Doctoral Thesis

Investigating the Psychological Typology of Social Recovery in Individuals with First Episode Psychosis

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Abstract

Background

Social disability has long been linked with psychosis. However, at what stage disability occurs, whether it exists for all individuals, and factors predicting outcome are still under debate. Assessing social functioning in first episode psychosis (FEP) presents a methodological challenge as many existing tools were developed for chronic schizophrenia and are confounded with psychotic symptoms.

Aims

This study explored the prevalence and typology of social disability in FEP. Different trajectories of social recovery were examined as well as predictors of outcome.

Method

A sample of 878 individuals with FEP were assessed upon entry into Early Intervention for Psychosis (EIP) services and followed up over 12 months. Social disability was assessed using weekly hours engaged in structured activity on the Time Use Survey (TUS). Recovery profiles were examined using two approaches: transition between clinical and non-clinical cut-off scores on the TUS, and Latent Class Growth Analysis. Baseline predictors of outcome were examined using ordinal and multinomial regression.

Results

At baseline, over 80% of participants scored below the non-clinical cut-off of 45 hours per week in structured activity. Male gender and poor premorbid adjustment in adolescence predicted baseline levels of social disability. Over 50% of participants remained socially disabled following 12 months of EIP service provision. Social recovery over the 12 month study period was predicted by baseline time use, gender,

ethnicity, age of onset of psychosis, duration of untreated psychosis, negative symptoms, and premorbid adjustment in adolescence.

Conclusion

Social disability is prevalent in FEP, although a significant minority do not experience any social disability and make a full social recovery. Where social disability is present upon entry into EIP services it can remain stable over time. Social disability may occur in adolescence, even before the onset of psychotic symptoms. The clinical and theoretical implications of the findings are discussed.

Table of Contents

List of Tables

List of Figures

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CHAPTER ONE

1. Introduction

1.1 Overview

The typology of social recovery from psychosis is not as well researched as the typology of symptomatic recovery. The identification of pathways of social recovery from a first episode of psychosis (FEP) is an essential starting point in understanding why some individuals remain socially disabled following remission of acute psychotic symptoms. Moreover, identifying individuals who may be at risk of social disability could help with treatment planning in order to deliver progressively more selective and intensive interventions for more socially disabled individuals. This thesis aims to: (1) investigate the prevalence of social disability in a cohort of individuals with FEP; (2) investigate the existence of different social recovery pathways over the first year of early intervention service provision; and (3) examine factors predicting social disability and social recovery in individuals with FEP.

This opening chapter addresses key issues concerning the context in which the research that follows is set. The major concepts of interest – predominantly psychosis, early intervention, social disability, and recovery – are defined, and an overview of theories of recovery and the techniques to be used in this research are discussed. Existing literature investigating predictors of social and functional outcome in psychosis is reviewed, and the importance of addressing social recovery in psychosis is discussed, along with current gaps in the literature. Finally, the research to be conducted is outlined, along with its associated aims.

1.2 Definition of Terms

1.2.1 Psychosis.

Psychosis is a broadly defined concept relating to a set of symptoms which exist across a range of diagnostic categories; including schizophrenia, schizoaffective disorder, and bipolar disorder (Sims, 2002). Psychotic symptoms can also occur outside of these diagnoses in non-clinical populations and secondary psychotic symptoms (i.e. those not occurring from psychiatric conditions) have been found to exist in a range of other disorders, including dementia and in individuals with brain tumours (Cummings, 1988). A psychotic episode is often described as involving a loss of contact with reality (Overall & Gorham, 1962) and this can be taken as a reflection of the level of disruption occurring to an individual's perceptual and thought processes. Characteristic symptoms of psychosis include hallucinations, delusional ideation, and disordered thoughts and speech. In addition, these symptoms are frequently accompanied by impaired social interaction, poor functioning, and a lack of insight (Cassano, Pini, Saettoni, Rucci, & Dell'Oso, 1998; Pini, Cassano, Dell'Oso, & Amador, 2001). However, symptoms of psychosis vary widely from person to person and can change over time. When occurring in conjunction with disorders of mood (i.e. affective psychosis), the content of symptoms is also generally influenced by the nature of the mood (Jones & Bentall, 2006).

