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PSYCHOSIS,  
SERVICE SATISFACTION  
AND THE  
PROCESS OF SUPPORTED  
RECOVERY

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A thesis submitted in partial fulfilment of the requirements  
for the degree of Doctor of Clinical Psychology, The University  
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# ABSTRACT

The current study aimed to determine the degree to which service users were satisfied with an early intervention service for psychosis and to explore their process of recovery. The research was based on the epistemology of pragmatism and utilised mixed methodology. The quantitative data were collected using verbal response scales and analysed with non-parametric statistics. The qualitative data were collected using narrative style interviewing and analysed with thematic analysis. Twenty past and present clients of an urban early intervention psychosis service were interviewed. The quantitative results demonstrated that the therapeutic relationship, feeling respected by the service and a longer duration of care were significantly associated with greater levels of general overall service satisfaction. Data were interpreted to produce clinically relevant inferences for the service being evaluated. The quantitative and qualitative data were integrated and interpreted to form three overarching themes related to Psychosis, Service Satisfaction and The Process of Supported Recovery. The early intervention service evaluated provided a service that the majority of participants were very satisfied with. The personality of the specific clinicians involved and their drive to provide a client-focused service appeared to be one of their most recognised strengths. The finding that a longer duration of care was significantly associated with greater levels of satisfaction, suggested that clients need time to find personal meaning from their experiences. It is suggested that this contributes to an integrated sense of self that positively influences recovery. The holistic nature of the service meant it was able to effectively meet the diverse needs of clients through individualised, social and community care.

TO CHRIS AND ELI

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# CHAPTER ONE: INTRODUCTION

Schizophrenia, and to a lesser extent psychosis, has become one of the most highly stigmatised conditions, associated with low expectations in terms of recovery. Early intervention services have challenged these notions by providing quality care to those experiencing their first episode of psychosis, and thus enhancing recovery. Early intervention services are informed by the recovery model as defined by service users. This study recognises that in the past, the experiences and perspectives of service users with psychosis have largely been disregarded. Service users have a valid perspective, and this perspective is integral to service evaluation and the ethos of the recovery model.

## Defining Psychosis and Schizophrenia

### Introduction

Schizophrenia has commonly been considered as the most severe and debilitating of disorders. A precise diagnosis that conforms to empirically validated standards has remained elusive, making it a contentious issue from its earliest conception through to the current classification issues. As a consequence, it has even been suggested by some that current diagnostic systems be abandoned and replaced with a complaint or symptom oriented approach to psychosis (Bentall, 2006). Many researchers have adhered to this and have sought to accurately define and investigate the precise mechanisms responsible for each symptom. Psychosis is conceptualised by a constellation of symptoms, including delusions, hallucinations and disorganised behaviour (American Psychiatric Association, 2000). The Scale for Assessment of Negative and Positive Symptoms (SANS/SAPS) of schizophrenia has, through factor analysis, divided symptoms into three dimensions: positive, negative and disorganised (Andreasen, Arndt, Miller, & Flaum, 1995). This chapter reviews the diagnostic issues related to psychosis and schizophrenia and defines the associated positive, negative and disorganised symptoms. The more commonly researched phenomena of each are discussed.

### Historical Context

Dementia praecox, the precursor to schizophrenia, was initially identified by Emil Kraepelin (1856–1926) as a disorder of dissociative and avolitional pathology, which progressed to include

10 subtypes of which emotional deficits, stereotyped behaviour, inattention, hallucinations, delusions, and universally, irreversible cognitive deterioration were features (Hippius & Muller, 2008). Kraepelin's approach to nosology was derived from a deductive biological understanding of mental illness in which he aimed to understand the relationship of symptoms to cerebral dysfunction (Shepherd, 1995). Kraepelin was primarily responsible for the dichotomy between the non-affective and affective psychoses, identified as dementia praecox and manic depressive insanity, respectively (Kraepelin, 1987). The two disorders were also demarcated by a differing course and prognosis, with dementia praecox considered to have a chronic course and poor prognosis, while manic depressive insanity was considered episodic with a better outcome (Lake, 2010).

Schizophrenia was conceptualised by Eugen Bleuler (1857–1939), who identified it as a loss of unity within the personality or “splitting of psychic functions”, and recognised that the onset and course of dementia praecox was variable (Bruijnzeel & Tandon, 2011). Bleuler's inductive method of investigation identified four fundamental symptoms of schizophrenia: loosening of associations related to contemporary conceptualisations of thought disorder, affective disturbances, autism and ambivalence (Keller, Fischer, & Carpenter, 2011). Two further contributions are associated with current understandings of schizophrenia: the positive symptoms and schizoaffective disorder. Kurt Schneider (1959) viewed schizophrenia as an impairment in empathic communication with associated reality distortions that he defined as the first rank symptoms. The first rank symptoms referred to positive symptoms, which included hallucinations, delusions and passivity, and categorised the form they took. Schizoaffective disorder was conceptualised to account for the convergent expression of both affective and non-affective psychosis (Kasanin, 1933).

## Diagnosis

Diagnostic classification systems attempt to provide a reliable and valid system to conceptualise disorders according to nosology, aetiology, epidemiology and treatment. They tend to rely on categorical approaches that aim to delineate homogenous groups of symptoms that are mutually exclusive from one another. Classification systems, like the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM; American Psychiatric Association, 2000), have facilitated clinical practice through communicating clinical information, that predicts clinical needs which can be managed with empirically based interventions (First, 2004). Further, they have provided a foundation for international diagnostic consistency (Jablensky, 2005a).



Psychosis can be expressed in psychiatric and physical disorders. The schizophrenia spectrum incorporates a number of disorders of which psychosis or psychotic-like traits feature (Mamah & Barch, 2011), such as schizophreniform disorder, delusional disorder and bipolar disorder with psychotic features. The Cluster A personality disorders also share some common features with the aforementioned disorders. Further, psychosis can also be conceptualised as affective or non-affective (schizophrenia) and can occur in relation to substance misuse or a general medical condition (American Psychiatric Association, 2000). Type I and II schizophrenia have been used to delineate the positive and negative symptoms, with Type I representing the former and Type II the latter (Crow, 1980). Primary negative symptoms are often synonymous with deficit schizophrenia, which is hypothesised to be a distinct syndrome within the schizophrenia diagnosis and is characterised by more severe negative symptoms, disorganisation and less severe mood symptoms than non-deficit schizophrenia (Cohen, Brown, & Minor, 2010).

The schizophrenia spectrum disorders have never easily fitted into the diagnostic paradigm, with the reliability and validity of the diagnoses of these disorders being questionable. Further, there are no pathognomic symptoms that demarcate the disorders from other conditions. The definition and conceptualisation of schizophrenia is believed unlikely to reflect a “true construct” with a common aetiology (Tsuang, Stone, & Faraone, 2000). The relationship between symptom expression and course is inconsistent and inconclusive (Gaebel & Zielasek, 2008). Moreover, the boundaries that demarcate the various psychotic disorders are poorly understood and the diagnostic criteria that outline duration, inclusion/exclusion and degree of impairment across classification systems is divergent (Peralta & Cuesta, 2003b). Validity relies on a consistent symptomology, aetiology, prognosis and treatment efficacy, none of which are apparent for schizophrenia (Bentall, 1988). In addition, the diagnosis of schizophrenia is heterogeneous (Jablensky, 2005b) and oversimplified (Peralta & Cuesta, 2003a). Consequently, the disjunctive nature of the diagnosis of schizophrenia may incur markedly different presentations of the disorder (Read, 2004).

## Epidemiology

### Prevalence and Incidence

The epidemiological boundaries of psychosis are poorly represented in the few systematic studies that exist, with the majority of research focusing on schizophrenia or within a limited age range (Baldwin et al., 2005). A meta-analysis provided lifetime prevalence rates of schizophrenia of between 1.4 and 4.6 per 10,000 (Jablensky, 2000). Two studies, the US Comorbidity Survey (*n*

= 5,877; ages 15–55) (Kendler, Gallagher, Abelson, & Kessler, 1996) and the Dutch National Morbidity Survey ( $n = 7,076$ ; ages 18–64) (van Os, Hanssen, Bijl, & Vollebergh, 2001) found that the lifetime prevalence rates of non-affective psychosis was 0.7%, and psychotic disorders 1.5%, respectively. A meta-analysis reported incident rates of schizophrenia of 0.16 and 0.42 per 1,000 (Jablensky, 2000). An annual incidence of first-episode psychosis (FEP) was reported as 0.30 per 1,000 population in Northumberland, UK (Proctor et al., 2004). The annual incidence of FEP in London was 0.21 per 1,000 (Singh, Wright, Joyce, Barnes, & Burns, 2003).

### Onset

The median age of onset for the non-affective psychoses is between the late teens through to early 20s (Kessler et al., 2007). Males have been shown to have a higher incidence of schizophrenia prior to the age of 30 compared to females, although they have a similar distribution within this age bracket. Males show a steady decline in incidence after the age of 30 years, whereas the female distribution of incidence shows a second peak between the 30 and 40 year age bracket (Sham, MacLean, & Kendler, 1994). This appeared to be reflected in first-episode data that showed that the majority of male FEP clients (26.6%) presented between the ages of 20–24 (mean, 26) while the majority of female FEP clients (23.4%) presented between the ages of 30–34 (mean, 31) (Bromet et al., 1992). In a New Zealand FEP sample, it was found that the mean age of onset was 22.35 (Turner, Smith-Hamel, & Mulder, 2006).

### Course

The course and duration of psychosis is widely variable; symptoms can fluctuate and vary in intensity (Sartorius, Jablensky, & Shapiro, 1977). At one end of the spectrum, an individual may experience only one episode, in which symptoms completely remit. At the other end, symptoms may be persistent with the debilitating effects exacerbated with each episode (Freudenreich, 2008). Psychosis is often phase-specific and develops from a prodromal to an acute phase and finally remission. One meta-analysis has suggested that the symptoms of psychosis are clearly demarcated during onset, but become less clear throughout the course (Mojtabai, 1999). The mode of onset can be acute or insidious and is often marked by non-specific changes in affect, cognition, perception, behaviour and in physical domains such as sleep, appetite, energy and volition (Aitchison, Meehan, & Murray, 1999). Qualitative research with a first-episode sample found that a sense of foreboding and subtle perceptual and affective changes were associated with the prodromal phase (Moskowitz, Nadel, Watts, & Jacobs, 2008). The acute phase is representative of an episode of psychosis when symptoms of hallucinations, delusions and/or

thought disorder are fully developed. The recovery phase is marked by an absence or reduction of symptoms (Turner, Nightingale, Mulder, & Maginness., 2002).

## Outcome

In a comprehensive prospective study that investigated the long-term outcome for individuals with psychosis ( $n = 1,633$ ), results suggested that 54.8% had a positive outcome. Positive outcome or recovery was defined by an absence of symptoms, resource utilisation and minimal social disability. If those lost to follow-up were assumed to have a negative outcome, the rate of recovered dropped to 41% (Harrison, Hopper, et al., 2001). Research has consistently demonstrated that individuals in developing countries diagnosed with schizophrenia have a significantly better outcome than individuals in developed countries. In the World Health Organisation (WHO) 10 country 2 year follow-up study ( $n = 1,070$ ), 62.7% of participants from developing countries experienced complete remission of symptoms compared with 36.8% in developed countries (Jablensky, Sartorius, Ernberg, & Anker, 1992). Lifetime suicide rates for schizophrenia have, through meta-analysis, been estimated at 4.9%, with results suggesting that suicide most commonly occurs within the prodromal phase (Palmer, Pankratz, & Bostwick, 2005). Lifetime suicidal behaviour was reported by 30.2% of inpatients with psychosis ( $n = 1,048$ ), with 7.2% attempting suicide prior to their first month of being admitted (Radomsky, Haas, Mann, & Sweeney, 1999). Suicide rates following the first episode ( $n = 166$ ) were 3%, with suicide attempts at 4 years post-first episode of 18%, while 10% had attempted suicide prior to engagement with the early intervention service (Clarke et al., 2006). In one first-episode study ( $n = 341$ ), 11% of participants attempted suicide prior to a 1 year follow-up, and suicide attempts were associated with being female, hopelessness, prior suicide attempts and hallucinations (Nordentoft, Jeppesen, Abel, et al., 2002).

## Gender Differences

Industrialised nations have shown higher lifetime incident rates for males developing schizophrenia compared to females with risk ratio estimates of 1.42 (Aleman, Kahn, & Selten, 2003). In the Early Psychosis Prevention and Intervention Centre (EPPIC) study, males had a higher incidence in all psychotic diagnoses than females, with male to female ratios of 7.7:3.3 for schizophrenia and 5.5:4.5 for bipolar disorder (Henry et al., 2007). New Zealand gender differences have been found to be comparable, with one study reporting markedly lower incidence rates of both schizophrenia and bipolar for females after controlling for urbanicity, socioeconomic status and ethnicity (Scully et al., 2002). New Zealand statistics show that the average proportion of men presenting at early intervention services is around 72% (Turner et al.,

2006). Gender differences exist between age of onset, course and symptom expression, with males having an earlier onset, a poorer prognosis, more chronic and severe symptoms and more negative symptoms (Rasanen, Pakaslahti, Syvalahti, Jones, & Isohanni, 2000). Females generally have higher premorbid adjustment than their male counterparts (Preston, Orr, Date, Nolan, & Castle, 2002). Within EI, females were found to have better engagement and better outcomes for negative symptoms (Theuma, Read, Moskowitz, & Stewart, 2007). Females have been shown to have a better recovery with fewer hospitalisations and better social functioning than males (Grossman, Harrow, Rosen, Faull, & Strauss, 2008). Psychopathological characteristics related to gender show that men have more severe negative symptoms, are less educated, are more likely to abuse substances and be unemployed, whereas women report lower self-esteem, more severe hallucinations and make more suicide attempts (Thorup et al., 2007).

## Positive Symptoms

The positive symptoms of psychosis, delusions and hallucinations, while quite distinct phenomena, share a number of commonalities, including their dimensionality and presence in non-clinical populations. A hallucination is defined as “a sensory experience which occurs in the absence of corresponding external stimulation of the relevant sensory organ, has a sufficient sense of reality to resemble a veridical perception, over which the subject does not feel s/he has direct and voluntary control, and which occurs in the awake state” (David, 2004, p. 110).

Auditory hallucinations have been defined according to the subjective accounts of voice hearers from the general public (questionnaires,  $n = 154$ ; interviews,  $n = 50$ ) in which the following criteria were developed: “(1) the content of the voices are personally meaningful; (2) the voices have a characterised identity; (3) the person has a relationship with their voices; (4) the experience has a significant impact on the voice hearer’s life; and (5) the experience has a compelling sense of reality” (Beavan, 2011, p. 63). Delusions are dimensionally characterised by the following features: (1) unfounded—the degree the belief deviates from cultural norms or is considered bizarre; (2) conviction—the degree the belief is believed to be true and is resistant to change; (3) preoccupation—the amount of time spent thinking about the belief; (4) distressing—the degree of distress related to the belief; (5) social dysfunction—the degree the belief interferes with social functioning; and (6) personally referencing—who the belief is associated with (Freeman, 2007).

Delusions and hallucinations are considered to be at the extreme end of a continuum of ordinary experiences and beliefs (Mullen, 2003; Strauss, 1969). Prevalence rates of positive symptoms in a random sample of the general public ( $n = 7,076$ ) found that 3.3% had clinically relevant

compared to 8.7% non-clinically relevant delusions, and 1.7% had clinically relevant compared to 6.2% of non-clinically relevant hallucinations (van Os, Hanssen, Bijl, & Ravelli, 2000). New Zealand prevalence rates are comparable, with a longitudinal study finding that 20.1% of the sample ( $n = 761$ ) at age 26 had experienced delusions and 13.2% had experienced at least one hallucination (Poulton et al., 2000). The prevalence of hallucinations in the general public ( $n = 15,318$ ) has remained relatively consistent over time with one of the earliest investigations reporting prevalence rates for males of 7.6% and for females of 12% (Sidgwick, Johnson, Myers, Podmore, & Sidgwick, 1894), which are very similar to current epidemiological ( $n = 18,257$ ) prevalence rates of 13% (Tien, 1991).

Positive symptoms are to some extent, socially and experientially constructed. The delusions of younger participants (18 to 30 years,  $n = 343$ ) were more likely to be themed with apocalyptic ideas, whereas older participants (60 to 75 years,  $n = 183$ ) were more likely to have delusions related to religion (Laroi, Van der Linden, DeFruyt, van Os, & Aleman, 2006). Gender differences have also been reported with females commonly reporting delusions of persecution, whilst their male counterparts report delusions of jealousy and grandiosity (Gutierrez-Lobos, Schmid-Siegel, Bankier, & Walter, 2001). Female inpatients with prior abuse history reported that many of their hallucinations reflected abusive experiences (Read & Argyle, 1999). One study found that adverse life events experienced a year prior to participants' first episode were reflected in their delusional content (Raune et al., 2006). Research had demonstrated an association between persecutory delusions and victimisation experiences (Mirowsky & Ross, 1983). Thus, positive symptoms may reflect themes evolved from personally relevant experiences and societal trends for explaining unusual events.

Verbal hallucinations have been theorised to be internally generated experiences, which the individual misattributes with varying degree to an external source. Inner speech has been demonstrated to account for some auditory hallucinations, with similarities in phenomenological accounts of auditory hallucinations and inner speech (Leudar, Thomas, McNally, & Glinski, 1997). Further, electromyography has measured movement in the speech muscles whilst individuals were experiencing auditory hallucination (Bentall, 2003). Neuroimaging studies have shown that prior to a hallucinatory experience subcortical areas of the brain are activated that trigger the modality-specific association cortex (Aleman & Laroi, 2008). Source monitoring is defined as the process of attributing cognitive events such as knowledge, memories and beliefs to the source of their origin (Johnson, Hashtroudi, & Lindsay, 1993). Bentall (1990) proposed that hallucinations are the misattribution of internally generated cognitive events to external sources. This

externalising bias has been researched in a number of studies that demonstrated that hallucinating individuals were more likely to attribute internally generated items to an external source (Keefe, Arnold, Bayen, & Harvey, 1999). Hallucinating individuals were also more likely to attribute distorted recordings of their own voice as belonging to someone else (Johns et al., 2001).

Cognitive distortions and attentional and attributional processes have been associated with paranoid delusions and delusional proneness. Delusions have been associated with a data-gathering bias, that is, a tendency to make rapid decisions based on limited information, the jumping to conclusions (JTC) bias and a disconfirmation bias, where information that would disconfirm a decision is avoided or discounted (Huq, Garety, & Hemsley, 1988). Research has also investigated attribution in paranoid and paranoia prone individuals and found a higher prevalence of externalising and reasoning biases. Delusional ideation had also been associated with an attribution process that demonstrates an exaggerated self-serving bias, where paranoid individuals externalise negative events and internalise positive events (Kaney & Bentall, 1989). Further investigations showed that paranoid individuals were also more likely to attribute negative situational events to others (Kinderman & Bentall, 1997).

Low self-worth or self-esteem is typically characterised by internal negative beliefs about self, others and the world. Psychosis has been associated with beliefs about self as vulnerable (weak, bad, worthless), others as untrustworthy (hostile, unforgiving, nasty, harsh), and the world as dangerous (unpredictable) (Fowler et al., 2006). Low self-esteem has been associated with a number of mental health problems including delusions and hallucinations. The relationship between paranoid delusions and low self-esteem has been defined psychodynamically as the process of projecting hostile thoughts about self on to others (Bentall et al., 2008). From a cognitive perspective, hallucinations and delusions represent negative automatic thoughts that are representative of core beliefs that are externalised (Beck & Rector, 2003). Negative self-esteem has been shown to be reflected in the thematic content of hallucinations, with negative self-evaluative comments being associated with low self-esteem (Close & Garety, 1998).

In a number of aetiological models of psychosis, negative self-esteem has played a prominent role. According to Morrison (1995), negative automatic thoughts that are ego-dystonic are externalised and interpreted as auditory hallucinations. Bentall et al. (1994; 2001) proposed that delusions act as a defence for negative self-esteem. Garety et al. (2001) proposed that delusions were developed and perpetuated through negative self-concepts. Iqbal et al. (2000) thought negative self-esteem arose as a response to psychosis and the related iatrogenic

process, that is, as one of the direct adverse effects of treatment. Positive symptoms have been associated with negative self-schema originating from early aversive events. Negative beliefs are thought to arise in relation to childhood trauma (Morrison, Frame, & Larkin, 2003), insecure attachment (Bentall & Fernyhough, 2008), social marginalisation, childhood loss (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001) and parental criticism (Barrowclough et al., 2003).

## Negative Symptoms

The negative symptoms of schizophrenia have been traditionally identified as affective flattening, alogia, asociality, anhedonia and avolition (Andreasen, 1989). More contemporary conceptualisations have identified two core symptoms: diminished expression and amotivation, with diminished expression incorporating affective flattening and poverty of speech; and amotivation incorporating avolition, anticipatory pleasure deficit and asociality (Foussias, Agid, & Remington, 2011). The various attributes that consist of alogia have been separated into disorganised “poverty of content in speech” and negative symptoms “poverty of speech” (Miller, Arndt, & Andreasen, 1993). Negative symptoms can be attributed to either primary or secondary symptomology, with the latter being attributed to medication side effects, institutionalisation and depression (Foussias et al., 2011). Fifteen percent of individuals with FEP and 25–30% with chronic schizophrenia are thought to suffer from primary negative symptoms (Kirkpatrick, Buchanan, Ross, & Carpenter, 2001).

Diminished expression or flat affect typically refers to the level of objectively expressed emotion, with a focus on facial expressions, spontaneous movement, expressive gestures, eye contact, emotional responsiveness and vocal inflection (Andreasen, 1989). Investigations examining expressed emotion in schizophrenia have shown that individuals with flat affect have reduced muscle expression in the upper face compared with controls when watching emotionally arousing stimuli and when engaged in conversation with others (Ellgring & Smith, 1998). Further investigations that have studied objective and subjective emotion with schizophrenic populations have found that compared to controls, an emotionally blunted group showed significantly less facial expressions, however they did not differ from controls or the non-blunted schizophrenic group in terms of their self-reported subjective response (Berenbaum & Oltmanns, 2005). Thus, diminished expression is represented by reduced outward behavioural emotional response, while subjective emotion remains intact.

Amotivation is defined as motivational deficits, avolition or apathy and includes an anticipatory pleasure deficit. Motivation is generally conceived as a process in actioning behaviour towards a

reward and is conceptualised as having four components: (1) pleasure; (2) prediction; (3) cost-benefit analysis; and (4) execution of goal-directed behaviour (Barch & Dowd, 2010). In an investigation that examined the associated pleasure and prediction of reward, schizophrenic patients were found to be similar to controls in their experience of evoked pleasure but not in their prediction of reward and learning (Heerey & Gold, 2007). Further investigations with the cued reinforcement reaction time task found that individuals with schizophrenia had incentive motivational deficits, demonstrated through their awareness of reward stimuli but impaired behavioural response directed at obtaining the reward (Murray et al., 2008). In a review of the related literature, Barch and Dowd (2010) concluded that deficits of reinforcement learning and reward prediction were associated with negative symptoms, which may be mediated by difficulties using internal representations of emotion and previous reward information for goal-directed behaviour. Amotivation has also been associated with poorer outcomes, specifically in the domain of social functioning (Foussias et al., 2011).

## Disorganised Symptoms

Disorganised behaviour is associated with the following symptoms: positive thought disorder, bizarre behaviour and inappropriate affect (Grube, Bilder, & Goldman, 1998), with more recent definitions including attentional impairment and poverty of content of speech (Foussias et al., 2011). The majority of research related to the disorganised symptom concerns disorganised speech.

The international classification of diseases defines thought disorder as “breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech or neologisms” (World Health Organisation, 2009, p. 554). Thought disorder is more accurately represented as incoherent speech and was defined through clinical observation as a disorder of thinking, language and communication (Andreasen, 1979b). Thought disorder can be a symptom of affective and non-affective psychoses and refers to the form of speech as oppose to the content (McKenna, 1994). Andreasen (1979b) outlined 20 subtypes of positive and negative disordered communication in manic, depressed and schizophrenic participants, with poverty of content (adequate amount of speech, but minimally informative), pressure of speech (excessive speed of spontaneous speech), tangentiality (irrelevant replies to questions), loss of goal (failure to reach relevant conclusion), derailment (frequent, unrelated to subject transitions in speech), and perseveration (repetition of the same word) being the most common (Andreasen, 1979a).

Neurocognitive testing has identified deficits in executive functioning as opposed to semantic deficits, with thought disordered patients (Stirling, Hellewell, Blakey, & Deakin, 2006). Further



research has provided more evidence in favour of executive function impairment over semantic deficits (Barrera, McKenna, & Berrios, 2005). Working memory deficits, in conjunction with familial interpersonal criticism have been found to trigger or increase disorganised speech in individuals diagnosed with schizophrenia (Rosenfarb, Nuechterlein, Goldstein, & Subotnik, 2000). One study investigated the relationship between evaluation sensitivity or beliefs about acceptance and rejection, cognitive impairment (abstraction, working and semantic memory) and thought disorder in a sample ( $n = 74$ ) of individuals diagnosed with schizoaffective disorder and schizophrenia, and concluded that evaluation sensitivity moderated the relationship between cognitive deficits and predicted thought disorder (Grant & Beck, 2009).

As with auditory hallucinations, disorganised speech has been attributed to source monitoring errors between what is thought and what is spoken. Thought disordered schizophrenic patients were significantly worse than non-psychiatric controls at discriminating the source of origin of new, previously thought and spoken material, and these differences remained when intellectual ability and verbal working memory were controlled for (Nienow & Docherty, 2004). Theory of mind is defined as the ability to infer the internal mental states, such as attitudes, beliefs, emotions and knowledge, of self and others to predict behaviour. Frith (1992) hypothesised that cognitive misrepresentations or theory of mind deficits characterised psychosis. Hardy-Bayle (1994) proposed a more direct association between disorganised symptoms and theory of mind deficits, suggesting that cognitive misrepresentations of the intentions of others led to a limited awareness of others' social signals, which negatively impacts communication.

## Summary

The diagnostic definitions of the schizophrenia spectrum disorders have encountered methodological problems since their inception. Psychosis is generally associated with a constellation of symptoms that can include delusions, hallucinations and disorganised behaviour. The negative symptoms associated with schizophrenia have also been included in the literature review because of their high prevalence within FEP populations. There are a number of similarities in the aforementioned symptoms including their occurrence in non-clinical populations, their dimensional nature and the personally relevant and socially constructed content that intrudes onto awareness. The various symptoms have been shown to be moderated by cognitive processes in differing ways, directly or indirectly, which in turn informs affect. These processes have included attributional style, source monitoring errors, jumping to conclusions biases, theory of mind deficits and negative beliefs about self, others and

the world. These processes have been hypothesised to serve a number of functions including hypervigilance for danger, defensive functions and the protection of self-esteem.

# Aetiology—The Biopsychosocial Model

## Introduction

Despite the potential causative factors of psychosis and schizophrenia being extensively researched, no single underlying aetiological factor has been indicated. Current theories suggest a multifactorial approach to aetiology consistent with the biopsychosocial model. Two models aligned with this approach include the stress-vulnerability model and the traumagenic neurodevelopmental model, both of which have prominent positions in research and practice. There are many different paradigms which conceptualise psychosis and other similar experiences, many of which will be unique to the individual experiencing them. Explanatory models represent the personal meaning that service users hold to describe and understand their experiences of psychosis that enhance their ability to cope and recover.

## Explanatory Models

Explanatory Models (EMs) were initially defined as the personal meaning ascribed to discrete periods of physical illness that have been found to influence treatment, management and the outcome of the experience (Kleinman, 1988). The concept has been adapted and implemented within EI services to facilitate recovery from psychosis. Explanatory Models are often culturally constructed and influenced by any number of factors such as spiritual beliefs, peer groups, pharmaceutical companies, and popular culture and media. This influence has made EMs relevant to clinical practice and research. Individuals who attribute mental health problems to endogenous (internal) causal factors, situated within a biological framework, are more likely to have a passive role in treatment compared to individuals who have exogenous (social) causal beliefs (Hill & Bale, 1980). Many media campaigns promote biological understandings of psychosis, through the terminology used and the explanations provided. Biological explanations are suggested to promote the idea of psychosis and schizophrenia as uncontrollable and unpredictable conditions, which exacerbates fear and stigma within the public's perception (Read, 2007).

Questionnaires have been created that examine the personal cognitive representations of health, related to the construction of a formulation. Explanatory Models can be assessed according to identity (symptoms), causation, consequences, controllability and course (Weinman, Petrie, Moss-Morris, & Horne, 1996). Other measures of EMs have examined mental health conceptualisations within ethnic populations and have included the following dimensions: cultural background, presenting problem, help seeking behaviour, illness conceptualisation,

locus of control and the interaction between clients and clinicians (Lloyd et al., 1998). Another questionnaire associated with the EMs for physical ill health measured the patterns of distress (including impact on self-esteem and marital prospects) and general beliefs about illness (Weiss, Doongaji, Siddhartha, Wypij, & et al., 1992).

A qualitative study that looked at the help seeking behaviours of 15 individuals prior to gaining a diagnosis within the schizophrenia spectrum disorders, found that data could be conceptualised as recognising and responding to changes. Recognising changes incorporated *normalising* experiences by perceiving them as part of the self, and *explanatory models* expressed how participants made sense of their experiences through associating them with psychosocial events, cultural factors and personal experiences. Responding to changes incorporated *withdrawal*, *avoiding help* and *coming to terms with psychosis*. Despite participants having an awareness of what changes they were experiencing none associated it with mental illness due, in part, to the fear of stigmatisation (Judge, Estroff, Perkins, & Penn, 2008).

Research that has explored individuals' EMs related to the experience of psychosis, has elicited a number of themes relating to the elusive nature of control in terms of symptoms, self-image, social competence and others' expectations (Williams & Collins, 1999). Further, the philosophical aspects of psychotic experience and the goals that can be met through therapy, have also been elicited: (1) fragmentation—integration: clients can feel fragmented, in relation to self, others and the world; (2) invalidation—validation: clients can feel invalidated from others not sharing their perception, from implied lack of insight and due to an unreliability of their own perception of perceived reality; and (3) spirituality: the importance of spirituality in deriving meaning from the experience (Geekie, 2007). Explanatory Models can provide a sense of coherence to an otherwise incoherent time of life, as well as contributing to a greater mutual understanding between clients and clinicians (Lloyd et al., 1998). Explanatory Models are often fluid and influenced by the services individuals engage with; through dialogue meaning is constructed and redefined (Larsen, 2004).

## The Stress-Vulnerability Model

Probably the most influential model of schizophrenia is the stress-vulnerability model (Zubin & Spring, 1977). The model suggests that an innate or acquired vulnerability in conjunction with the experience of internal or external adverse events results in an episode of schizophrenia. The threshold of symptom expression is unique in any one individual and is mediated by the degree of adversity interacting with the degree of vulnerability. The threshold determines the boundary between psychopathology and an adaptive response to an adverse event. Vulnerability can be

understood as a predisposing factor, whereas challenging events can be conceptualised as precipitating and maintaining factors.

Earlier research has often interpreted “vulnerability” as being biologically determined with the “stress” being associated with environmental influences. For example, Nuechterlein and Dawson (1984) considered vulnerability to be represented by dopaminergic dysfunction, information-processing deficits, autonomic reactivity and schizotypal personality traits, and stress to be represented by emotional over-involvement and criticism from family, an over-stimulating environment and stressful life events. However, both vulnerability and stress may incorporate many interacting genetic, neurophysiological, behavioural, cognitive and emotional influences, of which the early vulnerability and the stress may share a considerable overlap (Bebbington, 2009). From a behavioural perspective, for example, the onset of stressful events can be moderated by coping ability and information-processing (Pallanti, Quercioli, & Pazzagli, 1997). This finding was supported by Horan (2005) who found that individuals diagnosed with schizophrenia were more likely to perceive events as less controllable and underestimate their ability to cope with them.

## Traumagenic Neurodevelopmental Model

The hypothalamic-pituitary-adrenal (HPA) axis is part of the neuroendocrine system that modulates an adaptive stress response and consists of the hypothalamus, pituitary gland and the adrenal gland. A series of feedback functions act to release stress hormones, glucocorticoids (cortisol) and catecholamines (epinephrine and norepinephrine) into the system, and these bind with receptors in the hippocampus, amygdala and frontal lobes, areas associated with learning and memory. Potentially threatening situations trigger the release of stress hormones and enhance fear-related memories and adaptive learning. Prolonged exposure to stress hormones can lead to atrophy of the hippocampus and cognitive impairments (Lupien, Maheu, Tu, Fiocco, & Schramek, 2007). The diathesis-stress model of schizophrenia has informed research combining schizophrenia and HPA dysfunction. The diathesis is an increased responsivity to stress due to abnormalities in striatum dopamine receptors. When the stress response is elicited, an increase of dopamine triggers the behavioural expression of psychosis (Walker & Diforio, 1997).

Research that has focused on a psychosocial diathesis has given weight to the role of the HPA axis in mental health problems. Greater sensitivity of the HPA axis was found in groups which had experienced child abuse, this finding remained after controlling for a number of extraneous variables (Heim et al., 2000). Further evidence came from post-mortem studies of brains from

individuals who experienced child abuse and later committed suicide, with alterations in the HPA axis associated with a greater risk of suicide (McGowan et al., 2009). The traumagenic neurodevelopmental model (Read, Perry, Moskowitz, & Connolly, 2001) proposed that the biological abnormalities found in schizophrenia are the result of early traumatic experiences. Those biological abnormalities, including HPA dysregulation, neurotransmitter abnormalities, structural brain damage and cognitive deficits, are the same abnormalities seen in children who have been abused and neglected. Childhood adversity also appears to exert its effect differently depending on the type of abuse, with an association between sexual trauma and hallucinations and more chronic intimidating abuse being associated with paranoia (Read & Bentall, 2012).

