilitating recovery for people based in Cambridge.

The researcher envisages that these findings will prove useful in terms of providing guidelines for future research and as suggestions for areas of development for community organisations. The researcher hopes that this has contributed to the knowledge people already have about facilitating recovery for people based in small towns that are dependent on larger cities for service provision. So, hopefully a clearer picture has been gained of what is required to develop a recovery facilitating environment in Cambridge, because at the end of the day, it is the care for people within the community which is important. The thing which matters most is that people who experience mental illness have the best opportunity to have a fulfilling, meaningful and empowered life.

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## **APPENDIX A: Participant letter**

Department of Psychology  
The University of Waikato  
Private Bag 3105  
Hamilton, New Zealand

Phone - 07 838 4466 ext 8302  
Email - research@hotmail.co.nz



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

Dear participant,

Thank you for taking the time to read the information about this research. At the beginning of this research project, I sent a letter to doctors, counsellors, and hospital based mental health services explaining to them the research I was planning to undertake. I asked them to forward this information on to people who they thought may be interested in participating.

Since you have received this letter a health professional you are working with, or have previously worked with, thought that you might be happy to spend some time talking to me about your experiences with mental illness. Whether you decide to participate is up to you, the health professionals who sent this to you will not know whether you have chosen to participate or not.

### **What is involved?**

I would like to have a conversation with you about your experiences with mental illness, and your thoughts about recovery, and services available in Cambridge.

The interview will take about **30 minutes**, or as long as you need. I am able to meet with you in a private room at the Cambridge Community House in Leamington or at an alternative venue which suits you. Transport can be arranged if you need a ride to the venue. You are welcome to bring a support person with you for the interview. If there are more people interested in taking part in the study than time allows, some people may not be able to take part in the research.

### **What to expect if you take part in the interview:**

- You can refuse to answer any of my questions.
- You can stop at any time.
- You can withdraw the information you gave from the study, up until approximately 3 weeks after your interview.
- You will not be identified in any way in the final report .
- The interviews may be recorded to help me remember what we talked about, but only if you are comfortable with this.
- You will be given a \$15 grocery voucher to thank you for your time and to cover any of your costs associated with the interview.

I want to make it clear that taking part in this study, or withdrawing from the study at any time, will in no way impact upon your access to mental health services.

### **How to get involved?**

If you think you would like to be involved in this research project, or you just want to find out some more information about the study, please give me a call, an email or send the response section of this letter back to me in the prepaid envelope.

Thanks,

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Hannah Cleland (Researcher)

---

Health Professional who has sent this to you

## **APPENDIX B: Participant information sheet**

Department of Psychology  
The University of Waikato  
Private Bag 3105  
Hamilton, New Zealand

Phone - 07 838 4466 ext 8302  
Email - [research@hotmail.co.nz](mailto:research@hotmail.co.nz)



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

### ***How well do the services in Cambridge meet the needs of people who are on the journey of recovery from mental illness?***

My name is Hannah Cleland and I have lived in Cambridge for most of my life. I am studying Clinical Psychology at the University of Waikato. This research is part of my Master of Social Sciences Degree.

This research project aims to get a better understanding of the types of mental health services which consumers consider important for their recovery from mental illness.

It is important to talk to people, like yourself, who use or have used mental health services, as you have a huge amount of knowledge about effective services. I would be grateful if you would share your knowledge about what 'works' and what 'doesn't work' to get an accurate picture of how well the services in Cambridge are meeting the needs of the people.



In this study I want to find out about the following things:

1. Your experiences and thoughts about mental health services in Cambridge
2. What recovery from mental illness means to you?
3. What helps or hinders your recovery from mental illness?
4. What your recovery-related needs are?
5. Whether services in Cambridge are meeting your needs?
6. What mental health, or other services, you would like to be available?

I am specifically interested in what consumers see as important in helping their recovery process, and whether there are specific mental health services which aid this process. I am hoping to identify some of the barriers to recovery consumers' experience, and explore possible solutions to these hindrances.

This research will help to find out whether the services currently available in Cambridge are helping consumers with their recovery journeys. Finding this out may help to develop mental health services which are useful and meet your needs as a consumer.