Prevalence rates of psychosis vary depending on the diagnostic category under investigation (e.g. schizophrenia, schizoaffective disorder, bipolar disorder, etc). The lifetime prevalence of schizophrenia and bipolar disorder is approximately 0.7-1% (Kendler, Gallagher, Abelson, & Kessler, 1996; Woods, 2000), although individual psychotic symptoms have been found to be present in as much as 10-15% of the general population (Tien, 1991). The incidence of schizophrenia and other psychotic disorders

is highest in late adolescence to early adulthood and at this time point, it is males who are most affected (Riecher et al., 1989). However, the gender distribution of bipolar disorder is more equal (Walden & Grunze, 2004). The incidence of psychosis has been found to be associated with a lower socio-economic status; although it is arguable as to whether this is a cause or an effect of the disorder (Dohrewend et al., 1992). Psychosocial stress is thought to be a prominent trigger factor in psychosis, with numerous studies highlighting an association between trauma, significant life events and the onset of psychosis (Bebbington et al., 1993; Read & Ross, 2003; Ventura, Nuechterlein, Lukoff, & Hardesty, 1989). Social isolation, migration, and victimisation are also thought to be important risk factors (Bebbington et al., 2004; Cantor-Graae & Selten, 2005; Thornicroft, Bisoffi, de Salva, & Tansella, 1993).

1.2.2 First Episode Psychosis and Early Intervention.

First episode psychosis (FEP) is defined as the first time an individual experiences psychotic symptoms or a psychotic episode, where this is diagnosed as a mental health problem as opposed to having an organic cause. Eighty per cent of first episodes of psychosis occur when individuals are between 16 to 30 years of age, a critical time for intellectual and social development and emerging personal autonomy (Shiers & Lester, 2004). The term FEP is usually used after an individual has sought professional help for their psychosis. The time between an individual's first experience of psychotic symptoms and then receiving a diagnosis and treatment is defined as Duration of Untreated Psychosis (DUP). Research suggests that longer DUP is indicative of poorer outcome, both in terms of symptomatic recovery and psychosocial functioning (Norman et al., 2007; Wunderink, Sytema, Nienhuis, & Wiersma, 2009). Such studies are in line with the *critical period hypothesis* which suggests that much of the disability and distress associated with severe psychotic conditions occurs at an early

stage and can be used to predict long-term outcome (Birchwood, Todd, & Jackson, 1998). Thus, intervening during the critical period could have positive long-term effects.

Research into the critical period hypothesis led to the introduction of Early Intervention for Psychosis (EIP) policy (Department of Health, 2001b) and the commissioning of EIP services across the United Kingdom. These services provide targeted phase-specific interventions for people with FEP for a period of up to 3 years. The focus of EIP is on reducing DUP and stabilising individuals in terms of their psychotic episode using antipsychotic medication, case management, and psychological interventions. Other aims include reducing the impact of the psychosis by helping clients maintain their social and occupational contacts during the episode, and the promotion of social recovery in the aftermath of the episode (Birchwood, Fowler, & Jackson, 2002; Marshall, Lockwood, Lewis, & Fiander, 2004).

The efficacy of EIP continues to be examined by researchers. However, there is a growing evidence base that EIP has a positive impact on both symptomatic and functional recovery from psychosis (Fowler, Hodgekins, Howells, et al., 2009; Garety et al., 2006; Petersen et al., 2005; Singh et al., 2007), although much of this evidence is based on service evaluations rather than randomised controlled trials. Research also suggests that service users and their families value the care provided by EIP teams (Lester et al., 2009).

Despite this positive message for EIP, few studies focus directly on social and functional outcomes, with the primary outcome of most studies being symptomatic remission or recovery. Where social and functional outcomes are included, they are usually a secondary outcome and are assessed using a variety of different measures, many of which have not been validated in FEP samples. This makes drawing

conclusions difficult. A recent review of the evidence base underlying EIP highlights the need for more research, including studies focusing on social outcomes and whether initial gains are maintained long term (Marshall & Rathbone, 2011).