## Genetics

Research that investigated the prevalence of psychotic disorders in the offspring of psychiatric patients, showed that the children of parents diagnosed with schizophrenia and psychosis were significantly more likely to be diagnosed with these disorders than children whose parents were diagnosed with an affective disorder or were in a non-psychiatric control group (Erlenmeyer-Kimling et al., 1997). Twin and adoption studies have been used to control for the confounding effects of the shared environment, with one meta-analysis that examined heritable phenotypes in affected siblings and twins on three symptom dimensions: reality distortion, psychomotor poverty and disorganised symptoms, finding that only the disorganised dimension was likely to have a genetic association (Rietkerk et al., 2008). Further meta-analysis with twins has suggested an 81% point estimate of heritability for a liability to schizophrenia, with the authors concluding that schizophrenia was a complex trait expressed when a combination of specific genetic and environmental influences interact (Sullivan, Kendler, & Neale, 2003). Adoption studies also propose a genetic predisposition to schizophrenia. Of fostered children ( $n = 164$ ) whose biological mothers were diagnosed with schizophrenia or paranoid psychosis, 6.7% received a diagnosis of schizophrenia compared with 2% from the control group (Tienari et al., 2000). However, it was concluded that the adoptive environment of many of the children diagnosed with schizophrenia may have contributed to the onset of the disorder. A literature review that examined the evidence supporting a genetic basis of schizophrenia, concluded that despite all the divergent methods utilised, no robust evidence demonstrated a genetic predisposition for psychosis or schizophrenia (Joseph, 2006). Further, a comprehensive replication study found no evidence to support theories that indicated previously identified genes thought to predispose individuals to schizophrenia (Hamilton, 2008).

## Neurological Abnormalities

Neuroimaging studies have examined the brain structure of individuals coping with their first episode and with chronic schizophrenia, compared to controls. Findings have demonstrated ventricular enlargement, atrophy and cerebral asymmetry. Ventricular enlargement has probably been the most consistent finding, with meta-analysis concluding that progressive lateral ventricular enlargement is associated with schizophrenia and is 3–4 times larger than that associated with normal aging (Kempton, Stahl, Williams, & DeLisi, 2010). The authors concluded that enlargement was likely related to environmental as opposed to genetic causes.

Another meta-analysis that examined overall difference in brain structure with patients with schizophrenia, found progressive decreases in white and grey matter over a 10 year period, specifically within the frontal, parietal and temporal lobes (Olabi et al., 2011). An earlier review reached similar conclusions with more specific reductions noted in the temporal lobe and medial temporal lobe including the hippocampus, parahippocampus and the amygdala (Harrison, 1999). The medial temporal lobe such as the amygdala, hippocampal complex, parahippocampal gyrus and the neocortical superior temporal gyrus are responsible, in part, for verbal, communicative and auditory associative memory functions.

Other meta-analysis examined brain anatomy and found that decreased prefrontal, cingulate, insular and cerebella grey matter was associated with a transition to psychosis in a group of individuals identified as being of high risk due to having a first degree relative with a psychotic disorder (Smieskova et al., 2010). Meta-analysis that examined the frontal and temporal lobes of patients with schizophrenia ( $n = 4,043$ ) and controls ( $n = 3,977$ ) using neuroimaging, reported that the most consistent finding related to hypofrontality during task demand for the schizophrenic population compared to controls (Davidson & Heinrichs, 2003). The prefrontal association cortex is responsible for executive function, conceptualisation and temporal integration. Furthermore, it is highly integrated with other brain regions, attesting to the differential expression of symptoms and the heterogeneity of the disorder. First-episode clients were found to have reduced grey matter in the prefrontal cortex and increased volumetric measurements in the basal ganglia, thalamus and lingual gyrus (Dean et al., 2006).

## Neurotransmitters

There have been a number of neurotransmitters linked to psychosis and schizophrenia including dopamine, glutamate, serotonin and norepinephrine. The dopamine hypothesis of schizophrenia has been one of the most enduring theories (Howes & Kapur, 2009), evolving from

the observation that antipsychotic drugs increased dopamine metabolism (Carlsson & Lindqvist, 1963). Negative symptoms have been suggested to be caused by reduced dopaminergic functioning in the prefrontal cortex. An excess of dopaminergic functioning in subcortical regions such as the striatum, is hypothesised to be responsible for the positive symptoms of schizophrenia. The dopaminergic functioning in the striatum is suggested to be an overcompensation for that in the prefrontal cortex (Davis, Kahn, Ko, & Davidson, 1991). The more recent version of the dopamine hypothesis is an integrated model that links striatal dopamine dysregulation with various risk factors such as genes, stress, trauma and/or illicit drug use. Dopamine mediates the salience of internal and external events and dysregulation is hypothesised to attribute unwarranted salience to non-events, culminating in a hallucinatory experience (Howes & Kapur, 2009).

## Developmental Trauma

Childhood trauma is highly prevalent in psychotic populations. General populations surveys have consistently shown a high prevalence of childhood trauma in psychotic populations, with one study ( $N = 10,641$ ) finding a higher incidence of delusional disorder in individuals who had experienced childhood abuse, with a relative risk ratio of 2.68 (Scott, Chant, Andrews, Martin, & McGrath, 2007). Another general population survey of participants aged between 18–64 ( $N = 4,045$ ), demonstrated that individuals with positive symptoms were 7.3 times more likely to have been abused in childhood (Janssen et al., 2004). Literature reviews have also found high prevalence rates of childhood trauma in psychotic populations of between 28% and 73% (Bendall, Jackson, Hulbert, & McGorry, 2008). This finding is especially pronounced with child sexual abuse (CSA) that found an Odds Ratio (*OR*) of 10.14 for psychosis in a general population survey ( $N = 7,353$ ) (Bebbington et al., 2011).

One study that compared the medical records of a cohort of sexual abused children ( $n = 2,759$ ) identified through police and child protection services, to age and gender matched controls ( $n = 2,677$ ), found that 2.8% of the CSA population compared to 1.4% of the non-abused population had experienced psychosis. This increased to 3.4% when penetrative abuse was considered alone. The authors concluded that penetrative abuse was a risk factor for later psychosis, with an increased risk for those abused in adolescence (Cutajar et al., 2010). Another population survey ( $N = 8,580$ ) found that individuals who had experienced psychosis were more likely to have experienced a number of adverse events as children including sexual abuse (*OR* of 15.47), being taken into local protective care (*OR* = 10.71), spending time in a children's institution (*OR* = 11.49) and being homeless *OR* = 11.34 (Bebbington et al., 2004). A New Zealand study found



that 77% of adult inpatients currently experiencing psychosis had experienced child sexual or physical abuse (Read, Agar, Argyle, & Aderhold, 2003; Read & Argyle, 1999). Evidence suggests that not only is childhood abuse a risk factor, it is also a strong predictor of psychotic disorders (Read, van Os, Morrison, & Ross, 2005).

A dose-response relationship between childhood abuse and hallucinations has consistently been demonstrated. One general population survey found a linear relationship between experiencing adverse events and the risk of developing psychosis: one traumatic event had an *OR* of 2.12, two traumatic events an *OR* of 3.89, and three traumatic events an *OR* of 9.96 (Shevlin, Dorahy, & Adamson, 2007). In a review of the literature, Read et al. (2004) concluded that the severity of the abuse (measured by age of onset, degree of violence, duration and intrafamilial) predicted greater risk of developing hallucinations. This was substantiated in one study that examined the risk of a variety of childhood adverse events on the development of hallucinations and found that the experience of quantitatively more adverse events was associated with a greater risk of hallucinations (Whitfield, Dube, Felitti, & Anda, 2005). Scott (2007) found a significant dose-response effect between the number and type of traumatic events and delusional experiences. Thus, it can be concluded that childhood trauma, especially more severe or prolonged abuse is predictive of psychosis.

How aversive childhoods influence the later development of psychosis has been explored by the neurodevelopmental traumagenic model (Read et al., 2001), the integrative cognitive model (Morrison, 2001) and the threat anticipation cognitive model (Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002). Cognitive models tend to focus on the development of maladaptive schema and self-esteem in response to trauma in conjunction with dysfunctional interpretations of unusual events. Psychosis is often viewed as the end point of what began as a functional coping response to adversity, for example, the hypervigilance in paranoia may act to minimise the chance of further abuse (Morrison et al., 2003). Garety et al. (2001) have proposed that early adverse events act as a predisposition to maladaptive cognitions that support psychotic symptom expression, which is especially pertinent when the earlier trauma is similar in nature to a later trauma acting as a triggering event.

## Cannabis

Individuals who use cannabis have a higher risk of developing psychosis, with one meta-analysis reporting an *OR* of 2.9 (Semple, McIntosh, & Lawrie, 2005). Of the 11 case controlled studies reported in the aforementioned research, *ORs* ranged from 2.06 ( $n = 7,695$ ) (Andreasson, Engstrom, Allebeck, & Rydberg, 1987), to 4.36 ( $n = 420$ ) (Rolfe, Tang, Sabally, & Todd, 1993). In a

New Zealand birth cohort, an increased risk of developing schizophreniform disorder by the age of 26, was associated with cannabis use at 15 years of age with an *OR* of 4.5 and for cannabis use at 18 years of age with an *OR* of 1.65. Increased risk remained after controlling for early psychotic symptoms at 11 years of age (Arseneault et al., 2002). In New Zealand, a longitudinal study ( $N = 1,055$ ) that collected data on cannabis use and psychotic symptoms, at ages 18, 21 and 25 years, found that daily users of cannabis increased the risk of experiencing psychotic symptoms to between 1.6 and 1.8 times greater than non-users (Fergusson, Horwood, & Ridder, 2005).

Whether cannabis is a cause or a consequence of psychosis is still debated. The high prevalence of substance abuse or dependence in first-episode populations is not uncommon and has been reported to be around 51% (Addington & Addington, 2007). Cannabis use may act to lessen neurotic and negative symptoms and act as a means to establish interpersonal contact where the users need for acceptance takes precedence (Compton, Furman, & Kaslow, 2004). The high prevalence rates of cannabis users within psychotic and schizophrenic populations, in conjunction with the exacerbating effect it has on symptoms, and its use being often proximately tied to onset, has led some researchers to conclude that cannabis may be a causative factor. A dose-response relationship has been observed in one prospective cohort study ( $n = 2,437$ ), which showed that a higher frequency of cannabis use was associated with a higher risk of psychosis (Henquet, Krabbendam, et al., 2005). The mechanism of action is deemed to be through the dopaminergic pathway, with the active ingredient in cannabis, THC, precipitating an increase of dopamine in the striatum and prefrontal cortex (Lupica & Riegel, 2005).

One meta-analysis compared studies that had examined the “cannabis as self-medication for distress hypothesis” versus the “cannabis as causality hypothesis” with schizophrenia and concluded a bidirectional relationship between cannabis and psychosis (Henquet, Murray, Linszen, & van Os, 2005). The argument in favour of cannabis as causative is based on research that has controlled for premorbid psychological impairment and illicit drug use (other than cannabis). Cannabis users were also found to have an acute onset and a similar pattern of cognitive deficits, however negative background social influences were much higher in the cannabis sample than the control group. For example, 50% of the cannabis sample had witnessed parental abuse compared to 15% of the non-cannabis sample (Andreasson, Allebeck, & Rydberg, 1989). The National Comorbidity Survey ( $N = 5,877$ ) found that child sexual abuse (CSA) in conjunction with cannabis use increased the risk of psychosis from an *OR* 2.45,  $p < .05$  to

OR of 4.39,  $p < .05$  (cannabis use prior to CSA), 4.25,  $p < 4.39$  (cannabis use after CSA) with self-regulatory deficits being suggested to mediate the relationship (Shevlin, Murphy, Houston, & Adamson, 2009). Studies that aim to establish a causal link between cannabis and psychosis must control for child trauma due to the high prevalence of CSA in cannabis using populations (Houston, Murphy, Shevlin, & Adamson, 2011).

## Attachment Theory

Attachment theory suggests that the early reciprocal interactional patterns between child and caregiver, characterise long-term internalised schema, which influence how the child views self, others and the world (Bowlby, 1977). When the child's needs are met in a predictive manner, the child is likely to develop a secure attachment and have a positive self-concept. Insecure attachment on the other hand arises when the caregiver is unable to consistently meet the child's needs, which results in negative self-schema (Ainsworth, 1978). The relationship between psychosis and an insecure attachment style has been extensively reviewed (Berry, Barrowclough, & Wearden, 2007; Read & Gumley, 2010), with a high prevalence of insecure attachment within psychotic and schizophrenic populations. Insecure attachment may also mediate the relationship between the high prevalence of psychosis in children who were exposed to parental loss (Morgan et al., 2007) and are the product of unwanted pregnancies (McNeil et al., 2009). Whilst insecure attachment has been linked to a number of psychotic symptoms, one of the most comprehensive models that has included insecure attachment as its foundation is associated with paranoid delusions (Bentall & Fernyhough, 2008). The model has been derived from the attribution-self representational cycle model (Bentall, Kinderman, & Kaney, 1994), which integrates many of the cognitive processes related to delusions.

In Bentall and Fernyhough's (2008) model of paranoid delusions, insecure attachment is proposed to produce a negative self-concept that is exacerbated through prolonged chronic victimisation. These predisposing factors result in negative self-esteem and an externalising attribution style, which when influenced by theory of mind deficits, dysregulate the dopamine system, which is predicted to increase threat anticipation. When threat anticipation is coupled with a jumping to conclusions bias, the result is paranoid beliefs. Evidence for this model comes from research that has incorporated measures of paranoid delusions, and positive and negative self-esteem and asked participants to estimate the frequency of positive, neutral and negative events that they and another person had or were likely to experience in the past and future.

## Familial Communication

Negative familial communication, such as expressed emotion (EE), has been shown to precipitate higher rates of relapse in individuals with schizophrenia and other mental health problems (Butzlaff & Hooley, 1998). High EE has consistently predicted a poorer short- and long-term outcome following diagnosis with more frequent and longer hospitalisations (Marom, Munitz, Jones, Weizman, & Hermesh, 2005). High EE is comprised of attitudes and communication, from carers to the cared for, judged as critical, hostile and emotionally over-involved. Critical communication is defined as comments that express frustration and irritation; hostile communication is defined as generalised criticism and rejecting attitudes; and emotional over-involvement includes intrusion, an exaggerated emotional response, self-sacrificing behaviours and over-identification with the individual being cared for (Vaughn & Leff, 1976).

The underlying causal attributional processes adopted by high EE family members, has been found to be more predictive of outcome than EE itself (Barrowclough, Johnston, & Tarrier, 1994). Critical carers have been found to make internal causal attributions towards the individual they are caring for regarding schizophrenia. Hostile carers make internal, controllable causal attributions and over-involved carers make external and uncontrollable inferences about the causal nature of schizophrenia (Brewin, Maccarthy, Duda, & Vaughn, 1991). The relationship between attributional processes and high EE is thought to be mediated by the coping strategies utilised by family members trying to control the individual with schizophrenia's behaviour. Critical and hostile family members attempting to manage the person's behaviour through criticism and coercive means and emotionally over involved family members attempting to manage the person's behaviour through over protectiveness (Barrowclough et al., 1994). Further, the degree of distress and burden experienced by the family in relation to schizophrenia was associated with higher causal searching and blame directed at the individual with schizophrenia (Barrowclough & Hooley, 2003).

High EE has generally been associated with relapse. One literature review, which included a sample of 1,323 families, found that the median rates of relapse of schizophrenia over a 9 to 12 month duration, for high and low EE families was 48% and 21% respectively (Kavanagh, 1992). Evidence that suggests that high EE causes schizophrenia has come from research that has found a significant independent effect of family interventions designed to reduce relapse (Pilling et al., 2002), even after controlling for a number of confounding variables including medication (Nuechterlein, Snyder, & Mintz, 1992). In one investigation with individuals diagnosed with schizophrenia spectrum disorders ( $n = 59$ ) that examined the relationship between EE, self-

esteem and symptomology, findings suggested that critical EE resulted in low self-esteem and more positive symptoms (Barrowclough et al., 2003). Thus, evidence suggests that EE and other types of negative familial communication have a mediating role in the development and maintenance of positive symptoms.

How familial communication may result in positive symptoms can be demonstrated with a cognitive model of psychosis (Garety et al., 2001). Positive symptoms are thought to arise when a precipitant (e.g., life event, adverse environment, drug use, isolation), gives rise to an anomalous experience, such as a spontaneous memory into consciousness. Source monitoring errors in relation to the anomalous experience, in conjunction with a heightened emotional response associated with the precipitating life event, influence the on-going processing of the anomalous event, making it more personally relevant. The aforementioned processes led to a search for causal explanations. However, due to cognitive biases (jumping to conclusions, externalising attributional biases and theory of mind deficits) that are influenced by the heightened emotional response, and negative beliefs about the self, others and the world that are congruent with a negative self-esteem (developed in response to early adverse experiences such as negative familial communication) are interpreted as external to the self and diagnosed as hallucinations and delusions. Within this process it is the interpretation of events that can make the experience clinically relevant, and it is the interpretation that is coloured by experience. This model was substantiated in one investigation that showed that individuals who experienced distress associated with perceptual anomalies were significantly more likely to develop delusions ( $N = 7,076$ ) (Hanssen, Krabbendam, de Graaf, Vollebergh, & van Os, 2005), suggesting that it is the interpretation of these events that leads to delusional formation. The resultant negative emotion may lead to avoidance behaviours and selective attentional processes that forego reality testing of the hallucination.

## Social Adversity

### Income Inequality

Poverty is associated with child abuse and neglect, criminality, violence, alcohol and drug use, overcrowding and fewer opportunities many of which are highly prevalent in the backgrounds of individuals latter diagnosed with psychosis (Read, 2010). Social inequality at birth has been reported as having a relative risk ratio of 2.1 for schizophrenia (Harrison, Gunnell, Glazebrook, Page, & Kwiecinski, 2001). In an early study of the relationship between social class and mental health problems, individuals with psychosis were found to be 28 times more likely to be from

the poorest social class than the most affluent, and individuals from the poorest social class were more likely to be treated with lobotomy, electroconvulsive treatment and pharmacology (Hollingshead & Stone, 1960). Income inequality and poverty were associated with the treated incidence of first-episode psychosis after controlling for gender, age, ethnicity, urbanicity and employment status in an African sample ( $n = 160$ ) (Burns & Esterhuizen, 2008). Social disadvantage was also associated with higher prevalence rates of psychosis in African-Caribbean immigrants in the United Kingdom (Brugha et al., 2004). In New Zealand, 40% of consecutive inpatient admissions ( $n = 255$ ) came from socially deprived areas (Abas et al., 2003), the majority receiving diagnoses indicative of psychosis. It has been argued that poverty per se does not cause psychosis but, rather, that it is highly predictive of other factors (child abuse and neglect) that are predictive of psychosis (Read, 2010).

### Urbanicity

Individuals born and raised in urban settings have a higher risk of developing psychosis than those raised in rural settings. Meta-analysis has reported that the lifetime prevalence rates in urban areas is twice that of rural (Krabbendam & van Os, 2005). One literature review suggested the incidence risk ratio of developing schizophrenia in an urban setting was, for males 1.92 and for females 1.34 (Kelly et al., 2010). One of the largest retrospective population based cohort studies, found an increased risk of schizophrenia in the Danish capital with a relative risk of 2.4 (Mortensen et al., 1999). Lifetime prevalence rates of psychotic symptoms increased monotonically with the degree of urbanicity (van Os et al., 2001). A dose-response effect was found in a large birth cohort ( $N = 1.89$  million), between degree of urbanisation and increased risk of schizophrenia, and the more years lived in an urban environment and increased risk of schizophrenia. The study also demonstrated that the causal effect was most likely mediated by repeated exposure to the causal mechanism throughout childhood as opposed to at birth (Pedersen & Mortensen, 2001). In a review of the literature, regarding the impact of the social environment (deprivation, community organisational structure, ethnic composition) on rates of schizophrenia, neighbourhoods in which social disorganisation, characterised by instability, victimisation and minority status, were found to be predictive (Allardyce & Boydell, 2006).

### Ethnicity

Ethnic populations in both the United Kingdom and the United States have relatively high incidences of psychosis (Morgan & Fearon, 2007). For example, a meta-analysis found that black skin colour was associated with a relative risk ratio of 4.8 (Cantor-Graae & Selten, 2005). Research suggests that Māori are twice as likely to be diagnosed with schizophrenia as Pākehā

(Te Puni Kokiri, 1996). Research that assessed the different diagnoses attributed to different ethnic groups within adult mental health services, found that 60% of Māori and Pacific Islanders gained a diagnosis of schizophrenia compared to 40% of Pākehā, while the converse was true for mood disorders (Tapsell & Mellsop, 2007). Further, Māori and Pacific Islanders have been shown to be more likely to be treated under the Mental Health Act than Pākehā (Read & Ross, 2003). The high prevalence rates of psychosis in low socioeconomic, urban, ethnic and minority groups are well documented. The processes by which these risk factors are suggested to predict psychosis include discrimination, marginalisation, drug use, poverty, social defeat and racism. In New Zealand, high prevalence rates of psychosis in Māori are proposed to be related to social adversity stemming from colonisation, alienation, acculturation, dispossession, loss of economic base, urbanisation and deculturation (Herewini, 2008).

### Migration

Consistently high prevalence and incidence rates have been reported in migrant populations since 1932 (Odegaard, 1932). Meta-analyses have demonstrated that migrants have been shown to have higher lifetime incidence rates of schizophrenia, with a relative risk ratio of 2.7 (Cantor-Graae & Selten, 2005) and psychosis, with a relative risk ratio of 2.3 (Bourque, van der Ven, & Malla, 2011) with an increased risk for those migrating from developing countries. The risk is also high for children of immigrant parents with a relative risk ratio of 2.1. The relative risk ratio is increased to 4 for first generation black skinned immigrants where, in the country of migration, the majority is white skinned. This is increased to 5.4 for second generation immigrants (Bourque et al., 2011). Negative identification with one's own ethnic group, following migration, was associated with schizophrenia, with an *OR* of 3.29 (Veling, Hoek, Wiersma, & Mackenbach, 2010) as was being part of a low-ethnic-density neighbourhood with an *OR* of 2.36 compared to being in a high-ethnic-density neighbourhood with an *OR* of 1.25 (Veling et al., 2008). Further, higher prevalence rates of psychosis have been reported in refugee populations (Parrett & Mason, 2010). In New Zealand, where one in five individuals have migrated (DeSouza, 2006), there is a paucity of research that documents prevalence rates of mental health problems in immigrant populations (Kumar, Tse, Fernando, & Wong, 2006).

A high prevalence rate of schizophrenia in migrant populations has been hypothesised to be caused by discrimination. Evidence for this theory comes from the wide range of different ethnic group affected and the higher prevalence rates in darker skinned migrants (Cantor-Graae & Selten, 2005). A prospective study ( $N = 4,076$ ) found that after 3 years, the rate of delusional ideation increased with greater levels of perceived discrimination (age, gender, ethnicity,

sexuality, disability, appearance): 0.5% no discrimination, 0.9% one area of discrimination and 2.7% discrimination in more than one area (Janssen et al., 2003). This was substantiated in a population-based incidence study ( $n = 482$ ) that found that the higher prevalence of psychosis in black ethnic populations was mediated by the attribution of discrimination, with black psychotic populations internalising attributions of situational disadvantage as oppose to black non-psychotic populations who attribute social disadvantage to racism (Cooper et al., 2008). Discrimination may predispose individual towards a paranoid attribution style.

### Social Defeat

Social defeat, defined as an outsider status or subordination, is hypothesised to account for the higher rates of schizophrenia in migrant and urban populations (Selten & Cantor-Graae, 2005). Within competitive societies, disadvantaged members may be exposed to high levels of social exclusion and humiliation, which may precipitate psychosis. Evidence for this theory comes from the higher prevalence of psychosis in migrant groups characterised as the least successful due to high levels of crime, unemployment, welfare and drug use and in second generation immigrants (Selten, Cantor-Graae, & Kahn, 2007). Further evidence, arising from animal studies, showed an increase of dopamine in the prefrontal cortex and the nucleus accumbens of the rat, subsequent to it being forced into a subordinate role (Selten & Cantor-Graae, 2005).

### Spirituality

There have, over time and across cultures, been a variety of causal explanations for what, by western definitions, is termed psychosis. These are shaped by the individuals' world view, belief systems, culture and experience (Prince, 1992). For example, individuals who have a religious worldview are more likely to adopt a religious explanatory model for understanding their psychosis (Huguelet, Mohr, Gillieron, Brandt, & Borrás, 2010). The prevalence of delusions reflecting religious content is varied depending on the country studied—Austria ( $n = 126$ ) 21.4%; Pakistan ( $n = 108$ ) 4.6% (Stompe et al., 1999); Germany ( $n = 150$ ) 21.3%; and Japan ( $n = 324$ ) 13.3% (Tateyama et al., 1993).

The prevalence of religious experiences in the general population is between 20% and 44% (Fenwick, 2010). Eastern traditions have many ways of conceptualising and communicating about different conscious states (Douglas-Klotz, 2010). Further, psychosis or spiritual experiences may represent an incomplete withdrawal from entering into a spiritual dimension (Tobert, 2010). The reported commonalities in religious or mystical experiences are that they are characterised by ineffable, transient, unbounded qualities that hold the paradox between



rational and irrational. Furthermore they have the potential to be transformative experiences and can elicit a sense of unification and sacredness and foster positive emotion (Fenwick, 2010). Mystical experiences, shared by shamans, prophets or saints, have historically been revered.

Phenomenologically, psychosis and religious or mystical experiences are similar. Spirituality and psychosis are often interconnected through themes of grandiosity, social withdrawal, despair, delusions, hallucinations, suffering and a search for purpose and meaning (Hunt, 2007). Further, psychosis and some types of mystical experiences such as a “spiritual emergency” can present with disorientation, reality distortion, emotionally dysregulation and interpersonal difficulties (Randal & Argyle, 2005). The Western scientific paradigm can only account for events that can be quantified, measured and replicated and is therefore not in a position to falsify spiritual experiences (Miovic, 2004). Psychotic experiences, especially in the West, are often pathologised.

A number of different theories account for why these experiences occur. Jung, subsequent to experiencing his own psychotic break, conceptualised the experience in terms of neglecting his own spiritual development (Jung, 1909) and others have faced a spiritual/psychotic experience when confronting existential issues (Chadwick, 1997). Other causative explanations include demonic possession (Pfeifer, 1999), visionary experiences (Lukoff, 1988) and spiritually transformative growth (Nixon, Hagen, & Peters, 2010). The DSM-IV recognises spiritual or religious crises as defined by a loss or questioning of faith, conversion to a new faith, and a questioning of spiritual values (American Psychiatric Association, 2000).

Psychotic and spiritual experiences share many similar attributes, with the interpretation of these experiences depending on the individual experiencing them and the culture or society in which they live. The importance of considering different explanatory models is particularly relevant to the treatment of psychosis. By honouring the individual’s worldview, the iatrogenic and stigmatising effects of standard treatment may be avoided.

## Traditional Māori Perspectives

Traditional Māori concepts of health are closely related to spirituality and the preservation of social norms. Various issues need to be considered when presenting research relating to Māori perspectives of spirituality and mental health: (1) a true understanding of Māori spirituality is deemed an experiential rather than an academic process; (2) Māori tikanga was originally transmitted via oral tradition, and as a consequence many early writings related to Māori were authored and interpreted from a Pākehā perspective (even those authored by Māori were

subject to Pākehā editing); (3) spirituality and the associated practices and beliefs may be defined differently depending on the particular iwi; and (4) meaning is often lost through the translation of Te Reo into English (Taitimu, 2007).

Māori concepts integral to perspectives of wellbeing include wairua, mauri, tapu and noa (Best, 1954). Wairua is the spirit or soul of the person, which leaves the body in death and can also travel as the person sleeps; it comes from and returns to Io. Mauri is the life force, or spark of life, which connects the atua (gods) to all living things and holds the universe in an ecological balance. Two interrelated concepts, tapu and noa, have special relevance to Māori, tapu is a spiritual force associated with sacredness or prohibition (Walker, 2004). Durie (2005) conceptualised tapu and noa as having a pragmatic relationship to health and well-being, with tapu and noa representing a form of community regulation and control. Tapu is translated to a *state of being set apart* and noa translates to *balance or neutrality* (Mead, 2003). Places, people and events can be considered tapu, such as, women prior to and post-childbirth, men preparing for battle, and families following death. Places, people and events can be made tapu through the process of rāhui, such as, birds at nesting time during food shortages (Durie, 2005).

According to Walker (2004) tohunga were revered members of Māori society who specialised in a specific area or trade, two of which were the tohunga ahurewa and the tohunga mākutu. Tohunga mākutu were feared in Māori society due to the harm they could cause through ritual directed at wairua, which could incite conditions, such as, Pāwera (stirred or affected) and Pāhunu (anxiety and apprehension) in those it was directed at (Buck, 1950). Tohunga ahurewa are Māori healers who diagnose through detailed case and whānau history, interpretation of delusions, hallucinations or delirium and dreams. Tohunga also prescribe interventions that may incorporate karakia (prayer), rongoa (remedies) and utu (act of restitution) (Durie, 2005).

Traditional Māori explanations of mental health problems are referred to as Mate Māori or mate atua (sickness of the gods) (Buck, 1950). Mate atua is believed to occur for a number of reasons: (1) tapu violations, either by the person or their extended whānau, which can render the violator kahupotia (spiritually blind) and defenceless; (2) mākutu, being cursed; (3) separation from whānau and culture; (4) loss of traditional Māori tikanga; (5) an imbalance between spiritual, mental, physical and whānau needs; and (6) transgenerational sickness is also common, with the hidden grief or unresolved trauma from past generations surfacing in the memory and behaviours of subsequent generations (McLeod, 1999).

Contemporary qualitative research that asked a predominantly Māori sample ( $n = 57$ ) their interpretation of an *extra-ordinary* experience (EOE), potentially defined as schizophrenia, found that Māori hold multiple explanatory models of which spiritual is the most prevalent. For Māori, the experience of EOE was defined in a number of ways such as a: (1) common everyday experience; (2) Whakapapa/Tupuna, a relationship with ancestors who have passed on; (3) matakite, as a gift; (4) Mate Māori, porangi an imbalance, spiritual illness, wairangi, disconnection with wairua, mākutu and tapu violation; (5) trauma; and (6) haurangi, drug and alcohol abuse (Taitimu, 2007). This research was in contrast to a similar study that interviewed Māori and Pākehā who were diagnosed with schizophrenia, and found no differences between groups on the three primarily identified causative factors: (1) drugs and alcohol; (2) family relationships and abuse; and (3) biological causes, with only one in five Māori attributing their experiences diagnosed as schizophrenia to spiritual causes (Sanders, Kydd, Morunga, & Broadbent, 2011). These conflicting findings are attributed to the sampling methods with the latter study being comprised of service users compared to a more inclusive mixed sample in the former. As Taitimu (2007) noted in her research, EOE's can be defined by Māori as a Māori or Pākehā experience, delineated by content, control and context. Māori experiences are described as positive with Māori content compared to Pākehā experiences, that were negative and with Pākehā content. Thus Māori who have Pākehā EOE are more likely to utilise mental health services as a consequence of their experiences and view these experiences as schizophrenia.

## Summary

The stress-vulnerability model can account for many of the research findings that span biological and psychosocial literature. Consideration of the aetiological basis of psychosis and schizophrenia is important for two primary reasons: (1) a grounded understanding of causative factors can influence preventative measures at both an individual and societal level, and (2) for individuals experiencing psychosis and schizophrenia, gaining an understanding or adding to an already formed explanation can be an essential feature of recovery.

# Early Intervention and Treatment

## Introduction

Comprehensive treatment during the first episode of psychosis optimises the potential for recovery. Recovery can be broadly defined to include symptom remission; improvement in subjective quality of life, including a return to previously held roles within family and the wider community; and avoidance of the iatrogenic effects of treatment and the associated stigma. Recovery can be facilitated by a number of mental health initiatives including, but not limited to, supportive therapy, pharmacology, psychotherapy, psychoeducation, family interventions and support groups. Early intervention services incorporate the aforementioned treatments and have their own defining philosophies and aims.

## Early Intervention Services

### Aims and Principles

Early intervention (EI) consists of phase-specific, comprehensive, intensive and individualised treatment that aims to occur as proximate to psychotic onset as possible. The rationale for EI in the first episode of psychosis (FEP) focuses on achieving optimum outcomes and alleviating distress. Intensive treatment at onset is proposed to reduce long-term morbidity and enhance recovery (McGorry, Edwards, Mihalopoulos, Harrigan, & Jackson, 1996). An integrative approach to treatment in the early stages of psychosis incorporating pharmacology, psychotherapy, psychosocial support and psychoeducation is designed to prevent further deterioration (Wyatt, 1991). Rapid assessment and intervention is key to maximising outcome and this occurs through greater service coordination and facilitated access to care in the wider community (Buckley & Evans, 2006). Early intervention plays a pivotal role in addressing the psychological, biological, social and vocational implications of psychosis before they become entrenched leading to greater morbidity. The cost of early intervention is half that of standard care (Birchwood, 2007).

Prior to the introduction of EIS in the 1990s, care would often occur following a prolonged duration of untreated psychosis (DUP) subsequent to crisis, and offer limited continuity. Health care settings were often traumatic and alienating, and the alliance between patients and staff minimal (Edwards & McGorry, 2002). It was from this context that the early intervention model was proposed, which aimed to: (a) reduce the DUP; (b) increase awareness within the community of EIS and how best to access these services; (c) provide rapid assessment and

treatment; (d) maximise recovery and quality of life; (e) minimise the distress associated with psychosis; (f) manage co-morbid disorders; (g) prevent secondary disabilities; and (h) encourage supportive environments for those suffering with psychosis (Mental Health Commission, 1999).

The principles of EI focus on rapid access, culturally and developmentally appropriate care and multidisciplinary assessment and treatment (Mental Health Commission, 1999). The importance of establishing a positive therapeutic alliance rests with its ability to influence a thorough assessment and a collaborative approach to treatment, leading to greater engagement and a better prognosis (Keks, Blashki, Keks, & Blashki, 2006). It takes precedence over all other aspects of care. Rapid assessment and assertive outreach are key components in early intervention, and research has shown that these components positively influence treatment adherence (Jorgensen et al., 2000).

### Kaupapa Māori

Culturally appropriate services are another key element of EIS provision. Services within New Zealand have an obligation under the Treaty of Waitangi to provide culturally safe and responsive care to Māori populations. Kaupapa Māori services, consultation, employment of Māori mental health staff, and access to kaumātua or an interpreter all increase the likelihood of addressing mental health problems within this population and enhancing a more holistic interpretation of mental health (Mental Health Commission, 1999). Clinicians working within New Zealand have a responsibility to be both clinically and culturally competent, particularly with regard to Māori. Clinicians need to have an awareness of what may or may not be construed as “abnormal” within a cultural framework and have an understanding of the primary differences between Māori and Pākehā perspectives. For example, the ramifications of being from an individualistic versus a collectivist society can inform clinical practice. Treatment models that incorporate a Māori worldview and are recommended for working with psychosis include: Te Whare Tapa Wha model, Te Powhiri Poutama model, Te Wheke model, Rangī matrix, Dynamics of Whānautanga and Te Pae Maahutonga (Herewini, 2008).