The university supervisors for this study are Dr. Cate Curtis and Dr. Doug Boer from the Psychology department at the University of Waikato. The research has approval from Waikato University Ethics Committee and Northern Y Regional Ethics Committee. To contact the University Ethics Committee you can email: [r.isler@waikato.ac.nz](mailto:r.isler@waikato.ac.nz) or phone: Robert Isler 07 838 4466 ext 8401.

## APPENDIX C: Consent form

Department of Psychology  
The University of Waikato  
Private Bag 3105  
Hamilton, New Zealand

Phone - 07 838 4466 ext 8302  
Email - research@hotmail.co.nz



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

University of Waikato Psychology Department

### CONSENT FORM

#### PARTICIPANT'S COPY

Research Project: How well do the services in Cambridge meet the needs of people who are on the journey of recovery from mental illness?

Name of Researcher: Hannah Cleland

Name of Supervisor (if applicable): Dr. Cate Curtis & Dr. Doug Boer.

- I have received and read an information sheet about this research project or the researcher has explained the study to me.
- I have had the chance to ask any questions and discuss my participation with other people.
- Any questions have been answered to my satisfaction.
- The researcher has told me that:
  - It is my choice to participate in this study and I can withdraw at any time
  - I can refuse to answer any questions
  - I can ask for some or all of the data to be removed up until 3 weeks after the interview
  - I can read the information the researcher writes during the interview and make changes if I want
  - I will not be identified in the final report
  - Only the researcher (and possibly her supervisor) will see the data
  - I can have a support person with me for the interview

This research project has been given ethical approval from the Waikato University Ethics Committee and the Northern Y Regional Ethics Committee.

If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401, e-mail r.isler@waikato.ac.nz)

I do/do not agree to having this interview recorded.

I..... consent to take part in this study.

Date:

Signature:

Full names of researchers:

Contact phone number for researchers:

Project explained by:

Signature:

Date:

## APPENDIX D: Organisation invitation letter

Department of Psychology  
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Private Bag 3105  
Hamilton, New Zealand

Phone - 07 838 4466 ext 8302  
Email - research@hotmail.co.nz



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

21<sup>st</sup> June 2010

To Whom It May Concern:

I am in the Clinical Psychology Post Graduate Diploma course at Waikato University.

I am undertaking research for my Master in Social Sciences Degree which is focussing on the recovery journeys of people with mental illness.

I am specifically interested in what consumers see as important in helping their recovery process, and whether there are specific mental health services which aid this process. I am hoping to identify some of the barriers to recovery consumers' experience, and explore possible solutions to these hindrances.

I live and work in Cambridge and am passionate about supporting people in my local community. Therefore this research will be focussed on people living in Cambridge, and the services available to them within the Cambridge region.

I am approaching mental health services, which provide services for Cambridge people, to assist in recruiting participants.

***Participants need to be 18 years or older, either past or present users of mental health services and live in Cambridge.*** Cambridge includes Leamington, and rural areas approximately within 10km of Cambridge Township.

***I would greatly appreciate if you were able to send/give out letters, on my behalf, to individuals who you think may be interested in taking part in this research.*** I have included a copy of the letter and information sheets which will be sent to participants so you are aware of the project and I have also included an interview guide for your information. There is a space at the bottom of the letter for health professionals to sign their name, so the recruitment process is transparent for participants.

Participants can be at any stage of the recovery process; however, I ask that you don't include people if you think participation would in any way be detrimental to their well-being. I will cover the cost of postage.

**Once the letters have been sent/given out your job is over!** Participants will be asked to contact me directly if they are interested in participating.

If you are interested in helping me recruit participants please contact me and I will send you extra copies of the letters which are to be sent out to participants.

Many thanks,

Hannah Cleland

## **APPENDIX E: Interview guide**

Thanks for taking the time to meet with me today. I believe that your knowledge is very valuable and I am humbled that you are prepared to share some of that knowledge with me.

Firstly I will go over your rights as a participant, and then if you are happy we can sign the consent form.

Your rights:

- You may refuse to answer certain questions if you do not feel comfortable answering.
- You can decide to end the interview at any time.
- You can remove your information up until two weeks after you receive the transcript of the interview.
- You can ask for anything in the transcript to be changed and/or removed.
- You will not be identified in any way in the final report.

It is important to me that I am accurate about what you share with me. I cannot remember everything you say, so I will take a few notes as we talk.

Do you mind if we also record the interview? No-one else will hear this tape.

Sign consent form.