1.2.3 Social Disability.

Social disability refers to difficulties with social and occupational functioning (i.e. maintaining friendships, holding down a job), and has been described as a hallmark of severe mental illness (Couture, Penn, & Roberts, 2006). There is a large social cost attached to such disability, with much of the estimated cost of psychosis being due to unemployment and lost productivity (recent estimate £3.4 billion; Mangalore & Knapp, 2007). Much of the research investigating social disability in individuals with psychosis originates from studies of individuals with chronic schizophrenia, with the suggestion that such difficulties are a result of the disease process (Heinrichs, Hanlon, & Carpenter, 1984). However, more recently it has been suggested that social disability may precede the onset of psychosis, with functional impairment being evident in individuals in the prodromal phase (Addington, Penn, Woods, Addington, & Perkins, 2008; Cornblatt et al., 2011; Fowler et al., 2010; Jang et al., 2011). It has been hypothesised that poor functioning may play an important role in determining transition to psychosis, with individuals with Global Assessment of Functioning scores below 50 being at increased risk (Yung et al., 2003). Indeed, social withdrawal has previously been highlighted as a key factor in the development and maintenance of paranoia and other psychotic symptoms (Freeman, 2007; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001).

Individuals experiencing their first episode of psychosis have been found to exhibit social functioning deficits equivalent to patients with a more chronic course of illness (Addington, Young, & Addington, 2003). By the time young people present to services, they have significantly smaller social networks than their peers (MacDonald,

Hayes, & Baglioni, 2000) and almost 50% are already unemployed (Turner et al., 2009). Links have been made between functioning in the early stages of psychosis and long-term symptomatic and functional outcome (Häfner, Löffler, Maurer, Hambrecht, & an der Heiden, 1999). Understanding the factors underlying and contributing to social disability in psychosis will be important in designing interventions to improve outcome. It may be the case that EIP needs to be introduced at an even earlier stage, perhaps at the first signs of functional decline rather than waiting until psychotic symptoms emerge (Fowler et al., 2010).

1.2.4 Recovery from Psychosis.

According to the Oxford English Dictionary (2008), recovery is defined as "a return to a normal state of health, mind, or strength", with the emphasis being placed on an individual's outcome following a period of illness. When considering recovery in these terms, psychosis has traditionally been viewed as a debilitating condition with a poor outcome (Bleuler, 1908; Kraepelin, 1919). However, more recent studies have highlighted the heterogeneous nature of recovery from psychosis (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987; Harrison et al., 2001). A study by Davidson and McGlashan (1997) investigated the different outcomes experienced by individuals with psychotic diagnoses. About one third of patients were shown to experience a "good outcome", involving full remission of symptoms and limited problems with social and occupational functioning. Many other individuals experienced continuing residual symptoms and a relatively high level of social disability, with a smaller proportion of patients suffering repeated episodes of psychosis throughout their lives. However, this literature relates to individuals with chronic psychosis. More positive findings have been by Menezes, Arenovich, and Zipursky (2006) who conducted a review of studies

examining the outcomes of individuals with FEP, and found that 42% of patients had a "good outcome" following their first episode.

Whatever the outcome, experiencing an episode of psychosis can be a very traumatic life event affecting an individual's confidence, self-esteem and functioning (McGorry et al., 1991). The complex nature of recovery from psychosis is reflected heavily in the literature (see Liberman & Kopelowicz, 2002 for a review). Studies generally focus around three main aspects of recovery: symptomatic recovery; emotional and psychological well-being; and social and functional recovery. These will now be discussed in more detail.

1.2.4.1 Symptomatic recovery.

Symptomatic recovery from psychosis can be considered in terms of positive symptom recovery and negative symptom recovery.

1.2.4.1.1 Positive symptom recovery.

Symptomatic recovery from psychosis is defined as the remission of positive symptoms (e.g. hallucinations and delusions), often measured using scores on symptom scales such as the PANSS (Kay, Fiszbein, & Opler, 1987). Symptom remission is an important aspect of the recovery process and often forms the initial phase. This is what McGorry (1992) refers to as recovering from the "primary impairment" of psychosis. Recovery from positive psychotic symptoms is often dependent on an individual's response to medication (Johnstone, Crow, Frith, Carney, & Price, 1978; Kapur & Mamo, 2004), although psychological therapies have also been shown to be efficacious in symptom reduction (Fowler, Garety, & Kuipers, 1995; Kuipers et al., 1997; Morrison et al., 2002; Wykes, Steel, Everitt, & Tarrier, 2008). Estimates vary in the literature, but it is suggested that around 12-52% of individuals make a full symptomatic recovery from an initial episode of psychosis, depending on when it was diagnosed and how it

was treated (Jablensky et al., 1992; Mason et al., 1995; Rosen & Garety, 2005; Shepherd, Watt, Falloon, & Smeeton, 1989; Whitehorn, Lazier, & Kopala, 1998; Wiersma, Nienhuis, Slooff, & Giel, 1998; Wunderink et al., 2009). However, length of follow-up varies between studies and figures do not always take into account the prevalence of relapse.