### Youth Focus

Developmentally appropriate services are a key element of EIS. Due to the age at which the majority of people experience FEP, it is imperative that the services and staff are accessible to youth (Haddock et al., 2006). This is done through the physical settings in which treatment occurs and by the use of age appropriate language to increase the therapeutic alliance (Wade et al., 2006). Due to the loss of confidence, often experienced by young people following the experience of psychosis, group work has been recommended as it can provide support,

friendships and a place where skills learned within individual therapy can be practiced (Woodhead, 2008).

### Multidisciplinary Teams

To be effective, EIS need to address all aspects of an individual's impairment. Multidisciplinary teams with psychiatrists, occupational therapists, psychologists, social workers and nurses are thought to be better able to facilitate this approach. Together they can provide pharmacological interventions (Buckley et al., 2007), psychological interventions (Couture et al., 2007), vocational skills (Killackey, Jackson, Gleeson, Hickie, & McGorry, 2006) and physical health care (Sim et al., 2006) amongst other things. Comprehensive assessment and treatment is achieved through dynamic team interaction and positive working relationships.

### Efficacy

The efficacy of EI is commonly measured in terms of symptom reduction, relapse rates, treatment adherence and retention, quality of life, and social and community functioning. The two most prominent randomised controlled trials (RCT) that addressed early intervention efficacy were the OPUS trial (Thorupa et al., 2005) and the Lamberth Early Onset (LEO) trial (Craig et al., 2004). The OPUS trial ( $n = 547$ ) randomised clients into one of two groups: (1) integrated treatment service in which caseloads were 1:10 and clients were treated with the assertive outreach model that included family therapy and social skills training, and (2) a standardised service in which caseloads were 1:25. Results show that clients who received the integrated treatment had significant symptom reduction and significant increased functional outcome at 1 and 2 years post-baseline when compared with the standardised treatment group. The LEO trial randomised clients ( $n = 144$ ) into either a newly established EIS that offered biopsychosocial treatment and assertive outreach, or standardised care. Clients in the former group were less likely to relapse or be readmitted to hospital, and attrition rates for this group were also lower. Further analysis of the study also found that the integrated group were more likely to adhere to medication regimes, spend time on educational and vocational activities and were more socially engaged than they had been previously, when compared with the standardised treatment group (Killackey & Yung, 2007). Smaller studies have found more positive outcomes with EIS compared to community mental health care, with EIS clients having less suicide attempts, being more likely to be living with family, more likely to have returned to work or study, and less likely to suffer from relapses and be admitted to hospital (Agius, Shah, Ramkisson, Murphy, & Zaman, 2007).

Early intervention services have been found to be superior than standard care on a number of measures: symptom reduction and/or remission (Addington, Leriger, & Addington, 2003; Malla, Norman, Manchanda, McLean, et al., 2002; Malla, Norman, Manchanda, & Townsend, 2002; Malla, Norman, McLean, & McIntosh, 2001; McGorry et al., 1996; Nordentoft, Jeppesen, & Kassow, 2002; Power et al., 1998); improved quality of life and/or social functioning (Addington, Young, & Addington, 2003; Carbone, Harrigan, McGorry, Curry, & Elkins, 1999; Malla, Norman, Manchanda, & Townsend, 2002; Malla et al., 2001; McGorry et al., 1996; Nordentoft, Jeppesen, & Kassow, 2002); improved cognitive functioning (Malla, Norman, Manchanda, & Townsend, 2002); lower rates of inpatient admissions (Cullberg, Levander, Holmqvist, Mattsson, & Wieselgren, 2002; Malla, Norman, Manchanda, McLean, et al., 2002; McGorry et al., 1996); improved insight (Mintz, Addington, & Addington, 2004); satisfaction with treatment (Cullberg et al., 2002); less time in hospital (Cullberg et al., 2002; McGorry et al., 1996); fewer self-harm behaviours (Addington, Williams, Young, & Addington, 2004; Nordentoft, Jeppesen, Abel, et al., 2002; Power et al., 1998); reduced trauma secondary to psychosis and hospitalisation (McGorry et al., 1996); and lower suicide rates (Addington et al., 2004).

Early intervention services can operate from small outpatient clinics and achieve good outcomes for this population (Archie et al., 2005). Further, the quality of care can be improved with adherence to treatment guidelines and monitoring of clients (Chong et al., 2006). Early intervention addresses the complexity of psychosis and the stigma associated with it, which contributes to its success (McGorry, Killackey, Elkins, Lambert, & Lambert, 2003). Research has attested to the success of early intervention on all measures of outcome. In one study FEP clients ( $n = 189$ ) were shown to have a remission in positive symptoms (77%), and have low relapse rates (29.7%) over a 2 year duration (Malla et al., 2008). In a review investigating the efficacy of EIS, it was found that a combination of pharmacotherapy and psychotherapy predicted a better prognosis (Menezes, Arenovich, & Zipursky, 2006).

## Treatment

### The Therapeutic Relationship

The therapeutic relationship is the foundation of any intervention, and when experienced as understanding and egalitarian by the client, is conducive to better overall outcomes (Hewitt & Coffey, 2005). Engagement with individuals with schizophrenia and psychosis has been reported to be more difficult (Horowitz & Marmor, 1984) and can be characterised by mistrust and withdrawal (Bachmann, Resch, & Mundt, 2003). A therapeutic alliance may take longer and

occur less frequently with this population (Frank & Gunderson, 1990). Thus, having a concise understanding of how this is defined and experienced by service users is important.

The quality of the therapeutic relationship has consistently been associated with a number of positive outcomes. One investigation with 143 outpatients diagnosed with “schizophrenia”, found that a positive therapeutic alliance was predictive of medication compliance, continuing engagement in therapy and a better outcome at 2 years (Frank & Gunderson, 1990). Research has continued to provide evidence that the therapeutic relationship is central to change in any treatment modality and hence authors have endeavoured to define the specific relationship variables responsible.

The therapeutic relationship is diversely defined. Carl Rogers believed that change would occur within a context of congruence, accurate empathy and unconditional positive regard (Rogers, 1957). Transference is one of the core concepts related to psychodynamic understandings of the therapeutic relationship, and is defined as the feelings and attitudes formed in association with past relationships that are transferred on to the therapist and worked through (Freud, 2003). Counselling psychology has proposed that the therapist attributes integral to change, were credibility or expertness, attractiveness and trustworthiness (Strong, 1968). Egalitarian therapeutic relationships consisting of mutuality and empowerment are the focus of feminist therapies (Brown & Brodsky, 1992). A more generic definition from Gelso and Carter (1985) defined the therapeutic relationship as “the feelings and attitudes that counselling participants have towards one another and the manner in which these are expressed” (p. 159). Further, they agreed with Greenson (1965) in that the therapeutic relationship consisted of three main aspects: (1) the working alliance; (2) the transference relationship; and (3) the real relationship.

### Supportive Therapy

Within early intervention, the term supportive therapy encompasses aspects of a therapeutic relationship, and delivers routine care and counselling (Freudenreich, 2008). Routine care may consist of a weekly check-in, risk assessment, reassurance, encouragement and advice and psychoeducation in relation to psychosis and stress management. It is delivered in a conversational manner with an emphasis on listening, reflecting and empathising. The main aim in supportive therapy is to create an environment in which the client feels comfortable and motivated to attend (Randal, Simpson, & Laidlaw, 2003). The goals of supportive therapy can include: (1) the alleviation of symptoms; (2) decreased anxiety; (3) increased self-esteem; (4) mastery of adaptive skills; and (5) improved psychological functioning (Freudenreich, 2008).



## Psychoeducation

Psychoeducation aims to inform clients about the nature and course of psychosis, the treatment options and the resources available. The first step can include providing a diagnosis to clients which can have a positive and negative impact on service users. Qualitatively, four themes were related to gaining a diagnosis “means of access vs. cause of disempowerment and naming the problem vs. labelling the person” (Pitt, Kilbride, Welford, Nothard, & Morrison, 2009, p. 421). Working collaboratively with individuals by helping them to attribute functional meaning to their experiences and promote mastery over their lives can mediate the distress associated with engagement with mental health services. Further, re-establishing self-esteem and addressing stigmatisation are important concepts. The process of destigmatisation involves normalising the experience and promoting a dimensional understanding of psychosis. A blame-free approach to the aetiology within the individual and the family network encourages acceptance (Freudenreich, 2008).

Psychoeducation is found to be effective within a group format as it contributes to the support experienced by its members and helps to alleviate the isolation often induced by psychosis (Larsen, 2004). The specific considerations of psychoeducation for first-episode clients are: (1) to enhance understanding; (2) modify client and their families’ negative behaviours and attitudes; (3) to normalise the experience by explaining that symptoms occur on a continuum; (4) to encourage the development of an adaptive explanatory model; and (5) the appropriate use of language, such as “unusual beliefs” and “mood swings”, as opposed to “delusions” and “bipolar” to avoid feelings of shame and stigmatisation (Aitchison et al., 1999). Psychoeducation can be inclusive of family and collaborative relapse prevention strategies can be created, which include recognition of the early warning signs to predict a psychotic episode.

## Pharmacology

Pharmacological treatment for psychosis primarily targets symptom remission, however, quality of life and psychosocial reintegration are increasingly being considered during the administration of medication (Wolfgang-Fleischhacker, 1999). Antipsychotics are generally the first line of treatment, but mood stabilisers and benzodiazepines may also be used (Edwards & McGorry, 2002). Antipsychotics can be divided into first- or second-generation antipsychotics (FGA and SGA) and are intended to reduce positive and disorganised symptoms, with inconclusive evidence suggesting some efficacy for negative symptoms (Lee & Chang, 2009). The presumed mechanism of action is the down-regulation of dopamine through blockade of one or more of the dopamine receptors. Second-generation antipsychotics are also presumed to bind

with serotonin receptors and have a higher specificity than FGAs due to their different side effect profile (Freudenreich, 2008). Antipsychotics are hypothesised to influence a number of other neurotransmitters, which correspond to their effect on certain symptoms. For example, down-regulation of histamine is believed to result in sedation (Aitchison et al., 1999). Other medications that may be used in the treatment of the first episode include lithium for manic symptoms; benzodiazepines for treatment of insomnia, anxiety and agitation; and antidepressants for depression (Edwards & McGorry, 2002). Treatment with antipsychotics needs to be individualised due to its variable efficacy and tolerability.

Non-specific binding of the dopamine receptors associated with FGAs can cause neurologic side effects, such as the neuroleptic-induced deficit syndrome (negative symptoms and cognitive deficits), extrapyramidal symptoms (EPS) and/or tardive dyskinesia (Lee & Chang, 2009), while SGAs tend to be associated with metabolic side effects such as weight gain and hyperglycemia (Freudenreich, 2008). The side effects of antipsychotics are presumed to be dependent on the receptors they bind to. For example, dopamine receptor blockage is correlated with EPS and sexual dysfunction, and serotonin receptor blockade is associated with increased appetite, possible sedation, hypotension and ejaculatory problems (Aitchison et al., 1999). Antipsychotics that have a high binding affinity are associated with greater side effects, that is, increased efficacy predicts more severe side effects and a lower tolerance (Wolfgang-Fleischhacker, 1999). Clozapine has a risk of causing agranulocytosis, in which the bone marrow fails to make enough white blood cells resulting in an increased risk of infection (Freudenreich, 2008).

Clozapine, the first SGA, has been found to be the most effective antipsychotic, however due to the increased risk of severe side effects, it is generally only used with refractory patients (Wolfgang-Fleischhacker, 1999). Two large non-industry antipsychotic efficacy trials established that SGAs were no more effective than FGAs (Lewis & Lieberman, 2008). One of these studies concluded that all antipsychotics have various limitations, which was indicated by the high number of individuals that chose to discontinue with the study, due to problems with efficacy and tolerability for each of the drugs investigated (Lieberman, 2007). One large ( $n=225$ ) RCT found that SGAs had a small but significant improvement on neurocognition, which was associated with improvements in social and occupational functioning as measured by the Heinrichs-Carpenter Quality of Life Scale, however improvement could have been an outcome of overall treatment response (Keefe et al., 2007). Risperidone, one of the more popular SGAs, was found to have only marginal benefits when compared to placebo in 10 RCTs (Ratthalli, Jayaram,

& Smith, 2010). One in four individuals who try antipsychotics will have little or no benefit, while one in 10 will have no response at all (Freudenreich, 2008).

### Explanatory Models

Explanatory models can be explored with narrative interventions that aim to engender self-worth, a coherent sense of self and personal agency (Lysaker & Buck, 2006b). This approach effectively operationalised the recovery model, both of which focus on identity, social connection and self-esteem (Lysaker & Buck, 2006a). Narrative recovery-based individual therapy proposes a session structure divided into the beginning, middle and end, inviting the client to tell their story within the relational context between client and clinician (Lysaker, Buck, & Roe, 2007). Understanding distressing experiences through narration can act as a means of controlling and making sense of them (Larsen, 2004). In responding to some of the themes common to psychotic experience, clinicians can: validate clients through genuine collaboration and normalisation of the diverse understandings of psychosis; provide a trusting therapeutic relationship where clients can discuss delusional beliefs; engage in treatment that fosters integration through attention to the effect of the time-limited nature of therapy and be flexible when indicated; model integrated relationships, by creating a service philosophy that fosters positive team dynamics; and address spirituality explicitly within treatment (Geekie & Read, 2008). Providing clients with the space and time to express their experiences of schizophrenia and the impact it has had on their lives is regarded as a contributing factor in recovery (Lysaker et al., 2007).

### Cognitive-Behavioural Therapy

The relative resurgence of psychological treatment for psychosis and schizophrenia has arisen for a number of reasons: (1) approximately 40% of individuals exhibit antipsychotic refractory psychosis; (2) high rates of relapse; (3) non-compliance with medication; (4) intolerability of side effects; and (5) consumer advocacy, which encourages a choice of treatment options (Tarrier, 2005). Cognitive-behavioural therapy (CBT) for schizophrenia is a structured, time-limited intervention that can be used within an individual or group setting (Rector & Beck, 2002).

The typical stages of CBT consist of assessment, functional analysis of symptoms and associated problems, enhancing coping strategies, intervention and relapse prevention (Bachmann et al., 2003). The therapeutic relationship is based on openness, trust, empathic listening, collaboration and non-directive questioning (Beck & Rector, 2005). The frequency, duration, intensity and variability of symptoms and the associated problems are assessed and serve as the foundation to specific goal setting. Once a collaborative formulation and operationalised goals

are decided upon, a number of interventions can be utilised (Addington, Gleeson, Addington, & Gleeson, 2005). Goals can also cover a wide variation of problems, from symptom-related complaints such as the interpretation of delusions, beliefs about voices, reduction of negative symptoms through to health problems and elements that contribute to improved quality of life (Beck & Rector, 2005). Most of the change strategies can be considered as the process of verbal or behavioural reattribution (Morrison, 2004).

Based on the research by Chadwick and Birchwood (1994) that suggests that the distress derived from psychosis is related to the interpretation of psychotic experiences, rather than the experiences themselves per se, cognitive therapy aims to target the interpretative process, for example, beliefs about voices. The evidence that supports the belief is examined and alternative explanations are elicited, with the aims of reducing distress and improving quality of life.

Behavioural experiments can be utilised that test the veracity of beliefs pertaining to delusory and hallucinatory phenomena (Beck & Rector, 2005).

A meta-analysis of CBT for schizophrenia found a large statistical effect size of 1.31 on positive and 1.19 on negative symptoms (Rector & Beck, 2001). A literature review on the efficacy of CBT with schizophrenia showed a mean effect size of 0.37, with a consistent reduction of positive symptoms in chronic patients and a faster recovery for acute patients (Tarrier, 2005). A review of 12 previous RCT studies, that compared CBT to either treatment as usual or another treatment, found that 42% of the CBT sample compared to 25% of the treatment as usual or other treatment samples had clinically significant improvement in at least one symptom (Gaudio, 2006). Another review suggested that CBT showed benefits for auditory hallucinations and hopelessness, improved the duration of recovery, and enhanced quality of life for individuals with FEP (Morrison, 2009).

The Cochrane review of CBT for schizophrenia (Jones, Hacker, Cormac, Meaden, & Irving, 2012) examined the efficacy of CBT compared to other psychosocial treatments. The research defined CBT as consisting of a discrete psychological intervention in which the connections between symptoms, cognitions and the resultant emotional distress or problematic behaviour were made explicit and re-appraised. Outcome measures included mortality, mental state, adverse effects, engagement, global state, quality of life, satisfaction with treatment and economic cost over three different time points. Only those studies defined as randomised controlled trials were considered, which accounted for thirty articles relating to 20 trials. CBT was compared to a range of other 'talking' treatments such as psychoeducation, supportive therapy and family therapy. The results suggested that there were minimal difference between CBT and other

'talking therapies' for schizophrenia; however CBT was found to be superior at reducing negative emotion.

### Family Interventions

In the initial stages of engaging with an EIS for psychosis, clients are encouraged to involve their family (Gleeson, Jackson, Stavely, & Burnett, 1999). Families often benefit from the additional information and support that EIS can provide, and it can often have a positive impact on client engagement (Sin, Moone, & Newell, 2007). Family conferences can address high emotion derived from feelings of blame and self-blame, especially if compulsory treatment has been instigated by the family, which may engender feelings of betrayal (Aitchison et al., 1999). Intervention targeted at the family has shown promising results (Buksti et al., 2006). Specifically, lower relapse rates and less hospital admissions have been associated with family therapy (Pilling et al., 2002).

Family interventions centre on the dysfunctional beliefs and dynamics between family members. Therapists aim to challenge beliefs and "disrupt the system" to encourage positive change. Within this context emotionally sensitive topics can be raised and resolved whilst the therapist reinforces positive behaviour (Bachmann et al., 2003). Family intervention can address high expressed emotion within families, which has been shown to predict higher rates of relapse (Patterson et al., 2005). Some of the techniques used include circular questioning, paradoxical interventions, communication, reversion of excommunication/exclusion of a family member, treatment via omission and management of conflicts (Bachmann et al., 2003). Further, clients have a right to exclude their families from the treatment process and may receive advocacy to aid them in achieving this.

### Summary

There has been a great progression in the treatment of psychosis and schizophrenia with the advent of EIS. Psychotherapy, pharmacology and family interventions have been redefined to improve efficacy with these populations. Early intervention services have been in operation now for two decades and the benefits that this kind of service has had on individuals have been far-reaching. Service users have made these services what they are today and continue to offer a positive contribution to service design, development and evaluation. Service users satisfaction is an integral measurement of the standard of EIS delivery and is often associated with optimal outcomes.

# Service Users

## Introduction

Over the last century, the position of service users within mental health has been redefined. Their contribution to service development, delivery and evaluation has become increasingly respected and valued. Society has often masked its intolerance of difference by isolating and rejecting those who fall within its fringes. Users of mental health services and service users have been no exception. Institutional care and invasive treatments contributed to the forced compliance of many individuals experiencing mental health problems. Like many vulnerable populations, service users have experienced injustice in the name of treatment or as a means of controlling deviance. As service users became empowered and challenged the existing hegemony, mental health evolved as a concept that incorporated recovery from mental health problems. The concept of recovery placed responsibility back with the service user, which has led to a more egalitarian dynamic between service users and service providers.

## Institutionalisation

Mental health care during the beginning of the twentieth century was largely in the domain of privately run psychiatric hospitals that were responsible for the long-term care, rehabilitation and custody of those considered to have mental health problems. These hospitals or institutions valued order, compliance and safety over patient rights, individuality and privacy (Brunton, 2003). Many facilities took more of a custodial rather than a rehabilitation or care role, and the ill effects of institutionalisation became more apparent from the 1950s onwards.

Barton (1959) described an “institutional neurosis” that was associated with patients’ apathy, lack of initiative and loss of interest. These findings were further substantiated through the influential writings of Erving Goffman (1961), Thomas Szasz (1962) and Michel Foucault (1965) who criticised institutions for being an isolated system that infantilised patients and contributed to eroding their sense of self (Dain, 1989). More recent criticisms have suggested that institutional care contributed to a loss of liberty, depersonalisation, loss of autonomy, low material standards and social stigma (Jones & Fowles, 1984). It was within this context that public pressure to close large psychiatric hospitals commenced as early as 1950 in the USA and continued through to the 1990s in New Zealand (Barton, 1959).

## Traditional Treatment

Leucotomy and electroconvulsive therapy (lobotomy and shock treatment) were the unfortunate consequences of biological understandings of schizophrenia. In 1936, the leucotomy was introduced as a means of controlling aggressive behaviour in patients with schizophrenia and it was hypothesised that lesions in the frontal lobes would slow or stop the attributed disease process (da Costa, 1997). Current neuroimaging studies on patients who had the procedure, show lesions between 8 and 38mm in diameter in the frontal white matter with surrounding secondary atrophy (Uchino, Kato, Yuzuriha, Takashima, & Kudo, 2001). The associated sequelae of lobotomy included the prefrontal syndrome, primitive reflexes, epileptic seizures and minor motor defects, and an increased risk of homicide was also reported (Hakola, Puranen, Repo, & Tiihonen, 1993), which likely contributed to the common misconception of the relationship between violence and schizophrenia. It was concluded that leucotomy was an ineffective treatment for the management of schizophrenia (Sweet, 1973). However, the procedure has been carried out as recently as 1996 (da Costa, 1997).

Electroconvulsive treatment (ECT) involves chemically or electrically inducing a seizure, and was based on the premise that epileptic grand mal seizures acted as a protective mechanism against schizophrenia (Shorter & Healy, 2007). It was first used on patients with schizophrenia, but was generalised to treat a range of problems including “homosexuality”, and was also used as a means to coercively control and manage behaviour within psychiatric institutions (Petrides & Braga, 2009). There are inconsistent findings related to the efficacy of ECT, however literature reviews suggest that the costs far outweigh the benefits, with the benefit being marginal and short-lived (Breggin, 2008; Read, 2004). Further, no evidence has been demonstrated that suggests that ECT is better than placebo for depression (Ross, 2006). In a review of the literature, it was concluded that ECT was associated with nervous system deficits including retrograde and anterograde amnesia (Read & Bentall, 2010). Andre (2009) reviewed autopsy studies of individuals who had received ECT, and then either died due to complications associated with the procedure or through unrelated causes. She concluded that structural damage, namely through haemorrhages, atrophy, oedema and necrosis, was associated with ECT. Despite a paucity of research demonstrating positive outcomes from the use of ECT especially regarding schizophrenia, ECT continues to be administered.

## Deinstitutionalisation

Deinstitutionalisation represented the societal shift from traditional psychiatric hospital care to acute inpatient, residential and community-based care (Bachrach, 1976). It arose in response to

health policy reforms designed to decrease governmental spending (Rocheffort, 1984), public concern associated with inhumane treatment (Fakhourya & Priebe, 2007), a decreased need for hospitalised care due to the introduction of pharmacological interventions (Dowdall, 1999). The success of deinstitutionalisation was largely dependent on the replacement community-based strategies designed to meet the needs of service users. Deinstitutionalisation met with some criticism when these needs were not met efficiently within the community, which led to increased homelessness, incarceration, and abuse and neglect within community settings (Chesters, 2005).

Community support programs were defined as “a network of caring and responsible people committed to assisting a vulnerable population to meet their needs and develop their potentials without being unnecessarily isolated or excluded from the community” (National Institute of Mental Health, 1977, p. 325). They were designed to offer a holistic service that was inclusive of family and utilised community resources. Further, they were expected to identify those who needed their services and engage in assertive outreach. Through a case management framework, 24 hour crisis intervention was offered, as was rehabilitation, support services, medical and mental health care. Services were intended to be offered for as long as they were deemed necessary and adhered to practice that protected patient rights (Turner & TenHoor, 1978).

## The Anti-Psychiatry Movement

During the 1960s, a time of political and social unrest, individuals and groups started to emerge who questioned the fundamental assumptions of mental illness. The anti-psychiatry movement was led by a number of influential psychiatrists including R. D. Laing, David Cooper, Aaron Esterson, Leon Redler, Morton Schatzman and Joseph Berke (Crossley, 1998), and included other social theorists such as Thomas Szasz, Ervin Goffman, Jan Foudraine and Michel Foucault. The movement offered disparate (and often contradictory) theories, that were united in their criticism of the impact of psychiatry on the individual and on society as a whole (Dain, 1989). The anti-psychiatry movement criticised the basic fundamental assumptions of psychiatry, its purpose, the conceptualisation of mental illness and the dichotomy between normal and abnormal mental health (Crossley, 1998). Further, the movement challenged the hegemony of the medical model (Double, 2006). Psychiatry as a profession was criticised for objectifying patients and as a consequence contributing to their distress (Ironsides, 1975). Insanity was theorised to be a social invention, a product of capitalism or a means of social control, amongst other things (Dain, 1989). Schizophrenia was conceptualised as a normal response to abnormal



circumstances, which had the potential to deliver a transformative experience (Cooper, 1967; Laing, 1967). Although the movement was marginalised in many respects, with a mainstream shift away from social constructions of mental health (Ingleby, 1980), the anti-psychiatry movement represented more than just a phase—it instigated and inspired long-term changes that continue to be reinforced through research and the on-going critique of psychiatry (Double, 2002).

## The Consumer Movement

The consumer-survivor movement evolved in the 1970s and aimed to redress the power imbalance between service providers and service users. There was growing recognition that those experiencing mental health problems had often been stigmatised and denied basic rights within mental health care, often feeling coerced into hospitalisation and medication compliance (Frese & Walker-Davis, 1997). Consumer groups questioned how the mental health system was operationalised and provided support and advocacy for service users. Further, service users' accounts of recovery (Deegan, 1988; Leete, 1989) began to be published, which provided survivors with hope and a voice. They had an important role to play in constructing models of wellness. These models were considered to inform best practice for understanding and implementing strategies that were believed to support recovery. In New Zealand, over the last two decades, there has been an impetus placed on the need for consumers to have input into service development (Kent & Read, 1998). One initiative, popularised by the Ministry of Health, specified that “all contracted providers will demonstrate involvement and participation of consumers, including for major providers, employment of consumers” (Mental Health Commission, 2000, p. 5). This has been evidenced with the growth of consumer advocacy groups, support networks and service user-led research that endeavours to empower service users and enhance best practice.

## The Recovery Model

The consumer movement, in conjunction with research that supported the premise that recovery from severe mental health problems was indeed possible (Harding, 1986), prompted new definitions of recovery. Recovery was considered to be a unifying human experience and a process whereby one developed new meaning and purpose from distressing experience through a change in attitudes, values, feelings, goals, skills and roles (Farkas, Gagne, Anthony, & Chamberlin, 2005). Unlike narrow conceptualisation of recovery as being purely about symptom remission, the recovery model recognised the importance of considering individuals' subjective quality of life. Further, consideration of the multidimensional effects of having mental health

problems associated with stigma, the iatrogenic effects of treatment, limited opportunities for self-determination and unemployment are incorporated into treatment (Thornicroft & Tansella, 2005). It is based on the assumption that change is, for the most part, the responsibility of the service user; that support and optimism are integral to change; that individuals have different worldviews in terms of causation and treatment; and that often the consequences of diagnosis are more debilitating than the “illness” itself (Anthony, 1993). The recovery model aims to encompass hope, healing, empowerment and connection (Jacobson & Greenley, 2001). In New Zealand, mental health services have been required to implement the recovery model since 1998 (Mental Health Commission, 1998). New Zealand identified with many of the imported concepts of recovery, but it also contributed by acknowledging the importance of culture and cultural diversity and challenged the dominance of the biomedical model (O'Hagan, 2004).

## Service Users and Research

Service users have a primary role to play within mental health research. Their contribution can lead to more ethical and improved research (Philips, 2006). Subjective information can provide a more complete picture of an individual's quality of life (Ruggeri, Bisoffi, Fontecedro, & Warner, 2001). Traditional outcome research has often presented a narrow conceptualisation of recovery that has failed to capture service users' own sense of well-being (Mirin & Namerow, 1991; Perkins, 2001). Service users self-reported distress has been shown to predict perceived quality of life better than clinician-rated symptom measures (Lasalvia, Ruggeri, & Santolini, 2002). The assumption that symptom reduction is associated with improvement in subjective quality of life is unfounded—symptom reduction does not provide interpersonal relationships nor employment, nor increase self-determination (Perkins, 2001). Consumer perspectives of mental health services provide information integral to the development of effective service provision (Turner et al., 2002). Furthermore, when these qualitative perspectives are taken into account and combined with sociodemographic quantitative information, those factors that are likely to influence favourable outcomes become more transparent, enabling clinicians to tailor care regimes to suit individual clients (Mirin & Namerow, 1991) and better predict the outcome for certain client groups. Furthermore, individuals are judged to be experts on what they have experienced and what care can best facilitate improvement in functioning (Fossey & Harvey, 2001).

## Service Satisfaction

Mental health services are often utilised by the most vulnerable members of society who have limited choice in terms of alternative care if dissatisfied with service. Further, there are often

limited financial incentives for government funded mental health care services to provide quality service, thus service users' perspectives are important to ensure innovation and quality within the public health sector (Marvit & Beck, as cited in Larsen, 1979). One meta-analysis on patient satisfaction within hospital care, sought to define overall satisfaction in terms of the contributing attributes. From 12 potential contributing factors, six were identified that significantly predicted patient overall satisfaction including: (1) respect, "the quality or state of being esteemed"; (2) communication, "receiving information about medical conditions, treatment and possible results"; (3) competence, "having requisite or adequate abilities to treat patients"; (4) convenience, "speedy admission, efficiency in dealing with problems"; (5) empathy, "the action of being aware of, being sensitive to patients' thoughts, feelings and actions"; and (6) attention, "consideration with a view to action" (Liu, Amendah, Chang, & Pei, 2006, p. 55).

Service user satisfaction has been measured with the Client Satisfaction Questionnaire (CSQ; Larsen, Aittkisson, Hargreaves, & Nguyen, 1979), which uses a 4-point scale to measure attitudes related to: the quality of service received, the degree expectations and needs were met, potential recommendations of the service, satisfaction with the help received, improved coping, overall satisfaction and whether the service would be utilised again. Satisfaction on the CSQ has been associated with engagement, global improvement, therapy gain (client-rated) and negative emotion. Further, therapist perceptions of client satisfaction, and client satisfaction, and therapist satisfaction with work completed, were positively correlated (Larsen et al., 1979).

Research that investigated satisfaction with mental health services from consumers diagnosed with "schizophrenia", found that low levels of satisfaction were associated with unemployment, increased hospital admissions, higher levels of psychopathology, higher levels of unmet needs and less satisfaction with life in general (Ruggeri et al., 2003). Client satisfaction of mental health services has shown a positive relationship with symptom improvement on both client- and clinician-rated measures (Deane, 1987). Client satisfaction is suggested to be the result of the standard of care received and the extent treatment was being individualised to suit the client (Ruggeri et al., 2003).

In a literature review, the association between satisfaction, schizophrenia and treatment outcomes were examined in approximately 30 studies. General satisfaction was measured with a number of psychometrics designed to assess satisfaction with treatment, satisfaction with life and subjective response to medication at baseline and up to 225 weeks subsequent to medication commencement. Findings demonstrated that atypical antipsychotic were associated with improvement in subjective quality of life, patient satisfaction and functional status. The

factors deemed to negatively influence satisfaction with antipsychotic treatment, included side effects, lack of collaboration and lack of family involvement. Findings also demonstrated that the therapeutic alliance was imperative in gaining optimal outcomes through providing psychoeducation resulting in antipsychotic medication compliance (Chue, 2006).

## Service Evaluation

Due to the relatively recent introduction of EIS within New Zealand, and the diversity by which they operate, in terms of employing a multidisciplinary team and the types of treatment incorporated, it is important that these services are evaluated. A comprehensive evaluation would endeavour to provide knowledge pertaining to service efficacy, resource use and outcomes (Turner et al., 2002). At present, EIS collect quantitative and qualitative information that measures psychotic symptoms, depression, anxiety, substance use and quality of life. Consumer satisfaction surveys, best conducted by a third party, can provide another element to service evaluation.

Many mental health services in New Zealand strive to implement the recovery model (O'Hagan, 2001) that aims to empower individuals who are experiencing mental health difficulties and to provide appropriate services to meet their needs. One way of meeting this aim is by exploring the perspectives of mental health users currently in care. Service users have an integral role to play in providing information that could plausibly improve the EIS for future users. Currently, many EIS quantitatively assess client outcomes through psychometrics such as the Positive and Negative Syndrome Scale (PANSS; Kay, Opler, & Fiszbein, 1987) and the Health of a Nation Outcome Scale (HoNOS; Wing et al., 1998). These measures focus on the reduction of symptoms as a measure of success. Gaining individuals' in-depth accounts of their experiences with a service, offers valuable insight into what they deem to be the most important factors leading to recovery.

A multidimensional evaluation of an EIS in Auckland, New Zealand found that clients and their significant others were highly satisfied with the service and reported high levels of staff competence. Those aspects central to the service's viability included family participation, professionalism, staff attitudes, therapeutic approaches and access to service. Less helpful aspects of the service included changes in staff and appointment times. Suggestions for improvement included increased social opportunities, more attention to follow-up after discharge, continuity of staff and inclusion of the family throughout treatment (Stewart, Gedye, & Fernando III, 2002).

The current study is partially based on an earlier investigation that evaluated the same EIS. The main focus of that investigation was on quantitative measures of improvement, specifically the HoNOSS and the PANSS. It was found that consumers had significantly improved scores after 3 months contact with the service, which continued to improve. Furthermore, increased length of contact with the service and higher medication compliance and engagement were all associated with greater improvement. A small number of questionnaires ( $n = 13$ ) and interviews ( $n = 4$ ) assessed clients' satisfaction with the service and found that consumers value the therapeutic relationship and saw it as integral to their experienced level of satisfaction (Theuma et al., 2007). Thus, the current study aims to expand and replicate that component of the previous investigation that assessed satisfaction with an EIS from the perspective of service users.

## Summary

The consumer movement represented a societal shift in mental health care reform. Institutional care has been replaced with community care, which has encompassed recovery as its foundational benchmark. The status of service users is changing, from a minority group that faced extensive discrimination, to one whose experiences are gradually becoming more valued. Increasing numbers of service users are refusing to let their experiences negatively influence their identity, and the shame and stigma associated with mental health problems are being addressed at a societal level. Recovery can be viewed as a holistic process of growth and regeneration. Within mental health practice and academic research, consumers have provided a perspective that is enlightening and has transformed previously held narrow definitions of recovery. Service users are now perceived as contributing to innovative and quality health care, with early intervention services being no exception.

# The Present Endeavour

## Introduction

The present study aimed to understand the experience of service users as they engaged with an early intervention service (EIS). The study recognises that in the past, the experiences and perspectives of service users with psychosis have largely been disregarded. Service users have a valid perspective, and this perspective is integral to service evaluation and the ethos of the recovery model.