I am interested in your experiences as someone who has/is using mental health services. I am trying to find out whether people in Cambridge are getting the best possible service they can, or whether there are gaps in the services available. I want to assure you that anything you say about the services you have seen will stay within this room; the services will not find out about specific things you have told me.

I would like to hear about what you think recovery from mental illness is, and whether there are some important things that might help or hinder your recovery.

It is important to make it clear that this interview is not necessarily going to make immediate changes to the services available. I may find gaps or strengths in Cambridge services, and this research will make recommendations but is not going to be able to fix problems, if there are any, in the mental health system.

I have a number of questions about mental illness, recovery, and mental health services, but feel free to tell me anything you think is relevant.

When I talk about mental health services, I am referring to doctors, adult mental health services based at in Hamilton, counsellors that you may have seen. I am also interested in other things that impact you, like social supports (friends or family), financial pressure, and any other stressors in your life.

### **Part One – Personal information:**

To begin I have a few specific questions which you don't have to answer if you don't want. It might just help when it comes to comparing my results.

- What is your age?
- What is your ethnicity? Are there any services/support that you require which are specific to your ethnicity?
- Do you have a diagnosis? If yes what is it?
- When you are finding life difficult, do you have people you can turn to for support? What relationship are these people to you?
- How long have you been living in Cambridge?
- What past or present services have you used?
- What area in Cambridge do you live in? Rural/Leamington/Cambridge township

### **Part Two – Cambridge services:**

Now I have a few questions about the services in Cambridge. Feel free to tell me about any other services you used, which may be outside of Cambridge.

- Can you tell me about your experiences with mental health services in Cambridge?
- If you were able to access services, how easy was it to find out about services available to you?
- When you had found out about these services, how easy was it to access them?
- Did you know who to talk to? Who did you first go to? Were they helpful?
- Have there been any services which have either helped or not helped you?
- Are services in Cambridge meeting all of your needs?
- If yes, how do they meet your needs? If no, why not?

### **Part Three – Expectations of mental health services:**

Now I am interested to see if you have any ideas about how services can be made better.

- What mental health, or other services, you would like to be available?
- How would these different services assist your recovery?

#### **Part Four - Recovery:**

Lots of mental health services talk about “recovery” from mental illness.

*Can explain that recovery generally means living well in the presence of mental illness – having a fulfilling life regardless of a mental health diagnosis. This may clarify if participants do not understand the concept, however it will be interesting to get their perspective on recovery.*

- What does recovery from mental illness mean to you?
- What helps or hinders your recovery from mental illness?
- What are your recovery-related needs? What do you think will help you recover?

#### **Conclusion:**

- Are there any other things you would like to talk about?
- Would you like me to send you a copy of the transcript to check over, so you can make sure I have recorded everything correctly?
- When the study is finished would you like me to send you a summary of the results?

## APPENDIX F: Participant letter post-interview

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THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

Dear

Thank you for taking the time to meet with me and I appreciate your willingness to assist me in my research. Your knowledge is so valuable and I am privileged that you were able to share some of your experiences with me.

Here is a copy of your interview transcript, please read through it and let me know if there is anything you want to be changed. You are able to ask for sections of the interview to be removed, or to add extra thoughts in. Please send me the transcript back in the envelope provided, within 3 weeks, if you have made any changes. If I do not receive anything from you I will assume that you are satisfied that the transcript is an accurate record of our conversation.

I am aware that the interview may have been a difficult process for you, as reflecting on the past can sometimes be challenging. If you feel that our conversation has brought up some areas of concern and you wish to talk further to someone about it, I encourage you to access the support you need.

Once again, thank you for your time and willingness to share with me.

Regards,

Hannah Cleland (Researcher)

If you wish to talk to someone, and you do not know of a health professional you can contact, here is a list of Cambridge based people/services that may be suitable:

- Cambridge Community House (Counselling) – 07 827 5402
- Cambridge Family Therapy Centre (Counselling) – 07 827 6060
- Christine Suisted (Counsellor) – 07 827 7646
- Chrissy McCracken (Registered Clinical Psychologist) - 027 302 4444
- Kevin Mist (Registered Psychologist) - 07 544 6996 or 021 397 086
- MILE Community Trust (Counselling) -07 827 9922
- Pats Martin (Counsellor) - 07 856 7322

Robyn Cresswell (Counsellor) - 027 652 9139

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