Symptomatic recovery is proposed to involve a reduction in the frequency and severity of symptoms, combined with a gradual increase in insight and awareness. This may be accompanied by anxiety and depression as the individual begins to come to terms with what has happened to them (Carr, 1983; Drury, 1992; Sacks, Carpenter, & Strauss, 1974). These symptom recovery stages have been supported by research conducted on a sample of 91 individuals following the administration of antipsychotic medication (Mizrahi, Bagby, Zipursky, & Kapur, 2005). In this study, participants reported less cognitive and emotional preoccupation with symptoms shortly after the administration of medication, e.g. the idea or percept "doesn't bother me as much". However, complete resolution of symptoms took longer to achieve. It has been suggested that although antipsychotic medication may dampen the salience of psychotic phenomena, symptoms may require additional psychological deconstruction (Kapur, 2003; van der Gaag, 2006). Moreover even when symptoms have remitted, the emotional and psychological impact of the episode often remains.

1.2.4.1.2 Negative symptom recovery.

Although studied to a lesser extent than positive symptoms, negative symptoms are also important when considering recovery from psychosis. Indeed, 15-20% of individuals diagnosed with psychosis suffer from persistent negative symptoms, and this group typically have poorer treatment response and worse quality of life (Buchanan, 2007). Negative symptoms have been defined as the *deficit syndrome*, i.e. thoughts,

feelings, and behaviours that are absent or diminished as a consequence of mental disorder (Carpenter, Arango, Buchanan, & Kirkpatrick, 1999). In psychosis these include affective blunting (diminished expression of emotion), anhedonia (diminished pleasure), alogia (diminished speech), avolition (diminished motivation), and asociality (diminished interest in interpersonal relationships). Negative symptoms are considered to be a separate entity to other psychotic symptoms and as such are likely to require specific treatment (Kirkpatrick, Fenton, Carpenter, & Marder, 2006).

Negative symptoms have traditionally been viewed as direct manifestations of tissue injury in the brain (Jackson, 1884). This is a view that has been upheld for quite some time, with much research being conducted into the relationship between negative symptoms and neuropsychological functioning (Addington, 2000). Moreover, researchers have been searching for a pharmacological treatment for negative symptoms, but with little success (Buchanan, 2007). In recent years, there has been a move towards a more psychosocial view of negative symptoms (Tarrier, 2006) and the idea that they may represent an individual's response to psychosis, including defeatist beliefs, a manifestation of hopelessness, or a way of coping with difficult experiences (Rector, Beck, & Stolar, 2005). As a result, psychological treatments have been developed to target negative symptoms, including activity-based approaches akin to behavioural activation for depression (Bryson, Lysaker, & Bell, 2002), mindfulness-based interventions (Johnson et al., 2009), and cognitive behavioural therapy (Wykes et al., 2008). When viewing negative symptoms as a consequence of the emotional and psychological impact of the experience of psychosis, it is understandable how they may impact upon an individual's recovery. This is considered in more detail in the next section.

1.2.4.2 Emotional and psychological well-being.

Psychosis has been described as an experience of sheer terror and panic (Forchuk, Jewell, Tweedell, & Steinnagel, 2003). Thus, encountering an episode of psychosis can be considered as a major life event with the potential to impact heavily upon emotional status and evaluative beliefs about self and others (McGorry et al., 1991; Morrison, Frame, & Larkin, 2003). The experience of psychosis can be extremely personally threatening, particularly if the episode involved feelings of persecution (Shaner & Eth, 1989). This in turn can have a wider impact on long-term recovery from psychosis, even when symptoms have subsided (Chadwick, 1997; Fowler, 2002). Studies investigating the emotional and psychological impact of psychosis can be broadly split into two types: those examining the prevalence of emotional and psychological distress in large samples using standardised assessment tools; and smaller qualitative studies describing personal accounts of psychosis.