## Purpose

The current study aimed to be of value to both the service and the service users. For the service, the objective was to provide information that could contribute to clinician and service efficacy. For service users, the objective was to provide an opportunity to evaluate the service and share their story of recovery. These interrelated aims were achieved through measuring service user satisfaction on a number of variables related to service provision; exploring the process of recovery from service inception to the present, with an emphasis on the positive and negative factors that influenced this process; and integrating and interpreting these findings in a way that had clinical utility.

## Epistemological Position

Two primary theories of knowledge directly inform research, positivism and constructivism. Positivism attempts to measure a single objective reality that exists of its own accord, separate from outside influence. Constructivism is concerned with multiple realities; knowledge is believed to be fluid and socially constructed, and the researcher and the researched are deemed interrelated (McGrath & Johnson, 2003). Quantitative and qualitative methods are associated with positivism and constructivism, respectively. Quantitative methods often aim to determine causality and various techniques are utilised that attest to objectivity. Qualitative methods are associated with meaning and process and provide rich, in-depth data. Thus, the paradigms are demarcated by divergent ontological and epistemological positions and therefore measure different phenomena (Sale, Lohfeld, & Brazil, 2002).

The two paradigms differ in their relationship to theory and data, with quantitative methods of data collection generally being theory-driven, using deductive approaches that test theories and hypotheses. Qualitative methods are generally data-driven, using inductive approaches in which patterns emerge from the data to form theory. Even within these paradigms there is a great

deal of diversity in terms of the type of data collected and the researcher's relationship to the researched (Guba & Lincoln, 2005). In contrast to the preceding paradigms, a pragmatic approach can utilise techniques derived from both positivism and constructivism. The core concepts of a pragmatic approach to research include abduction, inter-subjectivity and transferability. The relationship between theory and data is defined as abduction, whereby observation informs theory, which informs action. Metaphysical constructions of research, such as ontological concepts of truth, are not viewed as mutually exclusive; inter-subjectivity suggests that there can be one reality with multiple subjective interpretations of that reality. Transferability is focused on the application of the knowledge produced and the extent it can be capitalised on (Morgan, 2007).

The pragmatic maximum states "the current meaning of an expression is to be determined by the experiences or practical consequences of belief in or use of the expressions in the world" (Johnson & Onwuegbuzie, 2004, p. 16). At its core, the pragmatic approach is concerned with the potential empirical and practical outcomes of research that are considered throughout conceptualisation and implementation. Pragmatic research aims to produce workable, useful findings that are accessible and meaningful (Morgan, 2007). The pragmatic approach is essentially a consensus of what is worth studying and studying it with the most suitable methodology available (Johnson & Onwuegbuzie, 2004). In recognition that many research decisions are value-laden, the use of reflexivity identifies the researcher's own values and biases and how they may influence the process (Maxcy, 2010). The connection between methodology and epistemology demonstrated a bottom-up approach as opposed to the top-down approach usually associated with constructivism (Morgan, 2007). Thus, the nature and generation of knowledge are inseparable and interconnected throughout the various levels of abstraction, from method through to axiology.

## Stratified Purposive Sampling

Stratified purposive sampling (Patton, 2002) was used to increase the transferability of inferences. Participants were selected for their capacity to provide data that could be representative of the broader EIS client base, in terms of gender and ethnicity. Sampling techniques range from probability sampling in quantitative research to purposive sampling in qualitative research. Probability sampling, defined as "selecting a large number of units from a population randomly, where every unit has the same probability of being selected", aims to produce generalisable findings. Purposive sampling is "based on a specific purpose" and aims to produce transferable findings (Teddlie & Yu, 2007, p. 77). Stratified purposive sampling is often

used in mixed method research and aims to recruit a smaller representative sample of a larger population to compare various groups within the sample, thus aiming to increase the likelihood of transferable findings (Patton, 2002).

## Mixed Methods

Mixed method research had been considered as the third paradigm or the “third methodological movement” (Tashakkori & Teddlie, 2010). It has been defined as “qualitative and quantitative projects that are relatively complete, but are used together to form essential components of one research project” (Morse, 2010, p. 209). Johnson and Onwuegbuzie (2004) outline a number of strengths and weaknesses of mixed methods research including: the strengths of one paradigm can be used to overcome the weaknesses in the other; convergence and corroboration of results can produce stronger evidence; and qualitative and quantitative data used together can provide a more complete knowledge, which can be used to inform theory and practise. Weaknesses include: the researcher needs to be familiar with both quantitative and qualitative methodology and have an understanding of how to mix them appropriately, which can be time consuming and expensive; methodological purists critique mixed methods on the grounds that they have conflicting ontological and epistemological standpoints; and certain issues arise specific to mixed method research for which suitable solutions have yet to be met, such as interpreting conflicting results and how to qualitatively analyse quantitative data.

A mixed method approach to this research was considered the most appropriate, due to the research questions proposed, that is, they had an interconnected quantitative and qualitative component, which could be analysed and presented separately and then integrated to produce more meaningful and comprehensive inferences (Tashakkori & Creswell, 2007). Further, it was deemed the most appropriate methodology for providing findings that would be useful to the EIS under evaluation. Quantitative results can be used to enhance a primary qualitative study (Morse, 2010). Quantitative and qualitative data can be collected concurrently to maximise compatibility and to provide a broader perspective than either method alone (Sale et al., 2002). Triangulation, that is, seeking corroboration between quantitative and qualitative data can also provide greater weight to the phenomena being studied (Johnson & Onwuegbuzie, 2004). Quantitative data can enhance the quality of the research by complementing qualitative themes. Mixed methods research is also purported to be a truer representation of what actually happens when research is conducted (Johnson & Onwuegbuzie, 2004).



## Quantitative Data

### Verbal Response Scales

Mixed methods research will often combine large quantitative survey data with fewer qualitative interviews. This procedure was not deemed appropriate for the current study as this method often results in low response rates. Alternatively, satisfaction could have been assessed quantitatively with a self-administered questionnaire prior to completing the interview. A number of these questionnaires are applicable with mental health clients including the Consumer Satisfaction Questionnaire (Attkisson & Zwick, 1982), the Opinion Questionnaire on Outpatient Services (Perreault, Katerelos, Sabourin, Leichner, & Desmarais, 2001) and the Verona Service Satisfaction Scale (Ruggeri, Dall'Agnola, Agostini, & Bisoffi, 1994). These questionnaires are reliable and valid measures of client satisfaction in health and human services, with some having been utilised with first-episode clients.

For the present study, however, Verbal Response Scales (VRS) were chosen. In general, measures are generally evaluated according to applicability, acceptability, sensitivity, specificity, reliability and validity. Verbal Response Scales met the criteria through: (1) applicability— was met through the simplicity of the measure, and is used with individuals from diverse educational and cultural backgrounds and when distracting situational factors are present. Further participants would have been familiar with using Visual Analogue Scales (VAS) as part of their treatment at the EIS, which are characteristically similar to the VRS used in the study; (2) acceptability—met through the verbal nature of the measure, which enhanced the likelihood of responding; (3) sensitivity and specificity—the VRS may potentially not reach acceptable standards of sensitivity and specificity, however the qualitative data would likely identify whether the VRS was overly sensitive or not specific enough at recognising those satisfied from those who were dissatisfied; (5) reliability and validity of the items on the VRS were ensured as they were based on items consistently presented in other validated measures of consumer satisfaction in health. Other advantages of the VRS compared to other measures were: simplicity and ease of administration; flexibility, they could be administered throughout the interview or when deemed most appropriate; congruence with the overall interview; and as information was elicited verbally, participants could be asked to qualify responses, with a greater likelihood of them doing so than would be expected using questionnaires.

This component of the interview aimed to provide quantitative data that could test a number of hypotheses related to service provision and explore a number of other potential factors. Those

hypotheses were derived through consultation and based on earlier research by Theuma (2004). They were also derived from many of the common items on the aforementioned questionnaires.

1. Females and Pākehā would be more satisfied with the service for all measures related to service provision.
2. Those participants who were more satisfied with the quality of information they received from the service would be more satisfied with the service.
3. Those participants who felt they had more perceived control over their treatment would be more satisfied with the service.
4. Those participants who were more satisfied with the quality of the therapeutic relationship would be more satisfied with the service.
5. Those participants who felt they were more respected by the service in terms of their individual differences would also be more satisfied with the service.
6. Those participants who were more satisfied with the quality of the information received would also feel that they had more perceived control over treatment.
7. Those participants who were more satisfied with the therapeutic relationship would also be more satisfied with the perceived respect of their individual differences from clinicians.
8. Participants would be more satisfied at discharge than at initial contact or throughout engagement.
9. Participants who were with the service longer would be more satisfied with the service.

### Non-Parametric Statistics

Non-parametric statistics are distribution-free statistics, which implies that they make less assumptions about the population from which the data have been derived. Further, they are applicable with various levels of measurement, which attest to their flexibility. Non-parametric tests are often reported as having less power than the equivalent parametric tests. This conservativeness was deemed appropriate for the current study due to its primarily exploratory nature. Further, rank-randomisation tests were chosen due to their convenience and ease of use with statistics software.

## Qualitative Data

### Narrative Interviewing

The qualitative data for the present study were collected using narrative interviewing techniques. Narrative theory suggests that individuals are continually subscribing meaning to

their experiences and that language is the form by which this is achieved (Doan, 1997). According to author A. S. Byatt (2000), narration is a central element of being human and experience is only fully realised through narration (Murray, 2008). Language or narration seeks to ground experience within the life context and this process gives rise to the notion of self (Howard, 1991). Narrative interviewing techniques were used for the current research due to their ability to extract descriptions of participants' experience within a specific social context (Bertaux & Kohli, 1984). Narrative interviewing attempts to gain insight into how the experiences of participants developed the way they did (Holstein & Gubrium, 2000). The current study is interested in service users' narratives whilst under the care of a mental health service and how the service impacted on them, for better or worse. This particular technique allows the participant space to develop their own narrative and is concluded by asking them to reflect on that particular time of experience.

Encouraging participants to tell their story and making them explicitly aware that the interviewer is genuinely interested can help facilitate some sense of coherence from a time that may have been confusing and distressing. Narrative approaches are, in essence, aligned to the recovery model of mental health service provision as they validate personal understandings of mental health problems and experiences of services (Bassman, 1997). Individuals experiencing mental health problems have been shown to benefit when their narrative is received in a way in which it is valued and respected (Neugeboren, 1999). A sense of self-efficacy or agency is central to the recovery from psychosis (Holma & Aaltonen, 1997) and telling one's narrative can enhance personal agency and reduce distress (Murray, 2008). Often individuals are denied the right to speak freely about their experience of psychosis due to the stigma attached to such labels. The sense of self can be compromised with the onset of a psychotic episode (Hemsley, 1998) and narrative is one way in which the self can be reintegrated.

One of the possible limitations of using such a method is asking participants for a coherent narrative of a time in their life which was potentially very difficult to make sense of. The narratives illustrated by individuals experiencing acute psychosis can vary considerably to those in the latter stages of recovery (Lysaker, Wickett, Campbell, & Buck, 2003). Disjointed narratives, lacking in content and form can arise when the narrator lacks agency, psychosis often impacts an individual's sense of agency due to the associated subjugation and disconnection from any life role (Lysaker & Lysaker, 2002). However, a study that tracked the narratives of individuals receiving treatment for psychosis found that the synoptic content of their stories were unaffected by the progression of treatment (Lysaker, Lancaster, & Lysaker, 2003).

## Thematic Analysis

Thematic analysis is theoretically flexible, and compatible with positivist and constructivist approaches, hence it was deemed an appropriate method of analysis for the current study. It represents a technique, opposed to an ontological or epistemological framework. Thematic analysis is a method by which data can be identified, analysed and presented according to common themes within and across sets of data (Braun & Clarke, 2006). Although essentially flexible, thematic analysis requires that a number of decisions are made prior to data collection, which relate to how data collection and analysis will progress. Decisions were made that were deemed congruent with the pragmatic paradigm and therefore more useful for the service being evaluated.

The predominant frame of reference for the thematic content analysis was post-positivist, with weight given to the prevalence of themes and their relationship to either service evaluation or recovery. The number of participants that referred to the theme and the overall number of times a theme was referred to was indicative of prevalence and recorded. The analysis also aimed to provide a rich description of the entire data set as opposed to focusing on a specific minor aspect within the data. The analysis was a data-driven inductive approach with a broad research question that was refined as the research progressed. Despite the interpretive potential of latent content analysis with participants who have experienced psychosis, a semantic level of interpretation was deemed more relevant for the service and was congruent with the pragmatic paradigm. Semantic level interpretation was also chosen as it was deemed the closer approximation for providing “participants with a voice” (Onwuegbuzie, Johnson, & Collins, 2011).

## Quality in Mixed Methods Research

Legitimation (Onwuegbuzie et al., 2011) in mixed methods research is the equivalent of validity in quantitative research or authenticity in qualitative research. Tashakkori and Teddlie (2009) have conceptualised mixed methods integrity with inference quality as it relates to study design and interpretive rigor. Study design incorporates: within design consistency, from the research question through to the implied inferences; design suitability, defined through congruence between the research questions and the method employed to answer those questions—for example, the first research question that relates to satisfaction, includes both quantitative and qualitative components; design fidelity, insures that the quality criteria for all methods have been considered during the implementation of the study, such as internal and external validity

and reflexivity; and analytic adequacy, determines whether the data analysis is the best suited to the research questions and is justified as so.

Interpretive rigor incorporates: (1) interpretive agreement, the extent of agreement within the reliability audit; (2) interpretive distinctiveness, that is, the process of according appropriate interpretations to the data that could not be better accounted for by another interpretation; (3) interpretive consistency, the extent inferences are congruent with their derived interpretations and with each other in terms of scope, type and intensity; (4) theoretical consistency, the extent inferences are congruent with other findings in related fields; and (5) integrative efficacy, whether the quantitative and qualitative components are integrated with the inferences from each being combined to produce findings that are more useful than either method alone (Teddlie & Tashakkori, 2009).

The most comprehensive framework for measuring validity in mixed methods research comes from Onwuegbuzie et al. (2011) and is referred to as legitimization. Legitimation incorporates many of the aforementioned criteria and consists of: (1) sample integration, the extent inferences are transferable or generalised due to the method of sampling used; (2) inside-outside, the degree both etic and emic perspective are incorporated coherently into the research as a whole; (3) weakness minimisation, using the strengths of one paradigm to minimise the weaknesses of the other; (4) conversion, qualitisising and quantitisising data, that is, analysing qualitative data quantitatively and vice versa; (5) paradigmatic mixing, the coherence between the researchers underlying axiological, ontological, epistemological and methodological beliefs; (6) commensurability, a mixed worldview is reflected in the meta-inferences; (7) multiple validities, meeting the quality criteria of each method and drawing appropriate inferences from each; and (8) political, the value of the meta-inferences within the context for which the research was derived. The researcher engaged in many of the aforementioned practices to ensure that an acceptable standard of research had been met.

Triangulation, collecting data from either multiple sources or multiple methods can contribute to the trustworthiness of qualitative data. The current study collected data in relation to the variables associated with satisfaction through both quantitative and qualitative means. Although the different methodologies effectively study different phenomena, it provides a broader perspective than either method alone and contributes to the authenticity of the research (Kisely & Kendall, 2011). Within the results section, the quotes provided have aimed to offer “thick descriptions” that can account for the context and depth of the theme being discussed (Morrow, 2005). Some of the explicit practices that the researcher engaged in to

ensure quality included a research journal that was completed throughout the process to demonstrate how the researcher's impressions of the topic of study was shaped and constructed. Process notes were also recorded after each of the interviews to describe any countertransference issues. Professional transcription and post-listening and reviewing transcripts by the researcher ensured accuracy of the qualitative data. Consultation with the service under evaluation was undertaken throughout the write-up of the thesis to ensure findings were framed practically and had clinical utility. One method of ensuring authenticity is by searching for "negative cases" within the data—the research question was interested in both positive and negative occurrences of a range of things that influenced recovery so this process was adhered to by default. The consistency in interpretations was ensured through inter-rater reliability. Qualitative findings should aim to produce a conceptual model that demonstrates the relationships between the categories and themes (Morrow, 2005). Results were disseminated at the University of Auckland "in house" presentations (2008) and Research Forum (2010), the Making Sense of Psychosis Conference (2009) and the Regional Auckland Psychosis Group meeting (2011).

### The Research Context

The EIS under evaluation is a specialist team that operates as part of a Community Mental Health Centre (CMCH). It provides government funded health care within an outpatient setting to a catchment area of 110,000 in the central Auckland area. The service is based on a recovery-oriented philosophy designed to establish hope and empower individuals through providing supportive relationships. Treatment is based on a collaborative process in which the client's perceived needs are foremost; this process focuses on building the client's strengths and enabling them to provide meaning to their experiences. A pragmatic approach is taken that addresses everyday needs such as housing and financial help. The philosophy of the team has remained constant over the 10 years it has been in operation and the staff turnover has been unusually low, which enhances the continuity of care and the levels of engagement between the team and their clients.

Clients are generally referred by their general practitioners or by other mental health services, if they are between the ages of 18 and 35 and are currently experiencing their first episode of psychosis or have received inadequate treatment previously (criteria are applied with some flexibility). The service works collaboratively with clients and their whanau in an endeavour to meet their clinical needs and remain client-focused. Inpatient care is arranged by the psychiatrist. Support is provided by former mental health consumers. The service also has a

small social budget that allows clients to receive treatment outside of the community mental health clinic environment, which may reduce the stigma experienced by individuals attending this setting. The service has 35 clients in the service at any one time to ensure intensive outreach and the majority of these individuals stay with the service for up to 2 years. The service takes on an average of 17 new clients per year and currently has a wait list. Assessment is usually conducted about a week after the referral has been received and family are invited to attend.

Subsequent to referral, clients undergo a comprehensive assessment including blood screen, cranial computed tomography (CT) and electroencephalogram (EGG) scanning. Psychometrics including the HoNOS and the PANSS are administered at initial assessment and at discharge. The service provides a number of treatment options including: medication, psychotherapy, psychoeducation, communication and problem solving skills, whanau involvement, vocational opportunities and groups (psychoeducation for clients, family support, recreation and philosophy). The team is multidisciplinary and consists of one psychiatrist, two psychologists, an occupational therapist and a nurse. The service works closely with other health professionals who can provide cultural support, inpatient care, accommodation, drug and alcohol services, community support workers and respite.

### Researcher as Instrument

The researcher is an integral part of qualitative research. They enter the research process with their own values, experiences and biases. Reflective practice endeavours to provide some transparency in relation to what the researcher brings to the research, what motivates them, their relationship to those providing the data, and how this may influence the overall analysis to provide credibility to the end result. This transparency can only occur through the process of self-awareness and being conscious of personal socially constructed belief systems that impact the research process (Grbich, 1999).

Having completed smaller quantitative scale studies in the past, I was driven to test the depths of qualitative investigation. As I was still figuratively the university's responsibility, I felt I had a secure base from which to explore different forms of analysis. With approximate amounts of education in both forms of data collection and analysis, I felt misleadingly prepared for the challenge. It would be fair to say that my initial motivation for completing qualitative research was self-serving. Clinically, I had no experience of psychosis, and amongst those I knew who had ventured in and out of various episodes, were some of the most amazing people I had ever met, hence I was relatively undaunted by the prospect of interviewing service users and still

considered myself very privileged to have listened to their stories. Further, as I was completing my training in clinical psychology it made sense to interview service users on what they found helpful and less helpful in relation to service involvement. Surely, at some stage this would enhance my own clinical competence.

As my motivation, at least to me at that particular stage, seemed so pragmatic it is no wonder that the pragmatic philosophical standpoint espoused by mixed methodology had quite the appeal. I did surely, on a deeper level, hope to do something that made some difference somewhere. My approach to subjectivity was only, in truth, established closer to completing, when there was time to reflect on such matters and when this occurred everything seemed to make so much more sense. Of course there were multiple realities, and of course there were and are different ways of doing things, if only I could be more mindful of that on a more consistent basis.

My anxiety as an interviewer led to humility as an interviewer, perhaps not the most well thought out strategy for managing the power dynamic, it was I believe at least effective. The assumptions, biases and expectations that I brought to the research were naïve and masked, developed implicitly through a liberal upbringing and deepened through the inspiring and challenging individuals I met in the preceding years who enabled me to form values that I was proud to hold and able to defend.

Early on in data analysis I tried to manage my own sense of being completely overwhelmed by grasping at the common factors approach as a filter for absorbing and recognising patterns within the data. The aforementioned issues were addressed through the writings of copious research journals, which included both theoretical and analytical notes and consensus was achieved through consultation, supervision and peer review.

## Summary

The philosophy of pragmatism informed the current project due to its congruence with the research aims of providing practical information to the EIS in terms of their practice. The pragmatic approach utilises mixed methods in order to address the research questions in the most applicable manner.

Quantitative data collection involved service users' demographic characteristics and answers to a number of Verbal Response Scales (VRS) to measure attitudes towards various aspects of service provision, which were analysed using non-parametric statistics. Narrative style interviewing was designed to elicit service users' impressions of what they found helpful and less



helpful throughout their process of recovery and then subject to thematic analysis. The quantitative evaluation was combined with qualitative data and interpreted to provide meta-inferences deemed most useful for the EIS. Scientific rigor was defined through both qualitative and quantitative paradigms as informed by the mixed methods concept of legitimisation.

# CHAPTER TWO: METHOD

## Research Aims

The study had three interrelated aims:

1. To determine service users' level of satisfaction on a number of variables related to service provision including:
  - i. the different stages of engagement;
  - ii. the quality of information received;
  - iii. perceived control over treatment;
  - iv. the quality of the therapeutic relationship; and
  - v. perceived respect of individual differences.
2. To explore the process of recovery from service entry through to service discharge and examine what factors positively and negatively influenced this process.
3. To integrate these findings to provide information that had clinical utility for the service evaluated.

## Consultation

The current research was designed in consultation with the early intervention service (EIS) under evaluation, which operates under a local Community Mental Health Centre (CMHC). Further consultation was undertaken with the Māori advisor at the CMHC and the Māori Research Review Committee at the Auckland District Health Board (ADHB), to determine the research suitability for Māori and to ensure representative numbers of Māori were included in the study. A Mental Health Consumer Advocate was consulted to devise the most sensitive way to engage with possible research participants. The research management team at the ADHB were also consulted to determine the appropriate way to access the National Health Index (identification numbers for all citizens who have used the public health system). The locality assessment was provided by the manager of the CMHC who also agreed to provide Māori health support workers for research participants during their interview process.

## Sampling

Participants had to have been with the EIS between 2006 and 2008. The 3 year time frame was chosen to maximise response rates. The service has retained a consistent philosophy over this time and there has been minimal staff turnover. Research participants were at varying stages of

treatment with some still presently being with the service and some having been discharged up to 3 years prior.

Recruitment occurred between June and July, 2009. The information management and technology services at the ADHB provided the EIS with a list of their past and present clients from the National Health Index. The EIS screened the list according to the following exclusion criteria: (a) they had not received more than 6 hours of face-to-face contact with the EIS; (b) they were non-English language speaking; (c) they were currently hospitalised; (d) they were being treated under the Mental Health Act; (e) they were acutely psychotic; or (f) if for any other reason relating to safety the EIS decided that it would be inappropriate for them to be interviewed. Once the exclusion process was completed, the final list was sent to the principle investigator. The study aimed to obtain a representative sub sample which matched the total sample in terms of gender and ethnicity. As the list included the name, gender, ethnicity, address and phone number of potential participants specific individuals were targeted to enable stratified purposive sampling to be conducted. Fortunately the 20 participants that agreed to participate broadly met these criteria.

Due to recommendations from the Mental Health Consumer Advocate, all those clients who remained on the final list whose address was included, were sent the Participant Information Sheets (PIS: Appendix I). As recommended by the ethics committee, the PIS did not identify the recipient as a user of mental health services due to the stigma attached to attending these services. Subsequent to the PIS being mailed potential participants were phoned to determine if they wanted to be involved in the study and answer any questions regarding the research. They were also informed prior to the interview that they were welcome to have a support person present.

In an effort to engage Māori clients, a limited amount of Te Reo was used during phone conversations and within the PIS and consent form (Appendix II). Māori clients were also informed that a Māori support person could be provided and that the interview could be conducted by a Māori interviewer. None of the Māori research participants opted for either of these options.

## Ethical Considerations

Ethics approval was provided by Northern X Regional Ethics Committee for this research project, number NTX/08/11/106. The details of this approval were included on the Participant Information Sheet and the Consent forms.

If the researcher had any concerns about the well-being of the participant, the research supervisor (a registered clinical psychologist), the EIS and/or the mental health service currently being utilised by the participant (if any, and if known) would have been contacted. If unethical practice was identified, this would have been taken to supervision immediately. The principle supervisor would pass this information on to the service manager and if indicated, notify the appropriate professional body (in keeping with the New Zealand Psychologists Board Code of Ethics). Should the matter have involved any illegal misconduct, the same course of action would be taken and the police would also be notified. Safety concerns were not an issue for any of the participants interviewed.

Participants were offered the choice of being interviewed at either the University of Auckland Tamaki or City Campus. Interviews commenced informally to enhance rapport and put the participant at ease. The researcher ensured that participants understood what participation in the study involved, answered any questions and made them aware of their rights as a participant. Consent was signed prior to the interview being conducted (Appendix II). All interviews were recorded with the participants' permission. Interviews lasted between 30 and 90 minutes. Following the interviews, participants were paid \$30 towards their time and transport costs. All participants were asked if they wanted a copy of the findings on completion of the study.

## Data Collection

The interview schedule (Appendix III) was an amended version of earlier research by Theuma (2004) designed in conjunction with the EIS, and in consideration of the aforementioned research. Participants were asked a number of closed questions related to their demographic and clinical characteristics such as name, age, gender and ethnicity, and a number of questions related to their care at the EIS, such as when they engaged with the EIS, when they finished with the EIS and the frequency of contact with the EIS. Further, they were asked whether they received as much contact with the service as they thought they required. The interview aimed to answer both the satisfaction and the recovery aspects of the research question.

The interview was designed to elicit the various phases of recovery by mapping participants' progression with the EIS from initial engagement through to discharge (if they had finished with the service). In line with the narrative approach, the interview endeavoured to elicit those elements that were most salient to participants in regard to service involvement. This was achieved through utilising a funnelling approach, whereby enquiry commenced with open-ended questions that become more specific as the interview progressed (Merriam, 2002). The

interview began by asking participants to describe their experiences when they first started with the service, with engagement being conceptually divided into three stages: initial engagement, throughout engagement and at discharge. At the end of discussing each stage of engagement, participants were asked how they made sense of their experience. If the participant had not discussed the following areas: what their life was like at the time of referral, how they were referred to the EIS, their needs and expectations of the EIS, what the first meeting was like, whether they gained an understanding of the contributing causative factors to their psychosis, how they viewed their treatment, whether they felt that they had made any improvements and what they found helpful and less helpful about service involvement (Appendix III), these areas were asked about.

Prior to use with participants, the researcher practiced the administration of the interview with both research supervisors. After the first interview was conducted, the transcription was provided to the second research supervisor and feedback was incorporated into the subsequent interviews.

Service evaluation was, in part, assessed through participants' attitudes towards varying aspects of service provision. In conjunction with the qualitative data from the interview, participants were asked to rate up to (depending on how long they had been with the service) eight Verbal Response Scales on a number of areas, including satisfaction, information, treatment, relationships and respect. The majority of questions were administered at the end of the interview (with the exception of the satisfaction stages) so they did not act as prompts for participants. The questions were as follows:

On a scale of '1–10', with '1' being completely dissatisfied and '10' being completely satisfied:

1. How satisfied were you with this service initially?
2. How satisfied were you with this service throughout engagement?
3. How satisfied were you with this service when you were discharged?
4. How satisfied were you with the quality of information you received?
5. How satisfied were you with the degree of control or influence you had over your choice of treatment? ('1' representing no control or influence over your choice of treatment and '10' representing complete control or influence over your choice of treatment)
6. How satisfied were you with the relationships you formed with clinicians at the EIS?
7. I would like to get an indication of whether you felt as though you as your own person being (male/female/Māori/gay) were respected by the service. How satisfied were you with the level of respect you felt from the EIS?

8. How satisfied were you with this service overall?

## Data Analysis

### Quantitative

Nominal data were collected for the following demographic variables: gender, ethnicity, stage of engagement and source of referral. Ordinal data were collected for the Verbal Response Scales (VRS) variables: satisfaction (x 3), information provided, control over treatment, therapeutic relationship, respect of individual differences and overall satisfaction. Interval data were collected for age at interview and duration of care were reported. All quantitative data were entered into Statistical Package for the Social Sciences (SPSS) 19 for analysis. As the majority of quantitative data collected was ordinal, the measures of central tendency of interest were the median and interquartile range. Interval data were presented with the associated mean and standard deviation. The mode was also presented, as this was deemed relevant for the EIS being evaluated, as it was the most commonly reported value of satisfaction provided by participants. Non-parametric statistics were deemed the most appropriate for analysis due to being distribution-free tests. The significance level was set at  $p < .01$  to ensure greater conservatism and reduce the chance of type II errors, which is the chance of rejecting the null hypotheses and claiming significant results when there were none. This conservatism was indicated due to the number of tests being computed.

The Friedman Two-Way Analysis of Variance by Ranks test was used to determine if there was a significant difference in satisfaction at the different stages of engagement. This test assumes that the sample is randomly selected and that the satisfaction scores at the different stages of engagement are continuous random variables that are measured on at least two different occasions. The Mann-Whitney  $U$  test was used to determine if there were any differences between gender (Male and Female) and ethnicities (Pākehā and other) on the VRS variables. The test assumes that the samples are independent and randomly selected with underlying matching distributions. The VRS scores were considered to be continuous random variables that are appropriate for use with a Mann-Whitney  $U$  test. The Kendall's tau test was used to measure the strength of association between the VRS variables and the duration of care data. The test requires data that are ordinal or greater and assumes that the two variables have a monotonic relationship and can be used with samples smaller than 20 (Sheskin, 2004).

## Qualitative

All interviews were professionally transcribed in their entirety and entered into QSR NVivo 9 (2007) software. Braun and Clarke (2006) outline the various phases in conducting thematic analysis: data familiarisation, generating initial codes, searching for themes, reviewing themes and defining and naming themes. Each interview was listened to on a number of occasions to gain familiarity with the data, including once to account for any errors within the transcripts. Transcripts were re-read and any potential themes were recorded. Initial codes were generated that identified the subsequent points of interest at their most simplistic level. As the research was data-driven, themes were elucidated throughout this process. Data were entered into QSR NVivo 9 (2007) and coded by tagging and naming relevant selections of text in each transcript. As many themes as were observed, were recorded. At this stage of analysis each coded piece of text was not refined to one specific theme, but could account for a number of different themes. Further, some of the text on either side was kept to ensure that the context remained valid. Once the data were coded and collated, the codes were sorted into their various themes. A thematic map illustrated the various relationships between themes and the overarching hierarchy that governed the relationships. All the data within each theme logically represented that theme and each theme was distinctly demarcated from the other themes. Once all the coded data and each of the themes appeared to meet criteria, the entire data set was re-read to ensure that the themes were an accurate representation of the data as a whole. During this process, missed data were coded and placed into their corresponding theme. Once the thematic map represented the data accurately, each theme was analysed to determine its significance, such as why it was of interest and how it fitted into the overall data to answer the research questions. Themes were analysed to determine if they included any subthemes. On completion each theme was described succinctly, including its content and scope to determine if it was a fair representation of each of the coded elements. To meet criteria for legitimisation, interpretive agreement was determined through inter-rater reliability (see the Results section). Themes were placed within a narrative, which illustrated the evidence for, and validity of, the analysis in relation to the research questions.

## Interpretation and Integration

As the qualitative data were analysed at a semantic level, the majority of interpretation was completed concurrently with the quantitative and qualitative integration within the discussion section. Further theoretical consistency was also determined through integrating the findings

with previous research. This method was incorporated as it was deemed the most practical way to make inferences that had clinical utility for the service being evaluated.



# CHAPTER THREE: RESULTS

## Total Sample

Of the 131 clients who had been with the EIS from 2006 until 2008, 90 (68.7%) were male and 41 (31.3%) were female. Ethnic populations represented included Pākehā ( $n = 41$ ; 31.3%), Māori ( $n = 19$ ; 14.5%), Pacific Islander ( $n = 23$ ; 17.6%), Asian ( $n = 16$ ; 12.2%), Indian ( $n = 12$ ; 9.2%), other ( $n = 10$ ; 7.6%) and not stated ( $n = 10$ , 7.6%) (see Table 1). Twenty-four of these 131 potential participants were excluded, due to: having less than 6 hours of contact with the EIS ( $n = 14$ ), limited spoken English ( $n = 3$ ), risk ( $n = 3$ ), lost to follow-up ( $n = 2$ ), suicide ( $n = 1$ ) and imprisonment ( $n = 1$ ). The Participant Information Sheet was sent to the remaining 107, with 15 being returned due to the participant no longer residing at the address. Fifty-eight potential participants were contacted by telephone while 49 could not be reached. Twenty-one agreed to be interviewed (one of whom was excluded from analysis due to limited spoken English), 33 declined to be interviewed and four were unavailable due to relocating outside of Auckland. The 20 participants represented 15.3% of the total sample and 37% of those asked and living in Auckland. Participants' declined to be interviewed for a range of reasons including: difficulty getting to the interview ( $n = 10$ ), busy ( $n = 8$ ), stigma ( $n = 11$ ), unwell ( $n = 3$ ) and memory problems ( $n = 1$ ).

Table 1 *Characteristics of Total Sample Compared to the Research Sample*

Characteristic	Total Sample		Research Sample	
	$N = 131$ (#)	$N = 131$ (%)	$N = 20$ (#)	$N = 20$ (%)
Male	90	68.7	14	70
Female	41	31.3	6	30
Pākehā	41	31.3	9	45
Māori	19	14.5	3	15
Pacific Islander	23	17.6	3	15
Asian	16	12.2	4	20
Indian	12	9.2	1	5
Other	10	7.6	0	0
Not Stated	10	7.6	0	0

## Sample Characteristics

Of those interviewed, 14 (70%) were male and 6 (30%) were female. Ethnic populations represented included Pākehā ( $n = 9$ ; 45%), Māori ( $n = 3$ ; 15%), Pacific Islander ( $n = 3$ ; 15%), Asian ( $n = 4$ ; 20%) and Indian ( $n = 1$ ; 5%). The total sample and research sample were closely matched

in terms of gender and ethnicity (see Table 1). All participants were between the ages of 18 to 35, with a mean of 25.45 ( $SD = 4.4$ ), and had been with the service from between 4 and 24 months with a mean of 16.2 ( $SD = 7$ ). Participants were at varying stages of their engagement with the EIS, including eight that were still with the service, four that had been discharged into the care of their GP, and seven who had been discharged into the care of other mental health services. Eight participants had been referred to the EIS through their GP, five through the crisis team, three from hospital and four from other health services. Six participants reported having been placed in inpatient care.

## Inter-Rater Reliability

Initial qualitative analysis yielded three categories and 30 themes. Inter-rater reliability was conducted to assess the validity of the coding process. Approximately 10% of randomly selected statements were provided to an independent coder. The degree of agreement was calculated by total agreement/total statements. Of the 119 statements provided to the independent coder, 30 were unassigned to themes. Of the 89 remaining items, 64 codings made by the independent rater matched the designated coding set by the primary researcher, representing an agreement rate of 72%. However, when the uncoded statements were included the agreement rate dropped to only 53%. Two main issues arose from statements being uncoded: (1) there was minimal context to situate the statement, and (2) themes included both negative and positive appraisals of the theme being discussed. It was therefore decided to separate statements into positive and negative themes for the service evaluation component of the research question. This was considered to be more informative. Further, any theme that had less than four participants contributing was excluded. Data were recoded to integrate the new thematic map, which netted four categories and 25 themes.

Again approximately 10% of randomly selected statements were subject to inter-rater reliability, with category one (Positive Influences) resulting in an 88% agreement rate; category two (Negative Influences) resulting in a 93% agreement rate; category three (Psychosis) resulting in a 91% agreement rate; and category four (the Process of Recovery) resulting in a 94% agreement rate (see Table 2). The overall average for inter-rater agreement was 91% indicating an acceptable level of reliability. In discussion between the independent rater and the primary researcher, it emerged that the majority of the disagreements were due to the primary researcher having more contextual information from the entire interview script. No further changes to categories or themes and their definitions, was deemed necessary.

Table 2 *Inter-Rater Reliability for the Four Qualitative Categories*

Category	Agreement/Total	%
Positive Influences	29/33	88
Negative Influences	27/29	93
Psychosis	20/22	91
The Process of Recovery	15/16	94
Total	91/100	91

## Categories

Four categories represented the data: (1) Service provision that positively influenced recovery; (2) Service provision that negatively influenced recovery; (3) Experiencing and understanding psychosis; and (4) The process of supported recovery. Over 1,000 statements informed 25 themes associated with the four categories. Due to the interconnected nature of themes, there was some replication of statements that informed a number of themes. For example, if participants spoke positively of respite in terms of it being a place in which they could make social connections the statement was categorised in *external resources* and within *social support and connection*. For those statements provided within the text, the intention was to provide a balance between providing the reader with enough information to situate the statement within the broader context and providing a discrete example of the theme being discussed. Often, however, more than one theme or subtheme is represented by the following cited statements.

The names of participants were changed to protect confidentiality. The titles of specific disciplines and specific services were changed to the generic term of clinician or service.

## Service Evaluation

### Quantitative Results

#### General Overall Satisfaction

Participants ( $N = 19$ ) rated their general overall level of satisfaction with the EIS, with a median of 8.5 (7–10) and a mode of 10 (see Table 3). Females ( $n = 13$ ) rated their overall satisfaction with the EIS higher with a median of 10 (6.5–10) than Males ( $n = 13$ ) with a median of 8 (6.75–10). A Mann-Whitney  $U$  test was conducted to evaluate if Females (average rank = 11.92), on average, rated their overall level of satisfaction higher than Males (average rank = 9.12). The

results of the test revealed no statistical difference ( $z = -1.05, p = .29$ ). Pākehā participants ( $n = 9$ ) rated their overall satisfaction higher with a median of 9 (7–10) than Non-Pākehā (Māori, Pacific Islander, Asian, Indian,  $n = 10$ ) with a median of 7.75 (6.87–10). A Mann-Whitney  $U$  test was conducted to evaluate if Pākehā (average rank = 10.56), on average, rated their overall level of satisfaction higher than Non-Pākehā (average rank = 9.5). The results of the test revealed no statistical difference ( $z = -0.42, p = .72$ ).

Table 3 *Measures of Central Tendency for the Verbal Response Scales*

	N	M	Median	Mode	Range
General Overall Satisfaction	19	8.18	8.5	10	2–10
General Satisfaction (SE)	19	6.68	7	7	1–10
General Satisfaction (ST)	18	7.94	8	10	5–10
General Satisfaction (SD)	12	7.92	7.5	10	5–10
Information	19	7.63	8	10	2.5–10
Treatment	19	7.35	8	10	1–10
Therapeutic Relationship	19	7.74	8	10	1–10
Respect	19	8.37	9	10	3–10

The Verbal Response Scales measured satisfaction on a scale between 1 and 10 (1 represented complete dissatisfaction and 10 represented complete satisfaction with various aspects of service provision including: General Overall Satisfaction; General Satisfaction at Engagement (SE); General Satisfaction Throughout engagement (ST); General Satisfaction at Discharge (SD); quality of Information; control over Treatment; quality of the Therapeutic Relationship; and Respect of individual differences

### Aspects of Service Provision

Kendall's tau was conducted to evaluate the relationships between overall satisfaction and the factors related to service provision. Tests revealed no statistically significant association between Overall Satisfaction and quality of Information received ( $tau = 0.45, p = .02$ ) and perceived control over Treatment ( $tau = 0.31, p = .09$ ). A Kendall's tau revealed a statistically significant association between Overall Satisfaction and quality of the Therapeutic Relationship ( $tau = 0.77, p < .01$ ), Respect ( $tau = 0.54, p < .01$ ) and Duration of Care ( $tau = 0.62, p < .01$ ).

Kendall's tau were conducted to evaluate the relationships between the factors related to service provision. Tests revealed no statistically significant association between the Therapeutic Relationship and Information ( $tau = .31, p = .09$ ), the Therapeutic Relationship and perceived control over Treatment ( $tau = .16, p = .38$ ), Information and Respect ( $tau = 0.49, p = .48$ ), and Treatment and Respect ( $tau = 0.19, p = .28$ ). A Kendall's tau revealed a statistically significant association between Respect and Therapeutic Relationship ( $tau = 0.68, p < .01$ ) and a significantly association between Information and Treatment ( $tau = 0.49, p < .01$ ).

Table 4 Kendall's Tau Correlation Matrices for the Service Provision Variables

		GOS	Information	Treatment	Relationship	Respect	DOC
General Overall Satisfaction	tau		0.45	0.31	0.77*	0.55*	0.62**
	sig		.01	.09	.00	.00	.00
	N		19	19	19	19	19
Information	tau	0.45		.49*	.30	.13	0.34
	Sig	.01		.00	.09	.49	.06
	N	19		19	19	19	19
Treatment	tau	0.31	.49*		.16	0.20	0.05
	Sig	.09	.00		.39	.29	.77
	N	19	19		19	19	19
Relationship	tau	0.77*	.30	.16		.68*	0.42
	Sig	.00	.09	.39		.00	.02
	N	19	19	19		19	19
Respect	tau	0.55*	.13	0.20	.68*		0.24
	Sign	.00	.49	.28	.00		.20
	N	19	19	19	19		19
Duration of Care	tau	0.62*	0.34	0.05	0.42	0.24	
	Sign	.00	.06	.77	.02	.20	
	N	19	19	19	19	19	

Service provision variables included: General Overall Satisfaction (GOS), quality of information received, control over treatment, quality of the therapeutic relationship and respect of individual differences, significant was set at the .01 (two-tailed) level.

## Information

Participants ( $n = 19$ ) rated their satisfaction with the quality of Information received with a median of 8, mode of 10 and an interquartile range of 7 to 9.5. The median of Males ( $n = 13$ ) was 8 compared to Females ( $n = 6$ ) 7.5. In terms of ethnicity, Non-Pākehā (Māori, Pacific Islander, Asian, Indian,  $n = 10$ ) rated the quality of Information higher with a median of 8 than Pākehā ( $n = 9$ ) with a median of 7. There were no significant differences in terms of gender or ethnicity.

## Treatment

Participants rated their perceived control over Treatment ( $n = 19$ ) with a median of 8 and a mode of 10. Females ( $n = 13$ ) rated their perceived control over Treatment higher with a median of 8.25 than Males ( $n = 13$ ) with a median of 8. Non-Pākehā (Māori, Pacific Islander, Asian, Indian,  $n = 10$ ) participants rated their perceived control over Treatment higher, with a median of 8.25 than Pākehā ( $n = 9$ ) with a median of 6.5. There were no significant differences in terms of gender or ethnicity.

## Therapeutic Relationship

Participants rated their satisfaction with the Therapeutic Relationship ( $n = 19$ ) with a median of 8 and a mode of 10. Females ( $n = 6$ ) rated their satisfaction with the Therapeutic Relationship higher, with a median of 10, than Males ( $n = 13$ ), with a median of 7. Pākehā ( $n = 9$ ) participants rated their satisfaction with the Therapeutic Relationship higher, with a median of 8, than Non-Pākehā (Māori, Pacific Islander, Asian, Indian,  $n = 10$ ) with a median of 7.5. There were no significant differences in terms of gender or ethnicity.

## Respect

Participants rated their perceived level of Respect ( $n = 19$ ) with a median of 9 and a mode of 10. Females ( $n = 6$ ) rated their perceived level of Respect higher, with a median of 10, than Males ( $n = 13$ ), with a median of 8. Pākehā ( $n = 9$ ) participants rated their perceived level of Respect higher, with a median 10, than Non-Pākehā (Māori, Pacific Islander, Asian, Indian,  $n = 10$ ) with a median of 8.5. There were no significant differences in terms of gender or ethnicity.

## Satisfaction

Median of Satisfaction for initial Engagement (SE), Satisfaction Throughout engagement (ST) and Satisfaction at Discharge (SD) were 7, 8 and 7.5, respectively. The mode for SE was 7, and for ST and SD were 10. All participants ( $n = 19$ ) rated their level of satisfaction at the beginning of

engagement with the EIS. Eighteen participants rated their level of engagement with the EIS throughout engagement—one participant had only been with the EIS for 4 months, so was not asked to rate this item. Twelve participants were asked about their satisfaction on leaving the EIS, with four leaving the EIS prematurely due primarily to moving out of the catchment area. Eight participants were still with the EIS, so were not asked this question. A Friedman test for comparison was conducted for those participants who had been discharged from the service ( $n = 12$ ) and had therefore experienced the three stages of engagement with the service. There was no statistically significant difference between SE, ST and at SD  $\chi^2(2, N = 12) = 4.32, p = .11$ .

## Qualitative Results

### Service Provision that Positively Influenced Recovery

Table 5 *Category One, Positive Influences, Themes and Prevalence of Sample and Statements*

Themes	Sample	Statements
The Therapeutic Relationship	20	131
Medication	20	56
Psychosocial Interventions	19	149
Case Management	19	33
External Resources	15	52
Supportive Therapy	14	27
Social Support and Connection	11	24
Family involvement	10	24
Totals		496

#### *The Therapeutic Relationship*

All 20 participants referred to the therapeutic relationship as influencing their recovery. Unlike medication or specific interventions that were relatively tangible, the interpersonal space between clinician and client appeared to be influenced by a number of dynamics. The therapeutic relationship was defined by the rapport or the connection between client and clinician that was referred to as *'attached to them'*, *'the way they reached out'*, *'honest relationship'*, and *'there was a lot of mutual respect happening between them and I'*. Participants spoke about *'the personable approach of clinicians'* that included the emotional, attitudinal and behavioural responses of clinicians that led to participants feeling at ease within the therapeutic relationship. Thirteen participants referred to aspects of the clinicians'

personality, in addition to the informal aspect of the therapeutic relationship that contributed to feelings of trust, comfort and security, which ultimately led to the development of rapport and continued engagement with the EIS.

*The [clinician] he was the only doctor we could call by name. That stood out. (Raybon)*

*I like the [clinician] a little bit much, because I find out that he was humorous, and when you were with him you feel like relaxed and you can feel a little bit happy. Sometimes humorous and his voice and his actions can make you laugh. (Dai)*

*The way they approach things made me comfortable. It was nice simple English. (Stella)*

*I think one thing I noticed was that they would shake your hand. You know, the [clinician] thing, I don't know what the methodology is behind it, but he'd point you in the direction, say you're entering the room, point his hand out. And these guys [EIS] would touch me and shake your hand, and it was like cool, that's great. And then you'd leave and they'd shake your hand, and it was like we're going to fix this problem, and it conveyed that a sense of purpose about it. Like we're in this together. More like a collaborative approach. It was good like that. (Josh)*

*The [clinician] was entertaining, I remember sitting there thinking I'm the one that's meant to be mad and he'd talk, roll his head back and he would play with his tongue. It was quite funny meeting with him, just because he was so over the top that it was entertaining. I remember sitting there thinking seriously this guy needs to be on meds himself. So he lightened it a bit for me. (Michelle)*

Twelve participants expressed the impression that the EIS was designed to meet their needs through providing a client-focused service and being flexible within the therapeutic relationship. Generic expressions of the interest the EIS had in meeting individual needs led to participants feeling valued and contributed to the development of rapport. Clinicians gave participants the sense that not only did they recognise their individual differences, but that they could work with those differences to build rapport and strengthen the therapeutic relationship.

*I felt he is good, and he said he had been to China once, and he wanted to explain a certain word to me, in Chinese. So he searched on the Internet and he pronounced the word in Chinese. This made me feel close to him, close to each other. I can feel that he's a good [clinician], he tries his best to help you. (Dai)*



*The relationships are good, it's good. They really do what they can. They check in on me. They always call so they always keep in touch, that's good. Like they don't forget about me. (Justin)*

*The EI team didn't know too much about Jehovah's Witness, but they looked up some information to try and find out a bit more, which is good. (Dave)*

*I think I felt that I was given special treatment even though I know I wasn't, I felt that I was getting looked after properly. I used to work and the [clinician] used to see me in his own time. It was 6.30 meetings in his own time. He was the only one left at the clinic, I think I was appreciative of his input and effort to me. (Ben)*

Participants also referred to feeling understood and reflected on sharing a relationship with clinicians that was honest and genuine. Participants referred to being provided with the space to express themselves to a sensitive, non-judgemental and open-minded audience. This created a treatment partnership that represented the uniting of client and clinician and was associated with mutuality, clinician disclosure and collaboration.

*I remember thinking, these guys, I don't really know them, I don't feel attached to them, but then that feeling grew quite quickly. They understand you. (Brendhan)*

*The [clinician] was an extremely personable guy, and he was pretty straight up as well from what I remember. I remember him saying, we were talking about the weight gain again, and I remember him saying oh we've already talked about this, have you got this sorted out. And I remember that, because that was pretty fair enough at the time too. It was an honest relationship. (Josh)*

*It's good the [clinician] talking about things that were happening in his life that are similar to ours which is good and how other people have overcome their problems. (Vaughan)*

*It was more like he was putting the ball in my court but covering himself I guess, he wasn't condoning it but just saying every case is different. At the end of the day it's not good to take drugs, but there might be times when you might be tempted, he said maybe just see what it's like. Then go from there. (Simon)*

*And when I told them this is what I do, I told them I drink alcohol and stuff, they didn't treat me badly. I thought it was a good place, because we talked as adults (Tevita)*

*I remember the first appointment, just meeting the team. It felt good, I felt I was in good hands. They seemed to know what they were talking about and the [clinician] was really understanding and he was always on my level. (Ben)*

### *Medication*

Medication was defined as the positive appraisal of pharmacological treatment including antipsychotics (first- and second-generation), antidepressants and mood stabilisers. All 20 participants referred to at least one aspect of medication that they found helpful. Participants varied in terms of their degree of positive appraisal, from, for example, [What do you attribute your improvement to?] *'It might have been the medication'* to *'It was the Risperidone that saved my life'*. Many participants reported that their improvement occurred subsequent to taking medication. Nine participants reported improved sleep, followed by six who reported a reduction in anxiety *'feeling calmer and more relaxed'* and improved mood *'feeling better'*. Others experienced a reduction in voices and improved thinking was also reported. Three participants reported a general improvement from, or helpfulness of, medication without providing specific detail on the how they defined improvement.

*It [medication] had the most benefit for getting my body clock in time and because a lot of my problem was the sleep and anxiety and all that, one of the first drugs I took was to help cure my anxiety. (Simon)*

*But once I started taking it [medication], I started changing. I stopped hearing voices. I stopped yelling at people and I stopped behaving strangely like going outside and acting weird and stuff. (Irene)*

*I think the medication kicked in, was doing its job and I started feeling a lot better about things in general. (Josh)*

*Most of my improvement was done as soon as I changed back to Risperidone to be honest. I changed immediately; I improved pretty much instantaneously. (Diane)*

*He gave me Risperidone and all of a sudden my mind just changed, and I could sleep well at night, I saw things more clear, instead of black and white, I was more positive. (Phil)*

*But after mum convinced me that it [medication] would help me sleep and it would be good for me, I took it, it had a pretty calming effect. I was very nervous and it relaxed me and made me feel a little bit better. (Jeremy)*

*[Medication] clears my mind. (Tevita)*

### *Case Management*

Case management referred to the overall frequency of contact and the treatment structure that incorporated the different phases of therapy that participants reported as influencing their recovery. Nineteen participants were satisfied with the level of contact that the EIS provided them with. Eleven participants reported that they felt some level of collaboration with the EIS in deciding the frequency of appointment times. In conjunction, five participants referred to various positive aspects of how the EIS structured their care and how it impacted on their recovery. Consistent and regular contact was viewed positively, as was being provided with a sense of routine. Other participants attributed the tapering and conversational content of sessions towards the end of their recovery as indicative of their improvement and participants referred to having a positive association with being discharged by the EIS.

*I guess having to see the EI team, even having to get up every morning to see them gave me a sense of routine or structure and just made life simple again, not having to worry about the stresses of uni and it took me away from psychoanalysing things as well.*

*(Raybon)*

*I think if I needed more [contact], they would have given more. I was part of that decision not to keep going. They said do you feel you need to come in every week and I felt the tablets were working and, things were getting better. It felt a bit better to be a part of that decision, at least you were getting treated like a human being. (Jan)*

*So the meetings at the clinic were getting fewer and far between which reinforced to myself that I was coming towards the end of my recovery and that which is good.*

*(Simon)*

*I bounced back quite fast I think and I know I made improvements because the time span between the actual meetings got bigger and bigger and bigger and I knew that I was doing better and I was on my way out of there [...] I think just leaving, having my last meeting and them letting me go and getting on with life and trusting me. It was like freedom in a way. (Ben)*

### *Psychosocial Interventions*

Psychosocial interventions were defined as the techniques used by clinicians, which facilitated client change, over and above the therapeutic relationship, case management and supportive

therapy. Sixteen participants referred to three primary interventions including psychoeducation, psychotherapy and vocational support.

### *Psychoeducation*

Psychoeducation was provided to participants through group interventions, individual sessions and resources, such as pamphlets and worksheets. The information through psychoeducation consisted of biological explanations of psychosis and the impact of recreational and prescription drugs on cognitive functioning, coping skills, community support and the course and prognosis of psychosis including relapse prevention.

*And if there was some information, like I remember he went over, because I had a couple of blips, and he, I can just remember him explaining what a blip was, brief something intermittent whatever it was. And I just remember him explaining it at the time and that was really helpful. (Josh)*

*Just talking about ways of coping with voices and all the things you can do, like distracting them with music and all these other things, work takes your mind off things, being active. (Vaughan)*

*They were helping a lot, what they were telling me about psychosis and the ways they can help with everyday living as well, what I can do for the body and mind, exercise or have someone to talk to. Do things differently. If there's a hobby or something that I really like, to get into it, keep my mind off things and sometimes when I'm normal then I think strangely and stuff. Like sometimes at that stage when I seem to be normal then all of a sudden I just start thinking strangely and seeing stuff and hearing stuff. (Irene)*

*The [clinician] was trying to figure out what triggered my psychosis and then once he realised what triggered it, it was more about helping to give me exercises and obviously to help steer me away from having that episode happen again. Such as taking myself away from situations where I might get back into psychosis or getting into the drug taking or feeling down which could lead me back into it. He said a lot of people, a lot of cases, after stopping the medication can slip back into psychosis but he said each person is different, so he said as long as you stay off the drugs and keep to your medication and keep everyone informed about what episodes you have. (Simon)*

## *Psychotherapy*

Psychotherapy included CBT, the development of insight and the integration of self/identity. Various components of psychotherapy were judged positively and were referred to by participants as being helpful, such as affective experiencing, reality testing, behavioural regulation and cognitive learning. Participants felt that the EIS had provided them with a space in which they could be emotionally vulnerable, which led to a catharsis and a reduction in tension. Being provided with accurate interpretation and feedback that fostered insight also contributed to changes in attitudes and belief systems for some participants. Reality testing was especially helpful for a number of participants and enabled them to see things from another perspective and behave differently. Psychotherapy contributed to participants making changes that positively influenced their recovery.

*Offloading my feelings, opening up about them, acknowledging feelings that otherwise I would have just suppressed and pretend that I have no problem and put on a façade, but that's all just a front it's not real, but I'm real, I'm real now. (Justin)*

*They help you figure out your feelings and that. I'd have a feeling I wasn't sure about it, and she'd help me to recognise it. I'd just think oh there's a feeling in my chest, but she would help me to figure out that it was related to something I was thinking about. I think that's, that's pretty neat. I think that's good for me, but I think that's something good that they do. It makes you feel quite good, after you finish talking about it you know what your problems are or your feelings. (Dave)*

*That's when I noticed a big improvement in how the cognitive stuff is starting to work for me as well. I started seeing the [clinician] who does therapy, and that's when I noticed a lot of big improvements from there as well through doing that. (Brendhan)*

*At first, I just didn't really get the [clinician] at all, for the first four times that I went there, I couldn't see the point, but there probably was a point, and I trusted that there was going to be a point, to what we were going through, but I wasn't really seeing it. And then I remember, it was about the fourth time that I saw him that he made me see something in a completely different way. It was like an aha moment. And then I was like, holy shit, the [clinician] really knows what he's talking about. That was really helpful what he said. And because he hadn't really said much, he's really surgical in what he said, like he'll get me to talk for ages, and then he'll say one or two things that are like, right on the button, and really helpful, and I was like woah, yes, really impressed.*

*And then when the [clinician] said that thing to me, that surgical thing, it was when I realised hey the content, I started believing the content. (Brendhan)*

*I think just the reality checks were most helpful for me, just the reality checks. I don't know if it would work for everyone, but for me it was good. I had my Dad in one ear, and the doctors in the other ear, and even if I didn't fully believe them, it meant that I would act like I believed them and I would just be more able to interact with other people without spurting bullshit. So that would help. (Josh)*

*I remember I was planning on going back to Australia and the [clinician], talked things out with me and she confronted me in a way that I didn't want to be confronted but that was helpful. She made me look at things, like to not look at things from how I was looking at it, but from how another person might look at it, but she really made me do it. I really didn't want to do it, but it was a good thing for me to have that at that point, because I really needed it. I think she obviously could see that I needed to have it shaken into me so she did. (Michelle)*

*We did a lot of work about alcohol and slowly we cut the alcohol down to just the weekends and then I just got better and better. I'm not allowed to drink any more. I've got gout. That's only recent. I wasn't a heavy drinker in the end anyway, so it's fine. I used to drink almost every night after work and got it down to the weekend and then got it down to bugger all and nothing much which was pretty good. (Ben)*

#### *Vocational support*

Participants also referred to vocational support with the EIS being instrumental in encouraging and empowering them to engage in employment and study, which contributed to recovery.

*I actually took their advice and went back to school and finished another certificate in computers as well, so I'm not that stupid. (Phil)*

*And my life had improved a little bit. I started my course three months ago. The [clinician] helped me to think about doing something like that, going back to work, finding out some courses. (Dave)*

#### *Supportive Therapy*

Supportive therapy appeared to encompass those statements that related to, but were divergent from the therapeutic relationship and psychosocial interventions. Fourteen

participants referred to interventions aligned with supportive therapy such as reassurance, advice and empowerment.

### *Reassurance*

Reassurance was often provided to participants in relation to experiences that led to self-deprecation. Statements were primarily related to diagnosis and the associated stigma. They often had the effect of normalising the experience of psychosis for participants. Reassurance supported recovery through providing hope to participants. Participants also commented on being provided with encouragement from the service and being reinforced for doing things that would increase the likelihood of recovery.

*The [clinician] used to tell me a lot of people, I was in the same boat as a lot of people with symptoms and stuff. He said with the general psychosis he assured me I'm not the only one and there's definitely ways through it. It felt like there was definitely a bit of light at the end of the tunnel. (Simon)*

*It was just nice to hear I'm not schizophrenic. (Jan)*

*I have an image of myself, I think of myself one way, but they are telling me that that's not how it appears. I think I appear one way, sometimes I say things that are crazy or I'm arrogant and that's the impression that I get, that's how I'm treating them, but they tell me that they don't get that impression, so just things like that. (Dave)*

*And so eventually I caught it, and half shook it a little bit, and I felt really just like I couldn't trust myself after that. But the [clinician] helped me to see that the fact that I was worried about it was probably a good thing. And if I hadn't been worried about shaking the rabbit, then maybe that would have been bad. (Brendhan)*

*The EI team they're good and they ask good questions, and tell you if something's wrong with you. They tell how to get better. And they just give you a bit of encouragement, like when you're in a spot that's not good, you can get out and try again, like you can get out and succeed. Like that really helped me achieve better relationships with other people. (Tevita)*

*The [clinician] reinforced you really are getting a lot better because you're becoming a lot more independent so the independence is going to help you a lot more. (Simon)*

### Advice

Participants reported finding the advice the EIS provided helpful. Advice ranged from interpersonal safety within relationships, gaining support from others, and involvement in recreational, vocational and academic areas.

*I'd have a problem and the [clinician] would help me to work it out. The advice that she would give me, like I wouldn't talk to anyone else about it, but I would tell her and she would give me advice, I became an alcoholic and she got me to inform my parents while I was at her office, cause I might leave the office and not done it. Practical things I guess. (Dave)*

*I think just having the team behind you and just coming over everyday makes a difference, they can guide you on what to do next, just like simple things like take meds, that's most important, sleep more. Just talking to my parents and how to look after me, just regular things like prevention, preventative plan. (Hiroshi)*

*Why the hell do you want to know my things and then she [social worker] spoke to me very nicely, we just want to try to help you. We're just trying to see how you cope, see how you're doing, I'm like okay what else do you want me to do, so she protected me, talked to me about guys, protected me from guys, because she talk to me about all the different places telling me about the guys, bad guys, good guys. (Rose)*

### Empowered

Many participants reported being empowered by the EIS, both generically by stating that change had to come from the participant and more specifically by providing practical information by which the participant could action.

*I always reach that conclusion where they're like we don't know what to do with you, it has to come from you, so I know I have to stand up and step up to the standard that I should be by myself with their support. (Justin)*

*I think myself about it, I realise I have to do this by myself because no-one is reliable helping, I can't go please do this for me, do this for me, do this for me. I can't do that. I have to stand on my own two feet which is I learn that from the social worker. (Rose)*

*I think the fact that they provided information, a lot of it you had to go get yourself, they would suggest web-sites and stuff like that, that was really helpful, I didn't follow any of*



*it, but it was helpful at the time. It was quite empowering that they let you sort it out yourself. So that's a good thing. (Josh)*

*I really developed, just knowing that I'm able to have those professional relationships with the mental health workers at the EIS and I could use those professional relationship skills with other areas of life. (Raybon)*

*I think I was given a DVD, I watched a DVD about I think it was life after mental health, like people that had had come out on the other side and it was an inspiration. I watched it, I think they looked like normal people so I think I was happy that it didn't just happen to drop kicks that do drugs and do naughty things, it just looked normal. (Ben)*

### *External Resources*

The EIS utilised a number of community resources to meet clients' individual needs. External resources were defined as the positive appraisal participants had of the EIS's efforts at liaising and advocating for them with third parties. Four types of external resources emerged that included: specific individualised services; respite care; government and non-government organisations; and programmes and groups.

### *Specific services*

Nine participants reported being referred to specific services or consultants that contributed to their recovery. Participants underwent neurocognitive testing, engaged with cultural services, visited a spiritual mental health consultant, had massage and were seen by a voice hearer. Further, the EIS was able to provide advocacy for clients within their academic and vocational occupations.

*I saw a Chinese health professional. Mostly he took me for driving. He belongs to Asian Mental Health. With him it's easier to communicate in Chinese. (Dai)*

*One thing that they did for me which was really good, and was quite helpful with that was they organised some massage for me which was not apparently in the budget or anything. (Michelle)*

*There's another lady that came to see me who hears voices as well. She listened to me one day. All these people were quite nice to me, hearing what I've gone through there, through the voices. (Stella)*

*They [the EIS] were able to work together with the mental health co-ordinator at AUT to address exam preparation to help me deal with my anxieties and it was really great.*

*(Raybon)*

#### *Respite care*

Seven participants were referred to respite care, with six having a positive appraisal of staying there. Of the six who had a positive appraisal, the environment was considered to be conducive to recovery. Participants enjoyed the fact that they got to 'relax', 'be away from their family', 'meet other young people' and 'engage in art therapy'.

*They were excellent with arranging two visits to a Christian based respite facility and they did really well despite the fact that I was so psychotic at my first visit. I'd say I'd associate the respite care as a home because it's nice and cosy and they've got nice beds and it's quite warm. So they [EIS] were great in arranging and liaising me to go there.*

*(Raybon)*

*When I was at the respite centre I did lots of art work there, painting and patterning tiles and stuff so if I can do that why should I have anybody in my brain to work it out. The more I saw the colours the more creative I got there and for me it was more relaxing than having these noises in my head 24/7 when they do nothing for me you know. I don't want to have that in my head. (Stella)*

*They had these places where they could refer me to, to have a break or have a think about things and I went to respite care and when I was first with the EI team and I went there for three weeks I think, that's when I started taking medication and I met other people that had mental illness and I was hanging around with them for a while when I was there and talking about stuff and how you're feeling and I felt it was good, it was helpful and it was good hearing them knowing that they had an illness as well and that I'm not alone and other people have it too. I stayed there for about three weeks then I had a meeting with them again and they just asked me how I liked it and what the staff were like and the people were like and I said I really liked it. It just seemed to keep my mind off hearing voices. (Irene)*

### *Non-government and government organisations*

Seven participants had utilised non-government and government organisations that the EIS had either referred participants to or informed participants about. Services used included advocacy, art therapy, guidance, resources, support workers, vocational skills and housing.

*The real good thing that they did for me was put me in contact with community of refuge trust and they gave me a flat so I have my own flat. It got me my own place, out of mums, so I can live more independently. (Justin)*

*The [clinician] told me about toi ora. I think it's like an arts centre, it's in Grey Lynn and they have guitar lessons and art therapy, painting and ceramics and that kind of thing which I quite like. She told me about that place and I looked that up or she sent me a link or something and I went there. I only went there once, but still I thought it was cool. (Michelle)*

### *Groups*

Five participants had a positive appraisal of attending skills based programmes and social and support groups. Socially, participants reported enjoying the youth focus and social functions organised by the groups, additionally, the programmes addressed healthy lifestyle options, and vocational and social skills. Overall, participants reported finding the groups and programmes rewarding and provided them with normalising experiences.

*The EIS ran an Active-8 programme which was run by two [clinicians]. This time it was focused on physical activity and lifestyle choices they were very similar, but the thing that I'm trying to get at is they do have programmes there and I enjoyed it because there's nothing else to do and I have a little certificate in the end which made it feel great, gave me a sense of achievement despite the fact that I've already got a degree. (Raybon)*

*Since they've been making me go to these groups, that's a lot better because my life is a bit more open because I'm doing other things. They're useful, they had a barbeque and I was happy to go because I have a feed and I like to have food. So I went there and played some sports and I never played sports in a decade so that was good to do that, different. (Justin)*

### *Social Support and Connection*

Social support and connection was defined as a positive appraisal of connecting with others through service initiated informal social relationships. Eleven participants referred to social connection as being a positive influence within their process of recovery. Six participants spoke positively of being socially connected through EIS initiatives that facilitated 'connection', 'friendship', 'I really enjoyed having to interact with people', 'relating to others', 'reassurance' and normalising experiences.

*Most helpful, probably the group meetings we had. Talking about your experiences and knowing you're not the only person stuck in the same world. [...] Respite is quite good, where they take you to Titirangi this house, its pretty good. You stay there away from everything else, just getting away from the family and meeting new people. (Vaughan)*

*I went to respite care and when I was first with the EI team and I went there for three weeks I think, that's when I started taking medication and I met other people that had mental illness and I was hanging around with them for a while when I was there and talking about stuff and how you're feeling and I felt it was good, it was helpful and it was good hearing them knowing that they had an illness as well and that I'm not alone and other people have it too. (Irene)*

*I started to reconnect with people my age, but it was also different because I'm reconnecting with people with mental health issues and I've never in my whole life had such attachment. [...] I developed friendships there, which was very odd because I've heard of so many negative experiences of inpatient care, not a lot, but I've heard some and it's not that bad. (Raybon)*

*In hospital I met some really gifted people and it was interesting because everybody was termed mentally ill and yes they were, but also in their own ways, in certain areas very, very gifted and more in tune and aware than the average Joe. (Michelle)*

*I learnt that they have these groups called Walk the Talk or the other group is Straight Talking group and I think that's nice because I get to see other people my age who are in the service and I can relate to them. (Justin)*

### *Family Involvement*

Nine participants referred to positive interaction between the EIS and their family, which influenced their recovery. Participants reported that family conferences: (1) contributed to

better family dynamics; (2) led to increased awareness of all parties; (3) gave families more insight in how best to support clients; (4) increased medication compliance; and (5) provided the EIS with an opportunity advocate for their clients.

*Family was good, very definitely very helpful. I think the best thing about that was they were able to have their little say and everything, their input and they could be on the same page as me. It wasn't second hand information. I wouldn't go home and tell them, Chinese whispers, they were getting it first hand, and that was pretty important. So they didn't just have my word, they could take the word of the [clinicians]. And if they had any questions they were answered immediately. Very good. (Josh)*

*My parents have been there right through. And they [EIS] even asked if my parents would like to come in, so that they could meet with them. My dad came in, and they briefed him, what was going on, what I had been doing with them, what they think about me, the psychosis, the demon attacks and stuff. Which was good for my dad cause I don't really talk to them too much about my depression and stuff, so it was good for him (Dave)*

*Every now and then me and mum would get into a bit of argument, if I was a bit moody or something she'd say she thought that was probably a bad move taking me off the extra ½ mg of drugs and I shouldn't have done that. We'll call the [clinician] tomorrow. She used to do that quite a lot and she used to call him up asking him a few times I went back to him, we went back just for drug queries, should the dosage be increased, Simon wants to decrease it but sometimes she didn't want me to, but the [clinician] was stuck in the middle but he used to say, he just always seemed to be able to come in between me and my mum, he managed to back me up, he said he'd sooner decrease it a little bit than increase it like my mum wanted. (Simon)*

## Service Provision that Detracted from Recovery

Table 6 *Category Two, Detracting Influences, Themes and Prevalence of Sample and Statements*

Themes	Sample	Statements
Medication	16	41
The Therapeutic Relationship	12	46
Psychosocial Interventions	9	58
External Resources	8	22
Disruptions in Care	6	23
Family involvement with the EIS	6	13
Inpatient Care	6	10
Totals		213

### *Medication*

Within this category, medication was defined as participants' negative appraisal of pharmacological treatment. Sixteen participants felt that aspects of pharmacological treatment had a negative impact on their recovery. Four participants reported stigma associated with taking medication, which contributed to a reluctance to take it. For a number of participants, some of the medication they tried had limited or no efficacy, which contributed to their frustration. The majority of participants experienced adverse side effects such as 'weight gain', 'tiredness', 'decreased motivation', 'low libido', 'menstrual problems', 'feeling glazed over', 'spaced out', 'unable to think properly', 'constipation' and 'shaking'. A number of participants felt that medication negatively impacted their lifestyle such as limiting their ability to engage in physical activity and socialise with friends.

*Clozapine was bad medication for me, it took away a lot of my motivation and I should never have been on it. I put on about 30kg in about three months and I had no motivation to do anything. It just made me sluggish and didn't help with my thinking or reducing voices or anything. (Diane)*

*Medication limited my physical activity and I would say that if anything, nutrition and physical activity is the key for mental health and wellbeing. (Raybon)*

*He put me on Prozac, and when I went on that, my mental health went downhill, I never recovered. It was worse. That was the worst thing I could have taken. I just went really*

*downhill. And it was on a low dosage too. And yeah, it was horrible. I just started staring off into space. (Jan)*

*I didn't want to take medication because I felt funny about it. I thought you know people will laugh at me and think I'm dumb and stuff. (Irene)*

*I was getting drowsy with the medication and wasn't able to stay up past nine o'clock and just feeling useless and that wasn't very good. (Simon)*

*I had some medication that I was taking and it wasn't really doing anything, so I was frustrated with that. I still felt quite depressed. (Dave)*

### *The Therapeutic Relationship*

The therapeutic relationship was defined as the negative relational elements between client and clinician that diminished rapport. Nine participants reported a belief that one or more aspects of the therapeutic relationship could have been better. Primarily, participants experienced some aspects of the approach of clinicians, whether attitudinally, emotionally or behaviourally, as detracting from potential rapport. Some participants offered suggestions as to how it could be improved or avoided. At times, clinicians were experienced as 'patronising', 'judgemental', 'mocking', 'too stand offish', 'dry' or 'rigid' with the majority of participants attributing this to a mismatch between the clinician and themselves or it being a reflection of their own perceptions of clinicians.

*But the [clinician] I don't like him too much, because I found him a little bit like rigid, rigid, like very strict. And he speak like, you must do this thing. And his voice like, like a teacher, not your friend. And he sounds like, you cannot do this, you cannot do that. So I feel a little bit, under pressure. (Dai)*

*Having more than the [clinician] talking to me [would have been helpful]. I think from my recollection it was solely the [clinician] who was present at the meetings. Where was the rest of the team? Maybe having the other team members and maybe try out different team members and see which team member works most well, sometimes it's a people issue. Some people might work well with someone. (Hiroshi)*

Participants felt that specific things that clinicians did undermined rapport such as the language used, certain facial expression, not striking the right balance between being too available and not available enough for others and not being listened to or asked for their opinion on matters relating to their care.

*I guess the way they talk is weird sometimes because they talk in their own language and sometimes they use different terms like co-existing disorders and what's that. So that's alright, the whole language barrier but I mean they're good people behind that. (Justin)*

*But, they also need to check their phone a bit more, cause I left a message for the [clinician] one day, I'm pretty sure he didn't call back until like two days later, maybe one day later. (Andre)*

*Well karakia is a good thing but they [EI team] don't do that. If they did karakia, because it does make me feel better, like it feels safe to do that. (Justin)*

### *Psychosocial Intervention*

Psychosocial interventions were defined as the therapeutic techniques used by clinicians, which were perceived as unhelpful by participants. Nine participants referred to the therapy content, reality testing and treatment rationale. In hindsight, five participants felt that the therapy content could have more inclusive, they reported wanting to have discussed issues pertaining to their culture, spirituality, sexual orientation or relationships to a greater extent.

*The guy I had fallen for, I'd never felt like that about anybody else, you can see it upsets me now and that's what I wanted to talk about. (Michelle)*

*The [clinician] was great, however I would have liked to talk about my background and being Asian in a European culture, if I had that understanding of what it is to be an Asian within a diverse culture from a [clinician's] perspective or an outsider's perspective it would have made me realise, made me understand my mental health or how I relate to people or how I perceive things. (Raybon)*

*It would be better if they talked more about the spiritual side. That would be better eh. (Vaughan)*

Unsuccessful reality testing or "not being believed" was problematic for four participants and led to feelings of invalidation and anger. Two participants attributed their experiences to psychosis later in treatment but still had a negative appraisal of how the process was managed.

*For me I was really upset that only I find them to be real and nobody is finding them to be real, the EI team think it is a part of my mind. I tried really hard to tell them, look I'm not the problem here, these people are real and I'm talking about real people and not*



*people in my brain. I got really angry. I got really angry that at least somebody has to believe me one day. (Stella)*

*I was frustrated because you're put here to help me but how are you helping me, by not believing me? (Michelle)*

Lastly, three participants reported misunderstandings related to the rationale of completing certain components of therapy, which led to a questioning of the benefits associated with completing them.

*I was thinking about, how we did that, autobiography thing and the [clinician] didn't tell me what's the purpose of it. Sometimes I wonder if that would have been more helpful, cause it didn't feel like it was doing anything for me at the time. Maybe it was. (Brendhan)*

*The [clinician] would give me exercises to do with your feelings, how everyday you'll have lots of emotions and all these survey type questionnaires to fill out like on a scale of 1–10, how you're feeling and stuff like that. It didn't help too much. I mean he was a nice guy, but some of the surveys just seemed a little bit like, even if I wasn't happy I could just write happy. It was obviously done on honesty, but all this questionnaire survey, the questionnaire that he gave me seemed, I didn't do them too much. A lot of them were saying write 10 good things about yourself all the time and it just seemed a bit cheesy for me. I knew where he was coming from, but I just felt it was for little kids. (Simon)*

#### *External Resources*

Nine participants reported either having had negative experiences with some of the services the EIS linked them with, or in hindsight, suggestions on how external resources could have been better utilised. Four participants reported having negative experiences with the various services the EIS put them in contact with. These included feeling insecure or lonely at respite services, clinician over- or under-involvement at drug and alcohol services, bad advice from the crisis team (which appeared to arise from a misunderstanding of the purpose of the crisis team), and a heterogeneous support group.

*I attended one group meeting, but I think the group stopped, for some reason, I'm not too sure what. I wasn't big on that. I wasn't really that in to it to be honest. It was a bit, it was funny, I thought it was going to be like an AA meeting where we all get up and say this is what we've been through. And it was sort of like that, but I just found that*

*everybody's situation is so different to everyone else's that it wasn't really, we were there as a group, but really we didn't have a lot in common. (Jeremy)*

*I don't really know, it felt weird being looked at by people, because once they filled the whole room up at the drug and alcohol service and they had the counsellor, the supervisor, but a different one and that was strange because they were all sitting there. I didn't know what to say because I'm going there to look for help, not to be, they bring along a lot of people that are learning to be nurses and they always ask questions and I don't really know what to tell them. (Justin)*

*I also went to see the drug and alcohol service people about my cannabis abuse. There it got stagnant because the counsellor I had at the drug and alcohol service decided to go to India to do meditation, so he left, he left me behind, I couldn't get in contact with another person who was going to take over my case. (Phil)*

Six participants offered suggestions as to how they would have liked to have engaged with specific services earlier and have had the EIS's help to do so—services such as parenting support, programmes the EIS was offering, or drug and alcohol residential care were specified. Other participants felt that they would have wanted more in terms of social connection, a keyworker and being advocated for more with an employer.

*They should have information about getting a social worker for your kid, advocating. They should almost automatically get one in, I was prepared to help myself, so it's not about removing the kid, it's about getting the family help. So I think that needs to be really addressed. (Jan)*

*Maybe just introduce me to someone else who's like my age. Just, make us closer, and get in touch with someone who is going through the same thing. That would be awesome. I just don't want to go to the group aye. (Andre)*

*Maybe if they had more social groups but I don't know they probably should make one big group in Auckland. One big place because it's a bit, everyone goes to different places, so not everyone knows each other. (Justin)*

### *Case Management*

Five participants had a negative appraisal of the treatment structure (frequency of sessions) and what was covered in the sessions. For the majority this occurred later in their engagement with the EIS, when they were ready to be discharged from the service. Sessions were referred to as

*'repetitive', 'routine', 'nothing new', 'broken record', 'frustrating', 'boredom' and the 'same questions'.*

*Everything got repetitive when I kept on going to the EIS the whole year. It became repetitive like I ended up saying like the same things. (Justin)*

*I think I was getting fed up with all the meetings at the time and every time I went there wasn't anything new. (Hiroshi)*

*How are you helping me, by frustrating me further because you're questioning me with the same questions all the time. It felt more like pain, like they're always ringing, we want to check up on you, we want you to come in and meet with us and you'd go there and you wouldn't feel like you were making any progress, it would always just be like so how are you going, have you heard any voices, what are they saying, okay good well we'll see you again next week and I was like well what a waste of my time and it was a lot of effort to get there. (Michelle)*

*This is where it really got to the broken record stage. I was seeing them very intermittently. And it was the same stuff every time pretty much and towards the end there, it was just a pain in the ass. (Josh)*

*It became like routine almost. Every visit became the same almost. It was like the same questions, but I wasn't unhappy with those guys, it's the same now whenever I go visit my [clinician] every three months and basically every single appointment is the same as the one before, just checking in and writing me a new script and asking me how I felt things were going medication wise and every appointment is the same, kind of deal. (Diane)*

### *Family Involvement*

Family involvement was defined as the negative aspects of the interaction between clients' families and the EIS. Six participants reported having a negative experience in terms of the interaction between the EIS and their family. For some, it was feeling a loss of privacy or control; for others, the balance between having their family involved or not was either too inclusive or not inclusive enough, while for others the presence of their family, was at times, frustrating.

*I had very little [control over my treatment in the beginning]. I think because my family was involved in the process, I didn't really have a say, there weren't many options for me and because everything was overwhelming in the beginning. (Raybon)*

*My preference would have been for them to work closer with someone that I trusted like a family member or something, because I would have to relay to my family members what was going on, and I don't know, it was a tough thing to do, because they didn't really understand. (Jeremy)*

*What has been a hard thing for me is how they try and get your family involved. I can definitely see the benefits of having a support person, for example if I was married, and my husband would have to have an understanding about what I was going through so I think it would be really important for him to get that help and support, but as far as my family are concerned, I'm 28 and I didn't want to be treated like a baby, I mean I lost my identity as it was. It felt like we'll come and talk to your mother like a child. (Michelle)*

#### *Inpatient Care*

Inpatient care was defined as the negative appraisal of aspects of being admitted to an inpatient facility. Seven participants reported having been placed in inpatient care, with six referring to some negative aspects of it. Participants reported restricted autonomy, violent interactions, high dosage medication and an unsettling environment.

*You're treated like a mental patient basically. It's like you're still capable, I'm a logical person, but I wasn't allowed to leave. [...] I was just like, I'll just do my time, but it would still be nice to be treated with a bit more respect and I had a few words with one of the [clinicians] because she just treated me like an absolute imbecile and I hated it. It was alright, I just felt like a caged animal. (Michelle)*

*I was admitted to inpatient care in Waikato which was not as close to my experiences in Auckland. There was a lot of yelling, a lot of screaming and I didn't recall any of that in the inpatient care in Auckland. The hygiene was appalling. I could smell urine or faeces in my room. (Raybon)*

*So had to go to hospital where they can make me settle down. They have a, it was like a little naughty place. In hospital and they lock you inside and they inject you with something that calms you and lets you sleep and they will hold, they having two tough guys that nail you down like a prisoner and push you inside a cell and lock you inside. It's*

*like being in prison except you get food but I think you get food in prison too. I have to say, that if they have to do that, they have to do that. I don't know what else to do. When I was there it was quite calm. But I had so much meds that I keep sleeping and they will put you in the naughty corner and then put you to sleep. It's funny how I can still remember it. I don't think they want you to remember it. That's why they give you so much meds you probably forget. (Hiroshi)*

### *Disruptions in Care*

EIS's operate within a strict geographical catchment area, which prohibits clients from obtaining care outside of the area in which they live. Further, EIS are often smaller subsidiary services attached to larger general community mental health centres to which clients can be referred when problems with engagement arise. Five participants experienced disruptions in care due to the aforementioned reasons. Some viewed the disruption as being poorly managed by the EIS, and felt either uninformed about the process or felt the coordination between services was lacking; one participant understood the transition as contributing to his relapse while others found it disconcerting. Participants often viewed the second service more favourably than the first, despite different services being discussed.

*I think there also needs to be some flexibility there as well, or else it will happen like what's happened to me, you will get moved about and then I don't get the psychological support that I need. I needed something ongoing. It doesn't help because I move about. (Michelle)*

*I didn't know the system at all, and I didn't know the process. And it's like I was saying before, when I got transferred out of the EI team, I had no idea I was, and I was wondering why are they changing, like it almost made me worse, cause I was thinking, why are they changing doctors on me, what have I done, and it's hard to explain. (Jeremy)*

*I suppose for a while I was on my own. But I still had my meds from [the first EIS], I wasn't meeting up with [the second EIS]. That's probably why I got into the second relapse. The [clinician] probably thought I was talking to the second EIS, and then I went into relapse and then firstly with crisis team and then the second EIS took me and hospitalised and came out and I probably picked up with the second EIS afterwards, so at the end of the service at the first EIS there was a broken link. (Hiroshi)*

*The second EI team have been, by far, better than I found the first EI team and I'm sure that had something to do with my stage in treatment. (Michelle)*

## The Process of Supported Recovery

### Qualitative Results

#### Experiencing and Understanding Psychosis

Table 7 *Category Three, Psychosis, Themes and Prevalence of Sample and Statements*

Theme	Sample	Statements
Excluded from ordinary society	15	97
Overwhelming and negative emotion	17	68
Using substances to cope	11	40
A loss of sleep and certainty	10	13
Wanting help, but fearing the worst	19	80
Total		298

#### *Excluded from Ordinary Society*

Within their narrative accounts of service involvement, 15 participants provided background information about what they believed led to their engagement with mental health services. Participants talked about many diverse experiences that were linked through an underlying theme of being excluded from many different domains of ordinary society. Subthemes represented problems in the social world, problems adjusting and family problems. Participants also talked about experiencing poverty, involvement with the justice system and not having access to the services they required. Each of the subthemes represent an area of life where participants talked about experiencing adverse life events, the events ranged in severity and where they were interpersonal experiences ranged from covert to overt. Participants talked about a range of ways in which they felt excluded, including general cumulative experiences and specific events.

#### *Problems in the social world*

Problems in the social world reflected isolation, discrimination, acculturation stress and rejection. These experienced ranged in severity and the impact that participants reported feeling in relation to these events. Isolation or '*not fitting in*' was referred to by 11 participants, whose experiences of loneliness, alienation, acculturation stress and discrimination were reflected in their lives at the time of engagement. Participants described loneliness as '*having*

nobody', 'being quite alone', 'a lack of company', and 'not being able to make a genuine friend'. Participants also reported feeling alienated and discriminated against due to their race, sexual orientation and mental health problems.

*I have friends but they don't really want to associate with me, because I'm not the ideal kiwi person. And that's something that I've come to realise over the years. I've met a lot of people and befriended them, but they don't really want to be attached to me because I'm an Asian. It's hard, but it's a reality. (Raybon)*

*I don't know like I think Pākehā still haven't bridged that gap between Māori and Pākehā, I think the colonial, I'm in a void I think because I don't really fit in at the Marae and I don't really fit in a Pākehā situation, I don't have a place. (Justin)*

*Well none of us [service users] really fit in do we, we're all a bit odd and daft or whatever you want to call us. We didn't really fit in with the rest of society so to speak. We fit in because we're a bunch of misfits, I don't know. (Diane)*

*I think I started getting depressed when I was 14 and that was when I was in school, being bullied by the classmates for being gay. I was a truant and I never went to school. (Justin)*

*There's a problem in my workplace. I think I have gone through a very hard time there, and I feel depressed, I feel I was not treated well by the people there, and I feel I should speak out, I should do something there, but it's too late, because I have already resigned. (Dai)*

*I think when I went to the EI team because I faced a big rejection from a girl. So the first episode follows this rejection directly so I went crazy. Basically I couldn't stand that rejection because then I just collapsed. I think it was because then I had lots of mood swings. I couldn't settle down, so that led to my first psychosis. (Hiroshi)*

#### *Difficult adjustments*

Six participants believed their problems commenced as they experienced a new developmental transition and coped with the associated stress. For some this was through the process of adjusting to new demands of university or work. Four participants believed their problems began when they had difficulty mediating the premarital and early marital stage and experienced separation from partners. Participants talked about the difficulty of adjusting to life as a single person and the role this played in relation to the onset of their psychosis. Further,

changes in participants living circumstances were talked about as contributing to their psychosis, whether they were moving out of home for the first time or moving overseas.

*Well they realised that I'd got a bit carried away because I'd just moved out of home, went flatting and so I'm getting paid more money and just going out extra, like three nights a week I'd be drinking and all that sort of thing and I was bringing myself up really. That was the start of everything. I was just overdoing it like working 60 hours a week and after work drinking and taking drugs and just wearing myself out to a point where it just got too much. (Simon)*

*It [psychosis] started when I split from my husband. It was consensual agreement. I moved to a new place, faraway from where I used to live and I thought I could handle it, I haven't said this to anybody, but I think that's what started it. I thought I could handle it, but by the end of 10 weeks, I just didn't want to move but it was too late. I was missing him quite a lot. (Stella)*

#### *Family problems*

Five participants reported long-standing problems within their family. Communication problems ranged from covert exclusion to overt physical abuse. Separation was also experienced by a number of participants. Four participants disclosed abuse. For some, it was within the family and ranged from verbal intimidation to domestic violence.

*I was told I could have this kid, it was mine, and everything was fine. And then my sister wanted the father there. And then his family started pulling, and all the pulling and pressure, his mother started turning up, and this was only days after I brought him home. She was up at the hospital too. And all that pulling and pressure, caused my mental illness, because I was feeling it all in there. But a lot of people don't want to acknowledge that. That's what was happening. And it messed my head up, I got quite sick. (Jan)*

*I was sick and tired of it, sick and tired of thinking I have to do what he [partner] want me to do. Me and him broke up because he did something really, really wrong. It was a very terrible night. You won't believe I almost died that night. Just couldn't breathe, he block my mouth and it wasn't very nice. Every time I sneeze it's still really sore. All the bleeding everywhere, bleeding on the bed, and all over the ground, which is why I called the cops. (Rose)*



*In my family it's a whole lot of chaos because family members die and depression and people are all depressed together so they all do the same thing and smoke. I'm watching them and I'm like oh my God, is this going to be life forever. (Justin)*

*My sister used to stay and wait for me, I'd go to a play group and she used to be at home waiting for me. You filthy, filthy woman, you've been out, and I wasn't, I was going to a play group. She used to call me filthy, dirty, she'd be waiting stamping her feet. She was getting quite aggressive with me, and she kept trying to take over. (Jan)*

### *Overwhelming and Negative Emotion*

Overwhelming and negative emotion was defined as the negative affective states that participants reported prior to engaging with the EIS. Participants reported feeling intense 'overwhelming' and mixed emotions with 'mood swings' with depression being the most common. Nine participants reported feeling or having 'depression' in conjunction with being 'down', 'couldn't stop crying', 'bad', 'negative feelings', 'like a zombie', and 'unhappy'. Four participants described feelings of hopelessness or suicidal ideation.

*If you would have met me a couple of years back, I would talk to you with my mind still thinking about something else, I was very negative, very cynical. Back then I was depressed, I was very cynical, very objective, I didn't make good company. I was very anxious, agitated, I couldn't stand still. (Phil)*

*I just thought I'd hit rock bottom. I thought there was nothing else, no-where to go to. I thought life was pretty bad and I was getting quite suicidal at the time, because I just couldn't take any more. (Jan)*

*I was angry before, I was very, very upset, I think I just go murder myself, I should go and do this bad thing I suppose blah-blah-blah, climb on top of the building and jump down. (Rose)*

Eight participants reported experiencing feelings associated with anxiety and referred to 'worrying', 'terrified', 'anxious', 'fear', 'scared', 'panic attacks', 'shock' and 'afraid'.

*I worry too much to the point where it's excessive. Too much worrying. (Justin)*

*There were things that I had done, that I felt guilty about, and I think they were causing me problems, anxiety, a lot of anxiety. (Brendhan)*

*It's like, gloomy, depressed, and anxious. And you feel you can do nothing but, mainly just wait. (Dai)*

Anger was also experienced by five participants and was referred to as 'I was throwing things', 'angry', 'pissed off', 'aggressive' and 'murderous'.

*I felt angry, quite angry, I can't control myself, and I become furious, and I just want to shout and sometimes want to fight, sometimes get justice. (Dai)*

*I was frustrated and angry and I was crying and upset and I was being a little arrogant prick. (Ben)*

Six participants reported feeling stressed: 'I was going through a lot of stress and pressure'. Two participants reported feeling guilt prior to engaging with the EIS, which arose in response to things they had done. For some participants their emotional distress was intrinsically tied to both their experiences of adverse life events and their psychosis.

*I know a lot of it was guilt. I don't know. I think it was just the psychosis coming on, it was just part of it, too much thinking. I was quite naughty back then. I had a lot of secrets from my parents and then it, I don't know the psychosis came on and before the crisis team came out I told my parents everything, stupid secrets even like looking at porn and silly stuff like that. It wouldn't get me into trouble. (Ben)*

Table 8 *Subthemes of Negative Emotion Experienced Prior to Service Involvement*

Emotion	Sample	Statements
Depression (Hopelessness)	9 (4)	19 (7)
Anxiety	8	12
Anger	5	12
Stress	6	8
Guilt	2	2

### *Using Substances to Cope*

Eleven participants reported being involved in alcohol and drug use, primarily cannabis and alcohol, prior to their engagement with the EIS. Participants primarily expressed their drug use as having the function of enabling them to cope with negative affective states, while some viewed it as having more of a recreational function and others understood it as having a causative influence on their psychosis.

*I just stick with smoking and it's really bad because it's controlling my life. When I was down it would make me not care about being in trouble. (Justin)*

*I started drinking and smoking again, habits that I gave up, I got a bit depressed and I started doing that again and, that's when my doctor referred me to them. (Dave)*

*I was obviously ignorant, never thought about the drugs. It's just they made me feel more confident, and when I had these panic attacks, if I take these drugs when the panic attacks were coming on, the panic attacks can be gone. [...] I know what's causing it, sort of, I just had drugs every day, one session in the morning and one session on the afternoon, and just too much of it, just brought on psychosis, and then I got into overdrive. (Andre)*

*When I came to University for the first year I trained to be a professional body builder, and I was taking creatine, proteins and glutamines just to get big. And also the drug use, I was a frequent drug user, I used to use marijuana when I was at university every single day, I used all that dopamine, all that serotonin increases and all that testosterone increases and it created a mess and exploded. If it wasn't for the Risperidone no matter how much counselling I had with them, the brain would still be damaged. [...] I spend all my money on the marijuana. I don't drink. If I would spend all my money on alcohol I wouldn't have any money for the marijuana. After the first year I thought I can't go on like this, I'm directionless, so I kept smoking drugs again, didn't look for jobs and stuff, so my life just went boom, downhill. (Phil)*

#### *A Loss of Reality and Shifting Certainty*

Within their narrative accounts of service involvement, all participants provided a description of their experiences of psychosis, even if they did not identify it as such. Five subthemes captured the experiences that participants spoke about including: a surreal environment, interpreting the experiences, the realness of experience, losing sleep and jumbled thoughts. Participants' experiences ranged from the subtle to the more tangible. Participants talked about how they made sense of these experiences, which led to a range of different interpretations. Participants recalled being subsumed by attempts to process past and present experiences. Many viewed their psychotic experiences as a breaking point after experiencing prolonged stress. Often participants reported feeling confusion and distressed. They spoke of the realness of their beliefs and how they often became immersed in them. They talked of thoughts and speech that became confused and disjointed.

### *A surreal environment*

Eight participants reported experiencing subtle perceptual changes in their environment, which had a surreal quality. Changes were experienced as a fluidity between themselves and others and the surrounding environment. For many, there was a surreal quality to their experiences: *'I felt quite strange', 'I felt like I was floating around', 'I was feeling like I was being watched', 'it was all a blur', 'I thought I could read people' and 'I'd get a lot of déjà vue, it's like you've already seen something and its going on again'.*

*I felt like I was walking in a dream, I felt like everything was happening for a reason and everything was staged almost. It's a strange thing to explain, but you're also extremely in tune with things and people and it was interesting, I had experiences where pretty much I could do anything I wanted, not do anything, but when dealing with a person I could be in tune with the person so much that whatever I wanted I could get, or have, and with perfect strangers I'd never met before and people I knew as well but not necessarily, unusual experience and amazing experience, because it made me realise the potential of what humans, what is possible with maybe certain things. (Michelle)*

*Cause for my experience with the psychosis, I didn't know what to believe, because for most of my life it had always been, how do I explain this, the books good, you read it and its good, and you enjoy it, and you can go back and read it a year later and it's still good but you're just familiar with the material, and then during the psychosis it was like I'd read a book, and it was amazing, and I'd read it three months later and it was just a book. And it was like what the heck's going on, where's the single reference point that you can pin everything on. And it was like everything is just a wish wash of everything it's like swimming in the ocean and you want a solid point, a bit of land to stand on. It's like swimming in the ocean and there's waves everywhere, and sometimes you're high and sometimes you're low, there's just no steadiness to anything. I couldn't trust what I was thinking anymore. Cause it would change and the next day it would be different. I would be certain of one thing one day and then completely uncertain of it the next day. (Brendhan)*

### *Interpreting the experience*

Often, part of this process involved naming their experiences, such as *'demon attacks', 'psychics', 'noises', 'spirit world', 'aliens', 'their conscience' or 'flashbacks'*. Not only were experiences named but they also often led to distinct narratives that were interwoven with

evidence that the participant had attended to, that they felt corroborated their experiences. Some participants talked of being immersed and preoccupied with their beliefs.

*I was hearing this stuff and then I'd be thinking something and you know how you have a voice in your head, your internal dialogue and you might be like, I don't know you might swear or something and I would say something in my head and he would repeat that straight away and it was for real. This wasn't made up stuff. Eventually I started realising that other people in the house were psychic as well and it was a bit of a community. They would have parties all the time, we'd have like 30 people in the house and then I'm freaking out thinking I don't know anyone who's not psychic here so everybody can read my mind and then my thoughts started getting troubled. (Michelle)*

*Psychosis I think is like people playing games, playing with your spirit, attack on the spirit really. Like there's a different world out there. Like the Matrix or something, that's how I explain it. Other people connecting to you in spirit or something like that. It's hard to explain to people because you know they don't believe it. A whole other world, spiritual world. (Vaughan)*

*I was basically in a scenario where I thought that I was on a TV show, like a read about it, they don't call it Truman Syndrome, but I've read about the Truman syndrome somewhere, and it was like that type of thing. I just thought I was on a TV show basically. And so I was extremely paranoid at the time. And I was in a pretty bad place. (Josh)*

*I could see this woman's face, [she was telling me] do this, do that, and I really stressed out and on top of that, this guy said where is my tie, you have killed someone, and I was more scared than anything else because there was nobody in the house, there was only me. (Stella)*

*Because what I hear with my voices, they just tell me that I'm shit aye, real negative ones. Just put me down all the time. It's like most people, when they have alone time, they have their own thoughts. But I used to get these voices and I had nowhere to go when I was alone, I just had constant mocking at me. [...] Like at the worst times it's literally like I'm standing on this stage with these people yelling at me saying "FUCK YOU". Going nuts, I really need to get rid of that. (Andre)*

*I was seeing things that weren't there, so I wasn't really concentrating, not responsive. [...] I think I saw people with eye sockets that are completely dark, you can't see their*

*eyes, you can see their eyes in position inside their eye socket but you see a dark hollow. I was seeing that on everyone's eyes. [...] I got into alien things. These crazy things about aliens just couldn't get out of my head. (Hiroshi)*

#### *Loss of sleep*

For 10 participants, distress was reflected in sleep disturbance with many having difficulty initiating and remaining asleep. For some participants this included being awake for three or four days prior to the episode that precipitated their engagement with mental health services.

*I kept having these flashbacks of my childhood days. [...] I thought something was wrong with me, my brain was going 24 hours a day, I couldn't sleep at night, and I just kept thinking and thinking and thinking. (Phil)*

*I had trouble sleeping properly my sleeping got really bad for some reason, I don't know but I was always waking up. My mind is awake, when I was sleeping I was asleep but still awake so I'd wake up and walk round and make a cup of tea and if I've got a smoke I'll smoke at 2am and it was crazy. (Justin)*

*I was stressing and a couple of weeks after, I just woke up one day and I was in a daze, I hadn't slept for about four days and I woke up and I cut myself. (Michelle)*

*I think that's why it started. I'd been awake for a few days. I don't know. Maybe a build-up of stress, and it all coming down at once. (Ben)*

#### *The realness of experience*

Participants who had a high degree of conviction in their beliefs also talked about being extremely confused. Often this confusion left participants feeling distressed.

*I had a flip out, thought the neighbours were talking about me. It got pretty bad at times, I'd think I could hear people outside and I'd go outside and start yelling out. It felt real for me. (Vaughan)*

*I was very confused about what exactly it was that was happening. Obviously I thought it was reality, which was probably extremely difficult for my family and so forth. (Josh)*

*I said to my husband one day, look I know they're real. I want to record them. Would you believe me and he said definitely. I did record them but it was too faint, only I could hear it because they speak in Hindi and they stopped speaking in English. (Stella)*

### *Jumbled thinking*

Nine participants reported having difficulty with their thought processes, describing ‘*jumbled, jumbled thinking*’, which often translated into difficulties with expressive language, for example, ‘*I was talking mumbo jumbo*’. Further, many participants made a connection between thought and verbal communication, while others attributed the change in thought processes to being distracted by perceptual changes. One participant referred to the process as trying to comprehend the incomprehensible.

*I was like hearing my voice, over my son, things were happening, but it's all getting locked up there, and you don't have time to deal with it, and you're thinking, why are these people doing this, this is really horrible. And suddenly people you love and trust don't seem to care for you or they say, they mean well but they don't, they're actually taking advantage. And you're thinking well, you couldn't be any more lower. And they're still doing it until you're left with nothing. And it starts to get locked up there. And I think I was babbling a bit, and the [clinician] said something and I got a bit upset, because I couldn't help it, and it all came out. What was happening up there you can't comprehend it. And it all just starts coming out. [...] I just started talking because everything that was happening, it was all bottled up there [in my head], and it just was unravelling, and I couldn't stop babbling it out. So I babbled it all out. Then I was able to talk normally. [...] But they sat another girl next to me, and she said something about the whole family being incestuous, and she was babbling away, because she must have had all her thoughts locked up there, all these funny experiences, you know, suddenly it's all coming out. You know within yourself things aren't right. (Jan)*

### *Wanting Help, but Fearing the Worst*

When asked what they needed from the EIS prior to engaging, 19 participants reported needing help in the form of support, understanding, information, practical help or medication. Eleven participants reported needing qualities associated with the therapeutic relationship such as support and understanding: ‘*I needed help, I needed understanding*’, ‘*I needed to talk to someone*’ and ‘*I just needed somebody to be there for me*’. Six participants also reported needing information from the EIS. For some, this was as direct as needing a diagnosis or wanting to know what was ‘*wrong*’ with them, while for others this related to advice. Four participants also reported needing practical help such as advocacy and input from specialist services, with needs ranging from the more explicit such as drug and alcohol residential care, a social worker for their child, to the more general. When asked what participants expected from the EIS prior

to engaging, participants expressed a range of mixed views, conceptualised as, negative, neutral and positive. The majority of participants had negative expectations of engaging with the EIS, with views commonly expressed as a fear of being placed in inpatient care. Seven participants had neutral expectations of the EIS: *'I didn't have any expectations'*. Another seven participants reported having positive expectations of engaging with the EIS and broadly expected to gain help. Many oscillated between having positive and negative expectations.

*What did I need, I think I needed someone who can understand what I'm thinking, that's quite important. It's not just support, maybe talking, not just talking from a medical perspective, but understanding what I was thinking and why I came to that start.*

*(Hiroshi)*

*I think really in that frame of mind when you're how I was, you just want people who understand. I didn't want people saying to me hearing voices is a lot of nonsense, there were times I didn't want to stop the voices because they were comforting and so you got doctors saying oh you want to stop the voices, well yeah sometimes I do because sometimes they drive me up the wall and then other times they don't and so I think just somebody that understood and was interested in talking to me about the experience that I had or the good things from the experience or why it had affected me so much.*

*(Michelle)*

*I was just, wrapped there's a professional to help, you need it, hurry up and get it over and done with. I didn't have any expectations of it. I was just thinking I hope these people will help me work through it. (Andre)*

*I needed to do things with life to try and draw me out of my head so much, get me involved in practical things that are going to benefit me rather than just sitting on the couch talking to the voices all day. (Diane)*

*I needed explanations as to why, it's hard to explain, why things were going on in my head and why what's going on around me was different. (Vaughan)*

*I thought they would send me to an institution or something, prison. (Tevita)*

*I thought they were going to tell me, this is what's going to happen, and do this, and do that, and I would have to do whatever they told me to do and not really giving me a say of my recovery, but it wasn't like that. (Simon)*

*I had visions of a paddy wagon and being in a strait jacket. (Jeremy)*



## The Process of Supported Recovery

Table 9 *Category Four, Recovery, Themes and Prevalence of Sample and Statements*

Themes	Sample	Statements
Labelling it means I've got it	18	51
Hopelessness, self-stigma and withdrawal from others	16	52
Evolving explanations	6	13
Focusing on the positive and being thankful	9	17
Totals		219

### *Labelling it Means I've got it*

Many participants reported wanting to gain more of an understanding about what they were experiencing from the EIS. Subsequent to service involvement, 15 participants referred to their experiences as “*psychosis*”. The majority of participants equated psychosis with a diagnosis. For Ben, who had struggled with his mental health for a number of years prior to seeing the EI team, gaining a diagnosis marked the beginning of his recovery. Five participants, all at different stages of recovery had rejected the term psychosis to explain their experiences, their interviews focused more on the psychosocial aspects of service involvement and what led to service engagement.

Participants differentiated psychosis from a diagnosis of schizophrenia, which had negative connotations. Six participants referred to schizophrenia, with two having gained the diagnosis from other services, while Jan referred to being told by her family that she was “schizophrenic” as a form of abuse. Phil feared gaining a diagnosis of schizophrenia and finally Stella recounted schizophrenia as being part of her hallucinations, which were also associated with negative imagery. Michelle talked about her voices and how for her, not being “believed” was equated with telling her she had schizophrenia. Brendhan gained a diagnosis of bipolar disorder.

*I think I was happy going there because I knew I had to get better and I knew that I wanted to get better if I wanted it [psychosis] to go away. They finally had diagnosed me and this was a team solely devoted to psychosis so they knew what they were talking about, it just wasn't some psychologist knew a bit about all areas and they were just trying to work out what you had. They knew what you had and knew what they had to do. (Ben)*

*I anticipated a judgement on my illness, first thing I anticipated a result of my illness, what it was in the first place, and they told me psychosis, and that was the illness they gave me. I was scared, very scared, like a scared little boy, going into the doctors for the first time, we were talking about a [clinician] and my whole life depending on a judgement from them, if they said, like some sort of terminal illness and I'd be screwed. If they would have said that I had something like schizophrenia, I thought oh, there goes my life by schizophrenia, I'm not going to get my life together after schizophrenia. (Phil)*

*So after the first meeting I saw them about three times a week and talked to them and they would tell me I had psychosis. I didn't even know what psychosis was. I thought it was, I didn't know I had a mental illness. And they said it's very common, a lot of people have psychosis and they told me what it was and what it does and stuff. I was shocked. Like a lot of things they were telling me were real and it was true and it was like hang on that's like me. They were just telling me all this stuff and I was quite yeah right, they are right. (Irene)*

*Good and bad, like good in the sense that there was a certainty attached to it, like it was bipolar disorder and labelling it makes it understandable and I can handle it. Bad in a sense that oh gosh, that means I've got it. Right. So it's a double edged sword, it cuts both ways. The way I was thinking then, it was probably the right way to look at it. The way I look at it now is there's just a gradations of everything and so you can't really say one thing is the same as another thing, because it's always going to be a little bit different. So now I look at it and I say, well, bipolar disorder, it's just a label, I don't know if you were to chart some factors, you would say that they have correlation, like mood swings and something. But the way I look at it now is it's just the way I am, there's no need to label it, it just makes it communicable, if you want to talk about it. The [clinician] said that if we had to chart things on a continuum with people who have real strong bipolar, well you don't have it so bad. Everyone's a little bit bipolar if you look at it that way, because everyone has emotion, so it changes, but he said I'm right down the end where it doesn't cause me too much problems in my life but it does restrict my lifestyle options, in a sense that I can't just do whatever I like. I can't just go clubbing every night. (Brendhan)*

#### *Hopelessness, Self-Stigma and Withdrawal from Others*

Sixteen participants referred to a phase of their recovery, either subsequent to acute symptom remission or after being engaged with the service for approximately six months, as a period of

hopelessness, whereby the lack of employment or other meaningful activities made the consequences of stigma more apparent. Many talked about withdrawing from friends and family as a way of coping. The process of recovery felt slow, and for many, the symptoms they associated with their psychosis were unremitting. Participants' frustration was also reflected in their impressions of the EIS during this time, with appointments feeling routine and repetitive. Seven participants had a negative appraisal of being without work or academic occupation. Some had stopped working prior to their engagement with the EIS and some remained unemployed, which contributed to their mental health problems.

*I think I was quite down because work kicked me out and that was my first career choice, that was down the drain and then I was jobless, and then it was impossible to get a job because no-one wanted to take me on because of my history. So I was down for a while I think. (Ben)*

*Time is just divided up into day and night. Every day is a challenge. Everything got repetitive when I kept on going to the EIS the whole year. It became repetitive like I ended up saying like the same things and they're never impressed when I keep on telling them that I'm still smoking. (Justin)*

*I think I just wanted to fit in again, and I wanted to be able to work again, and feel useful rather than a burden, cause I felt really bad for my parents at that stage, Dad was taking a lot of time off work, if they didn't I would have been in hospital. And just the desire to get out of there, my desire to do something useful yeah [...] I was frustrated, that I wasn't working at the time, I was just sitting at home twiddling my thumbs and I was just so absolutely bored.[...]. But yeah, I was frustrated with the pace of things. I also got depression, post psychosis, and that was pretty shit. But basically you just feel like time stretches out, for me, it was like every day just took forever, and so the pace quickened as I got out of it, but the pace was quite frustrating. (Josh)*

*I thought a lot of it would be irreversible. I thought I'd never go out of my trance like state. (Simon)*

*It probably, all up, has taken me a good six months to start feeling normal, then another three months to just gain energy I needed back and just feeling very lethargic and uninspired about life and whatnot for a long time, so it is a slow process. Can't rush it. (Michelle)*

*It doesn't even seem like four months to be honest. I don't actually think there's been much change, I still get the voices. I'm still real down. I don't actually think that there's been much change. I can tell that they're doing good, but I just don't feel like there's been much change. I still feel like I'm back at the start of the four months. (Andre)*

*I was so frustrated and depressed the fact that I wasn't moving on with my life in a structural way, in a proactive way, having a career, having a family. At that age when you're 25, 30 you're expected to have a family, expected to have a career by then. I was still in the doldrums, I was still depressed, on a sickness benefit, on the welfare, I was depressed. It wasn't happening fast enough, there wasn't enough velocity. I was still stuck, stuck like I was 19, 20 years old. I was still in the same stage when I was 18, 19. [...] They tried helping me get jobs and stuff like that. It was unsuccessful because, my qualification was still quite low, so I couldn't get good office work and stuff. I just did it because I had to do something for work, I don't want to be on a sickness benefit for the rest of my life. I indulge in job searching for time to time, and the social worker would help me out me out as well, but, there was no fruition for that. (Phil)*

Self-stigma was defined as internalised feelings of shame associated with having mental health problems. Eight participants reported feelings of shame that arose from maladaptive preconceptions or the assumed disapproval of others and led to reduction in positive coping behaviours. Seven participants reported either withdrawing from others such as being 'unresponsive' or being unwilling to discuss their experiences due to the experience or expectation of stigma.

*I don't want to put any person near me, I don't want anybody to know. [...] I hate the idea of going to the mental clinic as well because I thought to myself I'm not a mental person, I don't hate children. I don't hate people. (Stella)*

*I was just embarrassed about having false beliefs and I couldn't believe, what I'd gone through and I didn't really want to talk about it. I was really embarrassed is the word that I can best describe it [...] and I don't know, it's embarrassing to go through something like that. I mean it's not, and I shouldn't be embarrassed about it, but I felt like I'd let people down. (Jeremy)*

*My friends would call me up and I thought they were just feeling sorry for me and it took me ages to get back socially with everybody. I suppose with all the stigma around thinking that maybe they knew that I was taking medication, it just made me feel, even*

*though it's not too bad, but it made me feel a bit stink and I didn't really want to talk about it with them. (Simon)*

*I had been ashamed I'd been to Mental Health. (Ben)*

*It's all contained and I don't tell people that things are going on. (Justin)*

*I was so reclusive for such a long time when this happened, that I was just like I don't want to go out, I don't want to see anybody. [...]I wouldn't talk about it, given the opportunity, I wouldn't tell an employer, I wouldn't tell my friends. Like I said I don't even talk to my family about it because it's better to be normal. (Michelle)*

### *Evolving Explanations*

The majority (15) of participants had coherent narratives about how they understood those factors that contributed to the development of their psychosis and led to engagement with the service, which was reflected in the opening theme. Most participants appeared to have been allowed the space and time to come to their own conclusions and establish their own explanations within treatment.

*The whole thing is, it seemed more about the way I see things than the way they see things, is more what it seemed to be about, what the service seemed to be about. (Brendhan)*

*I think that possibly we had talked about why I had thought it had happened, but not why they thought it happened. (Michelle)*

*The EI team did have an understanding, not really an understanding, they didn't really display that, but I think they had an awareness [of what caused my psychosis]. (Raybon)*

Twelve participants reported developing a shared understanding in conjunction with the EIS. Often these participants had gone to the EIS wanting information and help. Stella was adamant her voice were external entities and spoke about the process of hearing the services impressions of what was happening to her:

*The [clinician] said that the brain, a part of the brain, just malfunctions every now and then, and I was argumentative about it, we started to put the ideas on the table and I was able to say to myself even if they don't believe me, they know what I think and they're not disagreeing with me, they're just putting their own ideas on the table too. They don't say 'look I disagree with you, I think this is happening', but listening to the*

*[clinician] he put more ideas on the table and although he didn't agree with me, at least I didn't get the impression that they're not even listening to me. (Stella)*

Two participants held conflicting perspectives to the EIS, which caused confusion and other negative emotions.

*I had religious belief about it [psychosis] and they had a medical thing. I didn't know which one to believe. I sometimes think it might have been a medical condition. It made me a bit confused, I believe that it was a religious thing and when I started to experience those demon attacks again, that's how I think of it if it's a religious thing, or if it's just a medical thing. (Dave)*

#### *Focusing on the Positive and Being Thankful*

Six participants reported making changes that positively contributed to their recovery such as: gaining help; engaging in physical activity; addressing nutrition; abstaining from drugs and alcohol; having routine and structure within their lives; and giving up other behaviours thought to contribute to psychosis. Recovery was associated with positive gains in self-esteem, which for 10 participants, meant redefining their identity to incorporate their experiences of psychosis. Self-esteem was influenced by rejection of an illness identity, finding new ways of relating to others, becoming independent and redefining their roles within the world through academic, vocational and other means. Towards the end of engagement with the EIS nine participants reflected on the sense of achievement they gained from their recovery in conjunction with feeling confident and being more future-oriented having made goals and feeling more optimistic about their future in general. Twelve participants expressed their gratitude towards the EIS, which was defined as the appreciation participants felt towards the EIS in aiding their recovery and helping them through the process. One participant was also thankful for the experience of psychosis. Gratitude appeared to be an integral part of a successful recovery.

*You're put in hospital, you get unwell and you have to treat yourself you just have to accept it. It's a big part of recovery, acceptance. A lot of work in finding out what causes it and accepting it and it just built up over time and getting better and better. [...] I think once I told people about it as well that helped with the recovery. I had been ashamed I'd been to Mental Health. I think one day I just decided that I am not going to hide it from people. Why should I? I haven't hidden it from anyone ever since. Everyone knows I've got it, not ashamed. Some people ask questions and some of them ask what it is. I'm fine with that. [...] I think I was happy. Deep down I was happy with myself that I had*

*come so far so fast. And I could get on with life. [...] Looking back I was in good hands and had the best possible team. (Ben)*

*And understanding that I got a mental illness and understanding that its normal, I'm no different to anyone else and they can help, it does work, like if you want to get help you can get help, but at first I didn't want help, I was like I'm okay, but now I'm so happy that they were there, because without them I wouldn't be as normal as possible. I wouldn't feel different to anyone else. (Irene)*

*My life's a lot more busier, and I have more interest in doing things, I'm more motivated to do things. (Dave)*

*I had to give up bodybuilding as well, because I was scared that the bodybuilding might exacerbate the psychosis, like I say the dopamine, the testosterone, the serotonin would rise, I couldn't control that, I was very agitated at home. I had to give up body building, unfortunately, because I got ill. That's what happens when you're young, you don't know what's hit you and you don't know what's happening to you, you don't know how to control it, you need professional people to tell you that something's wrong. [...] It's over now anyway, so I'm training to be a farmer, so it's something to do outside, keep your mind and body busy for eight hours, ten hours a day. And make some money for myself it will be quite good. [...] Big difference. My mind's at ease now, I have some objectives I need to do now, some things I need to get done. (Phil)*

*But these days I'm trusting myself more and trying to go with what I believe, so I've changed a little bit. (Brendhan)*

*I was like wow its interesting it seems like you lose a part of reality, but you also gain a part of reality that most people aren't aware of and that was my experience, it's been a crazy and very difficult time for me, but in many ways I wouldn't give it up, because of what I've gained from it. I think at that time what I was going through was not in reality, I was definitely not in reality and I had a lot of my own things in my head, big plans and I was concocting up all sorts of ideas and things that I wanted to do and anything was possible and its funny because now I've still retained that anything is possible idea but it's just different, it's more like okay if this is reality, and there's things I have to do to get those things, but I guess it all started from that point. [...] I'm a normal person. It's something that's just happened to me that is unusual, but I'm still me. (Michelle)*

*I think I've come a long way and I'm quite proud of that I have to say at least I have achieved something. (Stella)*

*I feel I'm getting better and now I have to arrange my future. Maybe in the future I need to go back to University and study. And every time I try to find a good job, so I'm keeping an eye on the internet and sending my CV in for the vacancies. (Dai)*

*I'm really quite happy. Very happy, all the new things coming up in my life. (Rose)*

*Everything was going well and I didn't really have too many worries or anything. Then I'd moved back out of my parent's house into flatting and everything was pretty much getting back to normal, which the [clinician] reinforced you really are getting a lot better because you're becoming a lot more independent so the independence is going to help you a lot more, because I told I was feeling a bit stink with my parents free loading at their house and they had to look after me but once they realised and I realised that I could live by myself and look after myself it was good being able to do that. [...] I felt like I had accomplished something. In the beginning I didn't think I'd be able to get a stage where I felt that well. I felt like a different person, right back to my old sense, how I used to be before the episode, which was rewarding. [...] I wanted to go to the [clinician] and thank him for all the work he'd done, but I didn't I should have really done that or wrote a letter but I didn't end up doing that. I just felt a little bit guilty, not that I had to but I just felt like I owed him something, because he really made it a lot less daunting than I thought it would be. (Simon)*



# CHAPTER FOUR: DISCUSSION

## Introduction

The present study had three interrelated aims: (1) to evaluate an early intervention service (EIS) from the perspective of the service's clients; (2) to describe the common themes associated with the process of supported recovery; and (3) to interpret and integrate the data to produce inferences that had clinical utility for the service and its clients. The service evaluation component utilised mixed methodology to provide inferences from both a quantitative and qualitative perspective that equated to more scientific rigor than either method alone. Further, it enabled triangulation in which specific service provision variables could be examined from different perspectives. The process of recovery component utilised narrative style interviewing and thematic analysis to conceptualise the narrative of participants as they embarked on a relationship with both psychosis and the service under evaluation.

This discussion chapter aims to remain true to participants' narratives. It begins at the second research question, related to the process of recovery and interprets the first five themes that set the context for service involvement, and is titled *Experiencing and Understanding Psychosis*. Subsequently, the second section discusses the first research question and integrates both the quantitative and qualitative data to determine whether service users were satisfied with the service and what factors influenced recovery. This is titled *Service Satisfaction*. The third section returns to the qualitative data and is concluded with an interpretation of the final four themes, and is titled *The Process of Supported Recovery*. Previous research related to the topics being discussed is interwoven throughout.

## Experiencing and Understanding Psychosis

### Excluded from Ordinary Society

The process of recovery often began prior to entering the service, with participants providing the context for which they arrived at the decision to seek help. For many, this was following events that engendered feelings of exclusion that ranged from insidious, which was generally within the problems with the social world subtheme where isolation was experienced by participants, to acute, which was captured within their difficulty adjusting to life-cycle transitions. The subthemes can roughly be equated with the causal factors of psychosis, with some individuals describing more generic attributions while others described more personal understandings. The

explanations provided by participants were aligned with the stress-vulnerability model and showed multiple factors of which the “stress” and the “vulnerability” may have shared considerable overlap. Further, the vulnerability could be innate or acquired and include various adverse experiences that could occur as late as adolescence (Zubin & Spring, 1977). Whether events are perceived as controllable appeared to influence the extent of subjective stress (Horan et al., 2005).

Exclusion from ordinary society appeared to underlie the associated subthemes, with participants feeling socially isolated, often due to their minority status. Difficulty negotiating typical life transitions, whether academically, vocationally or romantically, often entailed exclusion from other ordinary life events. In addition to being denied the same rites of passage afforded to others, participants were also often treated inhumanely and exposed to physical and verbal abuse. Zubin and Spring (1977) identified a number of ecological factors such as low socioeconomic status, social disorganisation, overcrowding and minority status in their conceptualisation of the stress-vulnerability model as being potentially causative. These findings appear to coincide with theories of aetiology related to income inequality, urbanicity, ethnicity and migration of which one hypothesis suggests that chronic and humiliating social defeat leads to the development of psychosis (Selten & Cantor-Graae, 2005). Further, these experiences are likely to result in low self-esteem and negative self-schema, which are thought to contribute to the development of psychosis (Fowler et al., 2006). This theory also relates social subordination to striatal dopamine dysregulation (Howes & Kapur, 2009).

## Overwhelming and Negative Emotion

Participants experienced overwhelming and negative emotion in relation to feelings of exclusion and stressful life events with some identifying it, in hindsight, as part of their approaching psychosis. Participants experienced an understandable emotional response to significant adverse life events. They may have also had an exaggerated response as a result of early cumulative stressful and traumatic experiences. The role of emotional dysregulation in psychosis was first identified by Bleuler (1857–1939) who believed that affective disturbance was one of the key features of schizophrenia (Keller et al., 2011). Although diagnoses that incorporate psychosis are often demarcated by the presence or absence of emotional dysregulation, the prodromal phase has been consistently associated with changes in affect (Aitchison et al., 1999), which have been found to primarily consist of intense negative emotion (Watts, 2006). Three pathways of emotional dysregulation have been suggested: (1) emotionality as an intrinsic symptom of psychosis; (2) negative emotion as a psychological

response to psychosis; and (3) as an outcome of developmental trauma (Horvath & Symonds, 1991). Moreover, negative emotional responses can act as a trigger for maladaptive schema developed in childhood that would likely act as a precipitant for dysfunctional coping and the symptoms associated with psychosis. These findings are consistent with the stress-vulnerability model in terms of contributing to adverse internal states that act as a trigger for a psychotic or schizophrenic episode (Zubin & Spring, 1977).

## Using Substances to Cope

Negative emotion in response to experiences of exclusion appeared to result in poor adaptation with participants either using substances as a way of coping with emotional dysregulation or as a way of connecting with others through recreational use. These findings were supported by research that found an association between child abuse and cannabis dependence in a first-episode African American sample, which suggested that participants used cannabis as a means to regulate negative emotion and gain social acceptance (Compton et al., 2004). The high prevalence of cannabis use among participants was unsurprising given the high use of substance use in first-episode populations, estimated at around 51% (Addington & Addington, 2007).

Substances were considered instrumental in the development and maintenance of psychosis by a number of participants, which is understandable given the EIS would have likely been targeting cessation of substance use during therapy. Cannabis has been thought to play a role in the onset and maintenance of psychosis, with risk being exacerbated with the experience of child abuse (Shevlin et al., 2009). Later evidence suggests that the relationship between cannabis and psychosis may be dependent on childhood trauma (Houston et al., 2011). Childhood trauma is theorised to impact on the developing brain, which has negative long-term impact on how stress is experienced and adapted to. The traumagenic neurodevelopmental model provides a description of how self-regulation is negatively impacted in this process (Read et al., 2001). The combination of a maladaptive stress response and negative self-schema appear to serve as risk factors for later cannabis use—for example, dysregulated emotions may be expressed as a heightened overwhelming experience lessened with cannabis use, while the self-schema associated with social exclusion would likely act to increase motivation for subculture group acceptance and diminish any natural restraint for engaging in illicit substance use. In conjunction with negative life events, cannabis also acts to deregulate the dopamine system (Lupica & Riegel, 2005).

## A Loss of Reality and Shifting Certainty

Prolonged exposure to exclusion, overwhelming negative emotion and maladaptive coping behaviours may have resulted in, or been a consequence of, disrupted sleep or insomnia. The experiences reported were diverse and often not representative of the reason they sought help. Many of the participants talked about the surreal quality of their experiences that ranged from subtle changes in the environment to outright delusions, hallucinations and thought disorder.

Many of the participants' experiences could be represented dimensionally. Many participants spoke of the realness of experience and having a high degree of certainty in the reality of their beliefs or hallucinations, but they varied and fluctuated with the degree of their conviction. Further, there was also a degree of being immersed or preoccupied with the experiences. For the majority of participants the degree of distress was not only related to the experiences per se, but also intrinsically related to their interpretation of experiences and the confusion surrounding them.

For the majority of participants, their experiences had personal relevance, with the boundaries between tangible and intangible experiences often being quite blurred. The dimensions inferred from voice hearers' experiences (Beavan, 2011) and the criteria used to define persecutory delusions (Freeman, 2007) were observed with participants' descriptions of both their beliefs and their hallucinations: "compelling sense of reality" or "firmly held" was reflected in the high degree of certainty or realness of the experience; "impact on the voice hearers life" and "preoccupying, distressing and interfering" was likened to participants level of immersion. Furthermore beliefs and hallucinations were often consistent with the experiences of the participant. Participants often understood their psychotic experiences in ways that made sense to them, such as Dave who was raised in a religious environment and who interpreted his experiences as '*demon attacks*'. The interpretation of delusions or hallucinations has been shown to be informed by previous experiences (Morrison, 2001)

Vaughan spoke about being of Native American heritage and this in conjunction with the American invasion in the Middle East fuelled his paranoia. Morrison (2001) suggested that the process of hallucinating or having delusions is not in itself an unusual event; rather it is the cultural unacceptability of the interpretation provided by the individual that is characteristic of psychosis. Further, it is the interpretation that is suggested to cause the distress (Chadwick & Birchwood, 1994). This was apparent in Jan's discourse, whose distress was associated with her son's schooling and whose experiences were interpreted as a source of advice:

*I always see things, even as a child, at night, and last year, when something kicked my bed really hard, and said get your son out of that school now, when he was getting sick and worse. I actually got a fright, and I actually made actions to get him out of the school very quickly. I have things like that happen.*

Some of the positive symptoms that participants described appeared to act as a defensive function to protect their self-esteem, or to allow them to escape the negative reality of their situation. Research has shown that adverse life events are reflected in the content of delusions (Raune, Kuipers, & Bebbington, 2009), with persecutory delusional content being a misrepresentation of past alienating experiences (Mirowsky & Ross, 1983). Stella's hallucinations appeared to symbolically communicate her problems with acculturation stress:

*Then a couple of months ago I was doing dishes and my husband comes in and said 'are you talking to your friends?' I said no 'I'm telling them to go away, f-off'. I asked my husband, 'do you want to really know what is in their mind?' and he said 'tell me'. I said they really like European people, what's not to like about them, but they want to be the both of them, this is what the stress is about, they really like blonde girls. We Indians we are living in the country where the majority is European people, so I mean they're living in our culture, we can live in their culture.*

Communication was negatively impacted through poor concentration, confused thoughts and distracting noises and sights. Those participants who referred to experiencing thought disordered type behaviour also spoke of a harsh family upbringing in which familial communication and traumatic childhood experiences appeared to predispose them to psychotic experiences. Negative self-schema related to acceptance and exclusion have been found to preempt thought disorder in a population with prior thought disordered behaviour (Grant & Beck, 2009). The relationship between theory of mind deficits and evaluation sensitivity purported in thought disordered psychotic populations may play a role in self-esteem maintenance. Thus, having a limited ability to read others thoughts and intentions as found with theory of mind deficits may protect self-esteem given the importance of acceptance in a population that already feels socially excluded.

## Wanting Help, but Fearing the Worst

Wanting help, but fearing the worst demonstrated that the majority of participants recognised that they needed help, but were reluctant to seek it due to having negative preconceived expectations of service involvement. The participants in this study varied greatly on why they

had sought help from the EIS. Often it was related to their low mood rather than their psychosis per se and was initiated by a visit to their GP. Research in the area of help seeking and psychosis has often focused on the lack of “insight”. Only four participants spoke of having a shift of orientation to one that described their experiences as a “mental illness”. Irene was one of them:

*At the time it felt real, I didn't think I had an illness or anything. I thought I was normal. I thought everything I was doing was normal but to other people they were like, she's really strange but I couldn't see it. [...] So after the first meeting I saw them about three times a week and talked to them and they would tell me I had psychosis. I didn't even know what psychosis was. I thought it was, I didn't know I had a mental illness.*

Qualitative research has found that people in the prodromal stage often recognise changes in their cognitions, emotions and behaviour, and that they normalise these changes and integrate them into their self-concept, often without seeking intervention (Judge et al., 2008). An inability to understand problems as “mental illness” and needing intervention is often referred to as a lack of insight, despite there being a number of reasons why someone may not want to engage in mental health services (Read, 2007). In this study, some participants actively sought help for problems related to their mental health, while five had been referred from the crisis team and three from hospital, which would suggest that a sizable portion of individuals are still waiting until problems are severe to access health services. Rather than this being indicative of a lack of insight, it seemed to represent a fear of stigmatisation or some of the realistic consequences that could come from engaging with mental health services. Such consequence include being admitted to inpatient care and having to take medication. Stigmatisation has been found to be a barrier to engagement with mental health services (Kessler et al., 1996).

## Service Satisfaction

As service involvement generally preceded participants deciding that they needed help, the service evaluation component of the study follows. The themes that emerged throughout service engagement were often dichotomised. These positive and negative aspects are integrated to provide an informative evaluation. Scales represent participants' ratings for the service provision variables; both the most frequently occurring score (mode) and the mid-point between the lower 50% of scores and the upper 50% of scores (median). Overall, eight participants reported being completely satisfied with the service and over 50% provided a VRS score of 8 or above (see Figure 1).

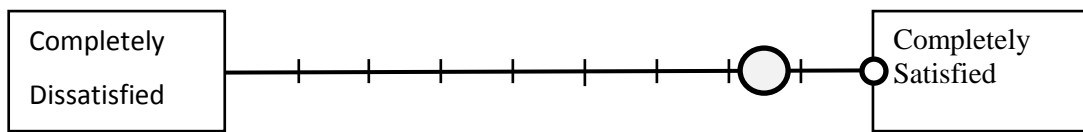


Figure 1 A visual description of the Verbal Response Scale for overall general satisfaction with the service with the median score of 8.5 represented by the large circle and the mode score of 10 represented by the small circle. Participants on a whole were satisfied with the service, as indicated by the mode.

## The Therapeutic Relationship

For the present study, the therapeutic relationship was defined as those elements between the client and clinician that engendered or diminished rapport. Half of the participants reported fearing the potential implications of service involvement, which may have increased the salience of efforts to establish rapport. Nevertheless, one of the main findings derived from the research relates to the therapeutic relationship. Over a quarter of participants interviewed were completely satisfied with the therapeutic relationship formed with clinicians and over 50% provided a VRS score of 8 or above (see Figure 2). Further, the therapeutic relationship demonstrated a very strong and significant relationship to overall satisfaction, which suggests that participants who were satisfied with the therapeutic relationship were also satisfied with the service. This finding was consistent with that found by Theuma (2007) that suggested that the therapeutic relationship was associated with service satisfaction.

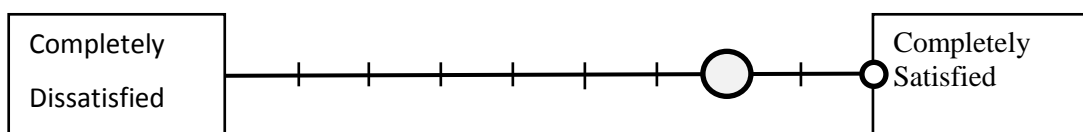


Figure 2 A visual description of the Verbal Response Scale for satisfaction with the therapeutic relationship with the median score of 8 represented by the large circle and the mode score of 10 represented by the small circle. Participants on a whole were satisfied with the therapeutic relationship, as indicated by the mode.

Qualitatively, all research participants referred to at least one aspect of the *therapeutic relationship* that they had a positive appraisal of, making it the most prevalent service provision theme referred to, compared to nine participants who referred to at least one aspect of the *therapeutic relationship* that they had a negative appraisal of. The positive and negative aspects of the therapeutic relationship focused on the personable or impersonal approach of clinicians

and the aligned behaviours that appeared to either result in the development of rapport and continued engagement or contributed to participants feeling ill at ease. For example, a personable approach for one participant was associated with language that was '*simple*' and made her feel '*comfortable*' as opposed to impersonal approach in which the language used was viewed as '*weird*' and was referred to as creating a '*barrier*'. This finding was consistent with the need of EIS to adopt a youth focus, which can be achieved through the physical setting and the language used by clinicians (Wade et al., 2006). It also suggests that the EIS was not meeting this principle consistently. Some participants reported that this was due to a poor match between themselves and clinicians and suggested that having more choice in relation to whom they work with would have alleviated this problem.

The therapeutic relationship is an essential ingredient in the majority of interventions. For the current project it was considered a dimensional phenomenon, with implicit rapport developing elements at one end, such as those within the therapeutic relationship theme, through to actual interventions. Qualitatively, the themes were ordered from the *therapeutic relationship*, *supportive therapy*, *psychosocial interventions* to *medication*. The process began by providing the necessary supportive context in which a climate of trust and security could be developed prior to introducing the information inherently needed to challenge existing maladaptive attitudes and beliefs, after a period of ambivalence, on-going behavioural change appeared to be evidenced.

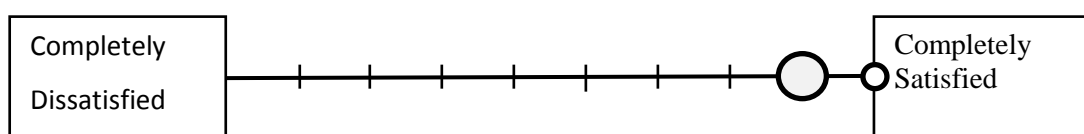
Due to the difficulty in defining something so intangible, it was often a feeling engendered in the participant as a result of something provided by the clinician that demarcated the therapeutic relationship from the other themes. This is not to say that the more tangible interventions do not have an effect on rapport. However, there appeared to be an association between early rapport building and later interventions. When the therapeutic relationship was solid, there appeared to be better treatment outcomes and conversely when the therapeutic relationship was poor there appeared to be worse treatment outcomes. For an example, see Two Paradoxical Experiences at the conclusion of this chapter. This finding is supported in the literature with more collaboration being associated with greater engagement and a better prognosis (Keks et al., 2006).

## Respect of Individual Differences

The therapeutic relationship was defined as those elements between the client and clinician that engendered or diminished rapport, often those attributes or actions that clinicians had or did seemed to account for this. It was often by attending to clients' individual differences or



providing a client-focused service that led to participants feeling closer to clinicians, which was also reflected in the strong significant correlation between the VRS of the therapeutic relationship and respect of individual differences. Seven participants interviewed were completely satisfied with the respect they felt from the service in regard to their individual differences and over a half provided a VRS score of 9 or above (see Figure 3). The perceived respect felt from clinicians was strongly and significantly associated with overall satisfaction, which suggested that participants who were satisfied with the service were also satisfied with how the EIS managed or responded to their individual differences.



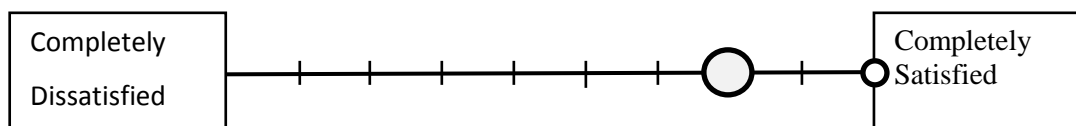
*Figure 3* A visual description of the Verbal Response Scale for satisfaction with perceived respect of individual differences with the median score of 8 represented by the large circle and the mode score of 10 represented by the small circle. Participants on a whole were satisfied with the perceived respect of individual differences, as indicated by the mode.

In the interviews, respect of individual differences appeared to be referred to within a number of themes. Within the *therapeutic relationship*, respect was often inferred through the provision of a client-focused service. Those things that were appreciated were the youth focus and flexibility of clinicians, which addressed their individual differences and which is consistent with the EIS model (Mental Health Commission, 1999). On a less positive note, one participant reflected that *karakia* (Māori prayer) would have contributed to rapport, which would have been consistent with the Kaupapa focus of early intervention services, which suggests that clinicians have a responsibility to work competently within a cultural framework (Herewini, 2008). Within *external resources* clinicians were referred to as not only respecting individual differences, but referring participants to other services that could adequately meet their needs, such as cultural and spiritual consultants. The need to respect individual differences was referred to within *psychosocial interventions* where five participants thought the content of sessions could have been more tailored to their needs. One participant reflected that he had wanted to discuss his sexuality, another the impact of trying to accommodate two different cultures and one participant spoke about the distress associated with unrequited love.

## Duration of Care

The majority of participants were no longer being seen by the EIS. The duration of care experienced by all participants ranged between 4–24 months. Four participants had been discharged into the care of their GP, while seven had been discharged into the care of other mental health services. Of these, four had been prematurely transferred from the EIS due to moving out of the catchment area or due to problems with engagement. Duration of care had a strongly significant relationship to overall satisfaction. Interestingly, there was no association between duration of care and the therapeutic relationship and no association with any other variables related to service provision. It is likely that participants who had been with the service longer, had had more time in which to reflect on their experiences and find personal meaning, a concept closely tied with the recovery literature (Lysaker & Buck, 2006a). Hence the relationship between higher levels of satisfaction and duration of care is suggested to represent subjective improvement. This finding may be explained by the health status of participants, given that recovery has been previously associated with higher levels of service satisfaction (Deane, 1993).

## Treatment



*Figure 4* A visual description of the Verbal Response Scale for satisfaction with perceived control over treatment with the median score of 8 represented by the large circle and the mode score of 10 represented by the small circle. Participants on a whole were satisfied with the perceived control over treatment, as indicated by the mode.

Over a quarter of participants were completely satisfied with their perceived level of control over treatment, with half providing a score over 8 (see Figure 4). Interestingly, perceived control over treatment was not associated with general overall satisfaction. A number of participants accepted that limited control over treatment, in the initial stages of engagement, was to be expected. Reasons for limited control included family involvement and the confusion experienced in relation to psychosis. Treatment and information were moderately and significantly associated suggesting that participants who were more satisfied with the level of information provided also felt more in control of the treatment process.

In the interview, *medication* was the most prevalent treatment theme with participants feeling that it had contributed to their improvement in one way or another. However, the majority also

said that this was associated with a cost, as they had to tolerate various side effects and other aspects that negatively impacted recovery. Participants ranged in their views in regard to taking it, with a number of participants feeling that taking medication was stigmatising. In terms of improvement, improved sleep was the most commonly cited positive aspect rather than symptom remission. Participants found it a challenge when medication had no or limited efficacy. Finally, family involvement with the EIS was viewed as a positive influence in ensuring medication compliance.

*Case management* accumulated the data related to service contact and treatment structuring. Despite the majority of participants saying they had the right amount of contact with the service, which was arranged in a collaborative manner, five felt that meetings became routine. This finding may be explained by: (1) the inherent nature of case management meetings that have the primary purpose of completing a routine check with the client; (2) participants may have been with the service longer than necessary as a precaution; (3) it may have been the result of the *hopelessness, self-stigma and withdrawal from others* that participants reported feeling; and (4) it may be that participants had an external locus of control and were taking limited responsibility to engender change. Previous literature suggests that psychotherapy is important in helping service users come to terms with their experiences (Judge et al., 2008). Approximately half of the sample was provided with psychological input.

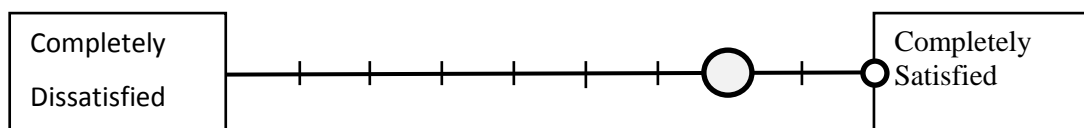
*Psychosocial interventions* were perceived as contributing to improvement through the provision of psychoeducation, therapy and vocational input. One of the primary therapeutic elements participants talked about positively was having an opportunity to process negative emotions. Having formed a therapeutic relationship, participants felt able to show their vulnerability with therapists and as Justin said it contributed to him feeling “*real*”. This finding is consistent with other research that has suggested that tolerating painful affect within a relational context helps the client to develop a coherent narrative and find meaning from experiences otherwise avoided (Lysaker & Gumley, 2010). A few participants were confused about why they were engaging in some interventions and felt that, providing a rationale might have allowed them to engage more fully in the process. Reality testing could result in feelings of invalidation if the therapeutic relationship was not fully developed. Many of the participants talked about going through a period of ambivalence. This seemed to represent a pattern of fluctuating between engaging in behaviours which contributed to psychosis and, for example, remaining abstinent from such behaviours.

*The [clinician] said that this would all be over with within a year, unless I kept going on the drugs. He said they could still be there. I don't really want to stop my life just cause of these voices, I just want to keep on moving. The voices hold you back sometimes. I feel real lost sometimes. And it's true that he should of told me that. But I'm not just going to stop for that. Keep living. (Andre)*

This ambivalence has also been suggested to have arisen in response to the positive experiences that psychosis can provide, an aspect that is often not attended to by clinicians (Geekie, 2007). Over time, however, many participants reported being able to action behavioural changes, which influenced recovery that occurred concurrently with the development of the therapeutic relationship.

Regarding *inpatient care*, only one of the participants had been admitted to an inpatient facility whilst under the care of the EIS being evaluated, and the admission was voluntary. Despite this, six participants had previously experienced inpatient care and had a negative evaluation of it. One participant was very matter-of-fact about it and saw it as the only option given some of the states that he had experienced. Another participant had enjoyed the experience and was able to connect socially with other whilst there.

## Information

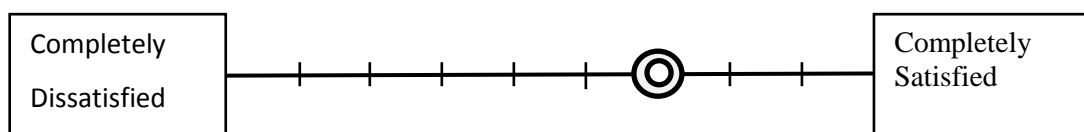


*Figure 5* A visual description of the Verbal Response Scale for satisfaction with the quality of information received with the median score of 8 represented by the large circle and the mode score of 10 represented by the small circle. Participants on a whole were satisfied with the quality of information provided, as indicated by the mode.

One fifth of participants were completely satisfied with the quality of information received, with over half providing a score of 8 or over (see Figure 5). The quality of information received was not associated with overall satisfaction. However, satisfaction with the quality of information received was significantly associated with perceived control over treatment. This finding may be explained by the choice of treatment (such as medication) participants may have made, subsequent to being provided with information (such as psychoeducation), which would have influenced how they perceived their degree of control over the treatment process.

The *psychoeducation* subtheme of *psychosocial interventions* was the most relevant theme, with participants reporting that information was provided in a number of different modalities, with two participants being encouraged to use the internet to obtain relevant information with which they could make informed choices. *Groups* were also a means by which information was passed on. Findings suggest that the EIS was able to engage in psychoeducation in a manner that provided the necessary information about psychosis and normalised experiences consistent with the EIS model (Freudenreich, 2008).

## General Satisfaction



*Figure 6* A visual description of the Verbal Response Scale for general satisfaction at initial engagement (SE) with the median score of 8 represented by the large circle and the mode score of 10 represented by the small circle.

Less than a seventh of participants were completely satisfied with the service at initial engagement; however half provided a score over 7 (see Figure 6). This was the lowest median score from all eight scales. A number of explanations could account for this: (1) participants' negative expectations *wanting help, but fearing the worst* of service involvement impacted their level of satisfaction; (2) the service was coercive at initial engagement; (3) the service did not manage the initial engagement as well as they did other aspects of service provision; and (4) service users' mental health status may have impacted initial satisfaction. The qualitative data suggested that participants did have negative expectations of entering the service, but there was only minimal evidence to suggest that this spilt over into initial engagement. Further, although there is a relationship between service users' expectations of the service and their later satisfaction, low expectations would generally predict higher levels of satisfaction (Jackson, Chamberlin, & Kroenke, 2001). The second explanation was suggested by a clinician who attended the Regional Auckland Psychosis Group dissemination of the research results, and although potentially true the insignificant correlation between perceived control over treatment and overall satisfaction would suggest that this was not the case. Previous research has shown mental health status to be a covariate in health satisfaction surveys (Hall, Milburn, & Epstein, 1993), which may support the last explanation. Further, the qualitative data also support this

conclusion as many participants reported being overwhelmed, confused and not wanting to engage with the service during the first couple of months.

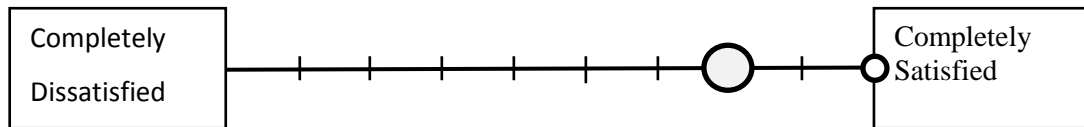


Figure 7 A visual description of the Verbal Response Scale for general satisfaction throughout engagement (ST) with the median score of 8 represented by the large circle and the mode score of 10 represented by the small circle.

Almost a third of participants were completely satisfied throughout engagement, with half of the sample providing a score over 8 (see Figure 7). This would have likely shown a significant difference with a larger sample size. Despite many participants reporting *hopelessness, self-stigma and withdrawal from others* at around this stage of engagement, they were also starting to engage in the groups run at the service and acute symptoms had started to remit.

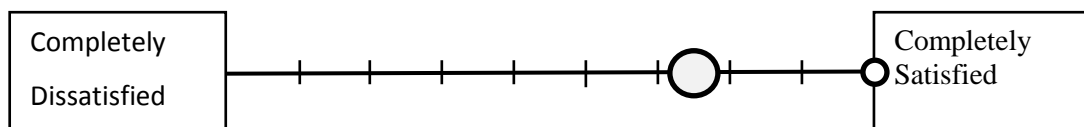


Figure 8 A visual description of the Verbal Response Scale for general satisfaction at discharge (SD) with the median score of 7.5 represented by the large circle and the mode score of 10 represented by the small circle.

Almost a half of participants were completely satisfied with the service at discharge, with half providing a score over 7.5 (see Figure 8). This was the second lowest score of all eight VRS. These scores may be accounted for by the qualitative themes of *disruptions in care* and *case management*. Four participants had to move to another service due to having shifted outside of the catchment area of the EIS and one appeared to have been referred elsewhere due to problems with engagement. The EIS gained lower satisfaction scores from participants who had moved from the service prematurely, due to a number of possible reasons: (1) discharge and service transitions are not managed particularly well by the service; and/or (2) mental health status at the time of the move was poor and therefore influenced the evaluation of the service. These are interesting findings given previous qualitative research has suggested that one of the central experiences of service users with psychosis is of personal and interpersonal fragmentation, which can be exacerbated with inconsistency in care (Geekie, 2007).

Satisfaction at the different stages of EIS engagement showed no statistically significant difference. The hypothesis that participants would become more satisfied as they recovered was not supported. It is likely that the small sample size ( $n = 12$ ) was insufficient to yield enough power to detect significant differences. If inferences were made from the quantitative analysis alone, it could be concluded that the service is as effective in managing clients at initial engagement, throughout engagement and at discharge, and while this may be true, the qualitative data, *disruptions in care*, suggests that the service may want to look at its discharge practices for clients who leave the service prematurely or look at more flexibility for treating clients that are more transient.

## A Holistic Service

The diverse service offered by the EIS was primarily captured within the qualitative themes. The provision of a holistic service targets many of the areas negatively affected by psychosis. The inclusion of family within the process of recovery was viewed positively by many of the participants. Given the role of family in a number of theories associated with the aetiology of psychosis, such as high expressed emotion (Butzlaff & Hooley, 1998), family interventions offer promising treatment targets for EI services and have proven effective in reducing relapse and hospital admission (Pilling et al., 2002). Through having family involved, the EIS managed to achieve two overarching aims: (1) educating and supporting families, and (2) advocating and improving family dynamics. Despite some participants having a negative perspective of family involvement, most participants understood these as tolerable. Of note, however, it appeared important to achieve a balance between respecting clients' wishes and having a more paternalistic role.

The provision of *groups* was viewed positively and allowed many isolated participants to meet people of a similar age and engage in activities. Not only was it viewed as an opportunity for *social connection*, but *psychoeducation* was also delivered effectively within this format. This has been found to be especially important in the treatment of psychosis as it is often associated with isolation (Larsen, 2004). The service appeared accessible to youth and met the principles of the EI that recommend groups as a means to gain support and skills (Woodhead, 2008). A number of participants spoke about craving more social interaction, with some still avoiding groups due to the associated stigma. All disciplines employed within the EIS were referred to by participants. The multidisciplinary team met a range of clients' needs.

# The Process of Supported Recovery

## Labelling it Means I've Got it

Recovery within the context of the service often involved labelling the experiences participants had as “psychosis”, with the majority of participants receiving this well. Previous research has suggested that the impact of gaining a diagnosis engenders mixed feelings (Pitt et al., 2009).

This finding was captured by Brendhan in the following excerpt:

*Good and bad, like good in the sense that there was a certainty attached to it, like it was bipolar disorder and labelling it makes it understandable and I can handle it. Bad in a sense that oh gosh, that means I've got it. Right. So it's a double edged sword, it cuts both ways.*

Previous research has found that a diagnosis has provided participants with a framework that enabled them to make sense of their experiences and that it “legitimised” their distress and enabled them to gain the help and support required (Pitt et al., 2009). In the service being evaluated, the term psychosis was used more often than a specific diagnosis. Not only did this seem to serve the same function as would a diagnosis, but it avoided the associated stigma attached to, for example, “schizophrenia”. In the current study, schizophrenia was referred to as a stigmatising label that represented an absence of recovery. None of the participants referred to receiving a diagnosis of schizophrenia from the EIS under evaluation, although two had received it from other services. The low number of participants who reported being given an actual diagnosis can be explained in two ways: (1) the service is reticent to provide participants with a diagnosis given the associated stigma, and (2) participants avoid discussing diagnosis due to it being a stigmatising topic. Those participants who rejected the term psychosis, tended to have a high degree of conviction in the realness of their experiences and felt invalidated or dismissed by their experiences being explained as, for example, ‘*delusions of grandeur*’ or ‘*brain malfunctions*’.

## Hopelessness, Self-Stigma and Withdrawal from Others

Once the florid symptoms of psychosis had passed many participants went through a phase of hopelessness. Following the decision to either seek or accept help, many participants had been initially quite hopeful of full symptom remission or a change in their circumstances. After waiting for a number of months for the change and trying different medications, participants often became depressed. Many had ceased working prior to engaging with the EIS, which



contributed to their low mood and boredom. Feelings of uselessness and frustration were common. Participants also had a negative future orientation. This occurred in conjunction with feeling stigmatised through taking medication or attending mental health services. Participants also felt humiliated and embarrassed about some of their experiences, which influenced their ability to be open and seek support from others.

Subsequent to the remission of acute symptoms, participants reported going through a period of *hopelessness*. Many said they felt frustrated with the service, with themselves and with life in general. *Self-stigma* influenced how participants viewed their experience and how well they were able to share what happened to them with others. Participants who felt they were able to speak openly about their experiences also considered themselves to be recovered. Participants who talked about being sensitive to stigma seemed to be on the process to recovery. Treatment for the majority of participants appeared to focus on allowing them to develop their own narratives and explanatory models around their psychosis. *Withdrawal from others* and *isolation* was a theme that appeared to occur on either side of the acute phase. Previous research has viewed withdrawing as a means by which individuals try to cope with the onset of psychosis (Judge et al., 2008), however the participants in the current study seemed to withdraw due to the expectation of rejection. Hopelessness has been reported in the literature elsewhere as it may serve to increase further vulnerability, and is believed to be derived from appraising events as uncontrollable and having a negative appraisal of personal coping strategies (Horan et al., 2005)

## Evolving Explanations

The EIS appeared to approach the treatment of psychosis from an explanatory model (Kleinman, 1988) perspective. This allowed participants to form their own narrative and through this process find personal meaning in their experiences and integrate their experiences into a coherent whole (Lysaker & Buck, 2006a). This approach has been supported by Geekie (2007), as it affords clients who are often fragmented by their experiences, both psychotically and otherwise, the opportunity to reintegrate and re-establish a sense of self. The service differed on the degree of input they provided participants with, in terms of establishing a shared formulation. Some participants wanted more input on this from the service while others were happy with none. Where there was a difference of opinion, as there was in two instances, where one client reported feeling listened to and one reported being confused. There appeared to be an art to finding the balance between validating the clients' experiences and providing them with alternative explanations. By appreciating and respecting the clients' own worldview,

it appeared to ensure the maintenance of self-esteem. A number of participants said they were with the service in order to access support while they were going through some difficult experiences with family. Despite having experiences that could be classified as psychosis and/or schizophrenia, it was apparent that interventions designed to address those experiences were unnecessary as they were not interpreted with any resulting distress.

The interview was designed to access the similarities or differences between clients' and clinicians' explanatory models. Despite the majority of clients not being asked directly about what they thought caused their psychosis, many still provided this information. This was apparent in the first theme *exclusion from ordinary society* which seemed to represent the rich narrative that participants had developed possibly as a result of therapy.

## Focusing on the Positive and Being Thankful

Understanding and acceptance was transformed into positive changes that supported the recovery process and allowed for a redefining and reintegration of self, informed by rejection of an illness identity, new ways of relating to others and academic and vocational attainment. Participants reported being future-oriented, having a positive outlook and making goals. Through their process of recovery, many gained confidence and a sense of achievement. Finally, participants reflected on the EIS with gratitude for supporting their recovery.

## Clinical Implications

The finding that many clients of a first-episode service felt socially excluded, having experienced more trauma, poverty, marginalisation and discrimination, is not uncommon. Further, psychosis often comes to the forefront during important life transitions in late adolescence and early adulthood. Clinicians should aim to undertake comprehensive assessments that ask about childhood events, trauma, sexuality, culture, spirituality, socioeconomic status and the clients' own understandings of their current problems and challenges. Assessments that are derived from the aforementioned topics establish meaningful formulations that inform treatment designed with the individual clients' needs at the forefront. Assessment continues throughout the therapeutic process and formulations need to be constantly evolving. Issues that may not have been the focus when clients first engaged with services can become important further into the treatment process as they establish a deeper understanding of their experiences. Delusions and hallucinations need to be viewed as understandable reactions to adverse life events rather than contextless psychopathology.

In early intervention many of the positive outcomes are primarily derived from the therapeutic relationships formed, of which rapport building is a central aspect. The personable approach of clinicians models an integrated sense of self and ease with which to relate to others. Reflective practice and quality supervision can provide awareness and promote a more grounded and mindful approach to the therapeutic relationship. As found in other research, the therapeutic relationship is still central to engagement and a better long-term prognosis (Davis & Lysaker, 2004). It provides a firm foundation by which supporting, challenging and empowering clients can have the most effect. The therapeutic relationship is essential to the treatment of psychosis. Due to the young age at which many clients find themselves engaged with early intervention services, it is important that these services retain a youth focus.

Every intervention should be implemented with a clear rationale. Providing this to the client not only orientates them to the purpose of an intervention, but also promotes buy-in. Providing clients with a rationale that makes sense to them, and gaining their consent to proceed with the intervention, is the basis of an effective and collaborative relationship. Clinicians may need to be mindful that even though an individual may be experiencing psychotic symptoms it may be just a small part of what they find distressing and it may not always be what they are seeking help for. The therapeutic space should be one which validates and encourages change, through both addressing the client's concerns and incorporating empirically based interventions. The modes by which participants choose to engage in therapy, whether through discussion, writing things down, and/or using the internet can be decided collaboratively. Being asked to do things they do not feel comfortable doing can alienate participants from the therapeutic process. The research demonstrated that the clients' worldview can be incorporated into treatment through time spent allowing them to develop their own explanatory models, making sense of their experiences and finding personal meaning. This approach conveys respect and maintains clients' self-esteem, which shows more long-term benefits.

The EIS under evaluation appeared to address the problems that participants were experiencing while concurrently avoiding the potentially iatrogenic effects of diagnoses and using the term schizophrenia. Achieving the balance between minimising the costs and maximising the potential benefits associated with naming psychosis is difficult but important. Participants were specifically sensitive to the language used by clinicians to describe their symptoms with, for example, the term "beliefs" used instead of "delusions"; they were also sensitive to non-verbal communication that would be interpreted in a manner that could cause distress if not addressed in therapy. More often than not, clinicians appeared to be able to validate the experiences

associated with the participants' situation whilst still challenging the problematic aspects, balancing the art and science of practice.

Biological explanatory models can often minimise the real reasons that individuals present to mental health services. It is essential to recognise these influences for what they are. Recovery often requires one to make sense of the experience and then make changes that are going to impact on how a person lives their life. Simplistic, reductionist conceptualisations of clients' distress can promote the iatrogenic effects of service involvement, medication and diagnosis. Clinicians will serve their clients better if they are mindful of the potential damaging effects that treatment within a mental health service can have on clients as they attempt to cope. Acknowledging clients' strengths provides hope and optimism and is more likely to engender recovery.

There is a considerable amount of research that has emphasised the importance of continuity in care. Continuity in care is especially pertinent for populations that are by their very nature quite transient, such as urban youth. Centralising services, although not without their problems, may result in more flexibility leading to fewer disruptions and discharges to other service. This would minimise any additional fragmentation due to a discontinuity of care. Service centralisation can also provide smaller teams with more resources and provides clients with more choice in terms of who they see, ensuring a larger scope for client-clinician matching.

## Limitations

### Study Design

Mixed methods research aims to meet certain quality criteria, in terms of study design and interpretative rigor (Tashakkori & Teddlie, 2010). Design suitability is concerned with whether there is a coherent match between the research question and the methods employed. Stratified purposive sampling was one method employed to address the research question. This achieved a largely representative sample in terms of gender and ethnicity, which enhances the transferability of the findings to the broader EIS context.

Nevertheless, sampling bias is problematic and precludes assumed transferability. Almost half of the total sample could not be reached by telephone (despite three attempts) or had moved outside of Auckland. Of the research sample, four had been discharged into the care of other EIS due to moving outside of the geographic area. These participants tended to be the most unsatisfied, suggesting a possible association between higher transience and lower satisfaction.

Design fidelity is concerned with whether the quantitative and qualitative methods employed reach acceptable standards of validity and authenticity. The validity and reliability of the Verbal Response Scales (VRS) is unknown. They may have not met acceptable standards of specificity and sensitivity. It is possible that sensitivity may have been improved through using an odd numbered scale (0–10). Qualitatively, authenticity was achieved through reflexivity, immersion in the data, peer review and through the use of an analytic journal. Improvements could have been achieved through member checking, that is, providing participants with a copy of their transcribed interview or presenting them with the results to establish whether it accurately presented their impressions of the EIS and of the process of recovery. However, due to time constraints, this was deemed outside of the scope of the project. Nevertheless, it must be acknowledged that there is no escaping a degree of subjectivity in the development of categories, themes and coding of statements. Another researcher may have structured these categories and themes differently.

## Interpretive Rigor

Interpretive agreement was obtained through the inter-rater reliability audit, in which agreement between the researcher and the independent coder ranged between 88% and 94%. Interpretive distinctiveness was ensured through data immersion and consideration of contrary statements. As the data was only interpreted at a semantic level, there was minimal threat to the consistency between the interpretations and the inferences. Further, the inferences appeared largely consistent with other qualitative data in the field of psychosis. Finally, the integrative efficacy aimed to present inferences that moved from an etic to an emic perspective (Onwuegbuzie et al., 2011) to describe the complexity of Psychosis, Service Satisfaction and the Process of Supported Recovery.

## Two Paradoxical Experiences

The thesis is concluded with extracts from two participants who began with similar experiences of persecution, but who had rather different experiences of the EIS. This hopefully allows the reader to experience the stories of the two participants in a more coherent fashion than experienced by reading quotes categorised into themes.

### Jeremy

*I suffered a psychotic episode. I became really hypersensitive to the media, on TV and thought that people were talking about me and stuff, and I thought there was a government conspiracy. [...] I wasn't provided with a lot of information when I first saw*

them, I remember they took me down to the clinic and I had an interview, I didn't know what I was supposed to be talking about with the doctor, and she just sat there and wrote down everything that I said, and I didn't really know what it was all about. It was a little bit weird and there wasn't a lot of information as to why I was doing this and how it was going to help me and what the process was. [...] There was probably nothing they could say to me that would make me instantly snap out of it and believe that this wasn't real. So I did think that they gave me the right amount of time, so just giving me time and space to come out of it by myself was possibly quite helpful to me, in the middle stages. But at the same time it was a little bit too stand offish about it, and not really explaining what was going on. [...] I felt like their attitude was, oh no, here we go again, and I could pick up on that. And even though it was that, that's really what was happening, oh no, here we go again, I was almost, not insulted, but just felt that no one believed me and yeah, that part didn't, made me not want to be too, have too much involvement with them. [...] If someone had more personal contact, rather than just the medication, cause their priority was to get me medicated, and my priority was to talk about what was happening and what wasn't, and we'd go off in different direction, where they were trying to get me to take medication, and I was trying to sit down and talk to them and ask them why all this stuff was happening to me. They had their priorities and I believed that I had mine, and they clashed a little bit. [...] There wasn't a lot of information going through to my mum, so I'd say that part was a little bit lapse about it. My preference would have been for them to work closer with someone that I trusted like a family member or something, because I would have to relay to my family members what was going on, and I don't know, it was a tough thing to do, because they didn't really understand. [...] Honestly I would believe that if someone had taken the time to sit me down and say how can all these things be happening and why would it happen to you and it's not happening and there's no one spying on you, I felt like that could have been managed a little bit better. Because I felt like I'd sit down and say to them I'm being spied on or people are monitoring me, and they'd just look at me as if, I wasn't all there, and I found that to be not that helpful, at the time. Cause I was really convinced that it was. Even though now I know it's not. But we're talking about how I felt back then, yeah, I felt that, there was some things that could have been done better in that way, yeah. [...] They were really nice people and they were totally understanding looking back now, and they understood what I was going through, they'd seen it before and yeah I was lucky to have them.

## Josh

*I was not well. I was basically in a scenario where I thought that I was on a TV show. And so I was extremely paranoid at the time. And I was in a pretty bad place. [...]The [clinician] came to my house. Introduced himself. I can't remember exactly what he said, I was quite ill, he just introduced himself, said this is what we do in our team, and that was the first time that I met him, and he's quite a personable guy, I didn't feel threatened or anything by him. And he introduced it in such a way that it sounded like the team would be good for me too. [...] I think one thing I noticed was that they would shake your hand. These guys would touch me and shake your hand, and it was like cool, that's great. And then you'd leave and they'd shake your hand, and it was like we're going to fix this problem, and it conveyed that a sense of purpose about it. Like we're in this together. More like a collaborative approach. It was good like that. [...] I found their manner quite good, conducive to me, particularly helping me address the unreality of my situation. They started to get to know me quite well, in the sense that they knew what I was up to, we had a few yarns of what we were up to and how the parents were and stuff like that, so it was quite a good feeling. They remembered who I was, I wasn't like a number in a file, they knew the person, and they treated me like a person. I never felt like a patient really. [...] The [clinician] was an extremely personable guy, and he was pretty straight up as well from what I remember. I remember him saying, we were talking about the weight gain again, and I remember him saying oh we've already talked about this, have you got this sorted out. And I remember that, because that was pretty fair enough at the time too. It was an honest relationship. [...] I think the fact that they provided information, a lot of it you had to go get yourself, they would suggest web-sites and stuff like that, there were a lot of meetings, it was helpful at the time. It was quite empowering that they let you sort it out yourself. So that's a good thing. [...] Family was good, very definitely very helpful. I think the best thing about that was they were able to have their little say and everything, their input and they could be on the same page as me. It wasn't second hand information. I wouldn't go home and tell them, Chinese whispers, they were getting it first hand, and that was pretty important. So they didn't just have my word, they could take the word of the doctors. And if they had any questions they were answered immediately. Very good. [...] I think just the reality checks were most helpful for me, just the reality checks. I felt that these guys were, they never overtly said that nothing's going on, which I did notice, but they were more confrontational about the whole thing really. I don't know if it would work for everyone,*

*but for me it was good. I had my Dad in one ear, and the doctors in the other ear, and even if I didn't fully believe them, it meant that I would act like I believed them and I would just be more able to interact with other people without spouting bullshit. So that would help. [...]They were really good to me, and I'm really, really glad we went there. Things have worked out really well since then, so it's been good.*

## Conclusion

The majority of participants who attended the EIS were completely satisfied with the service on all measures of service provision. The service, for the most part, appeared to deliver a service consistent with the ethos of early intervention and the recovery model. Participants' evaluated the service and provided information on the positive and negative elements of service provision. Their perspectives allow the service to redefine their practice with this knowledge at the forefront. By eliciting information about participants' process of recovery it was hoped that this would consolidate the work they had engaged in with the service and enhance their recovery. The service offered a diverse practice that met the needs of clients on a number of different levels.

The therapeutic relationship and respect of individual difference was associated with service satisfaction. This finding has been highlighted in other research in which the therapeutic relationship is associated with service satisfaction, better engagement and a better overall prognosis. How participants defined the therapeutic relationship depended on the level of connection, rapport and collaboration felt between themselves and clinicians. This connectedness was often engendered by the individual personalities of the clinicians and their ability to focus on the client and their needs, which established mutual respect. Once these elements had been experienced by participants the relationship between client and clinician could be established. Consistency and transparency engendered trust and strengthened the connection. Trust enabled clients to share their experience of psychosis and the context in which it developed. The therapeutic relationship represented the foundation for an effective intervention that encouraged change.

A longer duration of care was also associated with higher levels of satisfaction. It is suggested that this allowed participants the time and space to develop their narrative and to explore their own explanatory models, enhancing recovery. In the process, clients were able to find meaning and re-establish a sense of self that incorporated the experience of psychosis. At a time when



mental health services strive to deliver short-term empirically based treatment, long-term care consistently demonstrates better long-term benefits.

Recovery began with participants feeling excluded from society and feeling overwhelmed with negative affect. The therapeutic relationship served as a point of reference for many participants, one that allowed them to explore their experiences and establish a more integrated sense of self. This process was one that began with exclusion and ended when clients were again connecting socially with others. Within this relational context, participants gained trust of themselves and of others. Within the service, participants were able to retain their self-esteem and build on it, and the process of supported recovery was not one that exacerbated distress. The service managed diagnosis in a sensitive, yet informative way, and participants were encouraged to find meaning in their experiences.

Service users provide a valid perspective and information integral to service evaluation. It is a perspective that constantly needs to be considered when working within the public sector where clients do not have the freedom to choose from whom, from where and when they receive treatment. Practice can be enhanced as a result of asking service users what works for them.

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# APPENDIX I

## Participant Information Sheet

### CONSUMER EVALUATION OF A FEP SERVICE

You are invited to participate in an interview about the XXX service. Participation in this study is entirely voluntary and your decision to participate will in no way affect your current or future health care. My name is Sarah de Wattignar and I am a clinical psychology student at the University of Auckland. This research is part of the requirements for my doctorate. Hopefully the research will be useful to the XXX service and the people who use it. Interviews will take place in June 2009 and onward. If you think you might be interested please read the following information. I will be phoning you in about one week to see if you are interested; or you can phone me on (09) 373 7999 Ext 84990 and leave a message, I will return your call within a week.

#### What are the aims of the research?

To interview past and present clients of the XXX service to find out what was helpful or less helpful about the service.

#### What will participation involve?

This research project involves an interview which would last a maximum of 90 minutes. You would only answer the questions you feel comfortable answering and you may stop the interview at any time. The interviews will be held at the City or Tamaki campus at the University of Auckland. Parking is free at the Tamaki campus and costs \$6 per hour at the City campus. All participants will have their interviews audio taped to ensure accuracy. You may involve a friend, family member or whanau support person. If you would prefer the interview can be conducted by a Māori interviewer and a Māori support person can be provided. You are free to end your participation in the study at any time and to withdraw any information you have provided for a period of four weeks after the interview.

#### Koha

The researchers would like to make a contribution towards your travel and time.

## Results and Confidentiality

All the information gathered will remain confidential. No member of the XXX team or anyone else will have access to the information you provide. If the researcher believes that you or anyone else is at risk, steps will be taken to ensure safety. The results of this research may be published, but you can be assured of complete confidentiality. All information will be kept secure to guarantee your privacy. Only the researcher Sarah de Wattignar and her supervisor Dr. John Read will have access to your private information. All information relevant to any published articles generated from this research would be kept by the supervisor John Read for ten years following the completion of the study.

## Advocacy

Should you have any queries or concerns regarding your rights as a participant in this research you may contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioners Act.

Telephone (NZ wide): 0800 555 050

Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

## Declaration

In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the accident compensation legislation.

## Contact Details

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Māori Health Service Co-ordinator  
307 4949 Ext 23939  
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This study has received ethical approval from the Northern X Regional Ethics Committee  
(NTX/08/11/10)

## APPENDIX II

### Participant Consent Form

**Research Title:**

CONSUMER EVALUATION OF A FIRST-EPIISODE PSYCHOSIS SERVICE

<b>Consent:</b>	Please circle	
I have read and I understand the information sheet dated 19 March 2009 for volunteers taking part in the study designed to explore client satisfaction at the XXX clinic.	YES	NO
I have had the opportunity to discuss this study and am satisfied with the answers I have been given.	YES	NO
I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.	YES	NO
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way effect my continuing and future health care.	YES	NO
I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.	YES	NO
I understand the accident compensation provisions for this study.	YES	NO
I know who to contact if I have any questions in regard to the study.	YES	NO
I consent to my interview being audio-taped.	YES	NO
I would like the researcher to send me a summary of the research findings.	YES	NO



CONSUMER EVALUATION OF A FIRST-EPISODE PSYCHOSIS SERVICE

I agree to participate in this research

**YES**                      **NO**      (Please circle)

Date: \_\_\_\_\_

Full name (please print): \_\_\_\_\_

Signed: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

## APPENDIX III

### INTERVIEW SCHEDULE

Introductions  
 Research  
 Questions/break/not answering  
 Confidentiality  
 Audio tape  
 Consent

Date:  
 Time:  
 Location:  
 Present:

Name:  
 Age:  
 Ethnicity:  
 When did you start at the EIS?  
 When did you finish with the service?  
 Duration:  
 How regular was your contact?  
 Did you have as much contact as you liked?

#### The beginning of your time with the service

The following interview will address the various stages of your time with the FEP team. I am really interested in understanding your experiences of the FEP service and was wondering if you could tell me about the beginning stage of being with the service at the point where you first started going. Please take as long as you like.....

	Beginning	Middle	End
Referral			
Expectations			
Needs			
First meeting			
Relationships			
Information provided			
Formulation			
Treatment			
Personal differences			
Improvement			
Helpful/unhelpful			

Looking back how do you make sense of this time.....

On a scale of '1 – 10', with '1' being not satisfied and '10' being completely satisfied, how satisfied were you with this service initially?

### **Middle**

I'd like to spend some time now hearing about the middle stages of being with the service, again take as long as you like.....

[Clarify and summarise]

Looking back how do you make sense of this time.....

On a scale of '1 – 10', with '1' being not satisfied and '10' being completely satisfied, how satisfied were you with this service during this phase?

### **Ending**

I'd like to spend some time now hearing about how things ended for you with the service again take as long as you like.....

[Clarify and summarise]

Looking back how do you make sense of this time.....

On a scale of '1 – 10', with '1' being not satisfied and '10' being completely satisfied, how satisfied were you with this service when you finished?

### **Quantitative**

#### **Relationships**

On a scale of '1 – 10', with '1' being unhappy with the relationships that you formed at the EIS and '10' being completely happy, how happy were you with the relationships you formed at the EIS?

**Information**

On a scale of 1-10 with '1' being unhelpful information and '10' being completely helpful where would you place the quality of information you received?

**Treatment**

On a scale of 1-10 with '1' being no control or influence over your choice of treatment and '10' being complete control/influence over your choice of treatment where would you place yourself?

**Issues of difference**

I would like to get an indication of how well the EIS addresses issues of difference. On a scale of 1-10 with '1' being poorly addressed and '10' being perfectly addressed where would you place the FEP service?

**Satisfaction**

On a scale of '1 – 10', with '1' being not satisfied and '10' being completely satisfied, how satisfied were you with this service overall?

**We are just about to finish up and I was wondering if there was anything else you would like me to know?**

**Debrief and Safety Check**

Acknowledge and thank participant.

How has this interview been for you?

How are you feeling?

Safety check?