Social anxiety has been highlighted as a common feature of psychosis, with Social Anxiety Disorder (SAD) present in up to one in three individuals with a diagnosis of schizophrenia (Birchwood et al., 2006). Social anxiety often emerges during the recovery phase and is argued to be reactive to the psychotic episode (Pallanti, Quercieli, & Hollander, 2004). A recent study suggests the presence of typical social anxiety imagery in individuals with FEP (Lockett et al., 2012). Anxiety is hypothesised to contaminate social interaction, thus leading to social withdrawal and poor functioning (Birchwood et al., 2006). Social withdrawal following psychosis is hypothesised to protect the self from the stigmatising views of society (Strauss, 1989). However, this may result in social isolation which can have devastating effects on an individual's self-esteem and in turn lead to increased social withdrawal (Garety et al., 2001). Indeed, there is evidence to suggest that an acute episode of psychosis is often accompanied by

a reduction in social networks (Erickson, Beiser, & Iacono, 1999) which are very rarely replaced (Jackson & Edwards, 1992).

Depression is a further emotional disturbance which has been found to arise in the recovery stages of psychosis. A prospective study of post-psychotic depression (PPD) found that 36% of a group of 115 participants experienced low mood following psychosis (Birchwood, Iqbal, Chadwick, & Trower, 2000). Moreover, PPD has been found to be related to more frequent psychotic relapses, poorer social functioning, and even suicide (Drayton, Birchwood, & Trower, 1998; Power et al., 2003). Inextricably linked with anxiety and depression, low self-esteem and elevated negative beliefs about self have also been highlighted as common in individuals recovering from psychosis (Gumley, O'Grady, Power, & Schwannauer, 2004; Gureje, Harvey, & Herrman, 2004). Furthermore, societal stigma may contribute towards negative beliefs about others (i.e. feelings that other people are hostile), thus producing threat responses and exacerbating residual paranoia (Birchwood, 2003; Trower & Gilbert, 1989).

Emotional disturbance during the recovery stages of psychosis is hypothesised to occur as a result of cognitive appraisals of psychosis, including loss of role, and feelings of hopelessness, shame and stigma (Birchwood, Mason, MacMillan, & Healy, 1993). Birchwood et al. (2006) illustrated that individuals experiencing social anxiety following an episode of psychosis experienced greater shame attached to their diagnosis and also felt more socially marginalised than individuals without social anxiety. These associations remained even when controlling for depression. Estroff (1989) further postulates that social anxiety in schizophrenia may be triggered by loss of social status and stigma. Moreover, PPD is hypothesised to be linked with loss of autonomy and social role, combined with feelings of being entrapped in psychosis (Rooske & Birchwood, 1998). Anthony (1993) elaborates on the concept of loss and suggests that

recovery from the consequences of mental distress can be more difficult than recovery from symptom-related distress itself.

Personal accounts of recovery from psychosis also describe the lack of positive emotion present following an episode of psychosis (e.g. Chadwick, 1997; Deegan, 1997), including disempowerment and a loss of hope with regard to the future (Noordsy et al., 2002). This feeling of hopelessness is often instilled at a very early stage of the illness and is hypothesised to be related to the traditional idea that individuals with psychosis, particularly schizophrenia, will experience an inevitable and progressive downhill course (Corrigan, Giffort, Rashid, Leary, & Okeke, 1999). Overcoming this preconception is one of the main elements of recovery outlined in service user literature, a particular focus of which is the recovery of self-identity and regaining a sense of control and mastery over one's life (Deegan, 1988; Leete, 1989; Lovejoy, 1984; Pitt, Kilbride, Nothard, Welford, & Morrison, 2007; Unzicker, 1989). In a review of this literature, Anthony (1993) defines recovery as "a way of living a satisfying, hopeful, and contributing life even with the limitations caused by mental illness" (p. 14). He also refers to "the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" (p. 14).

With regard to ameliorating anxiety and depression in psychosis, a focus on the emotional impact of the episode and instilling hope for recovery are key features of EIP philosophy (Birchwood et al., 2002). Whilst CBT for psychosis includes strategies for coping with low mood and anxiety, recent studies have examined the efficacy of more targeted interventions with a specific focus on anxiety and depression in individuals with psychosis (Gumley et al., 2006; Power et al., 2003; Turner et al., 2011; van der Gaag, van Oosterhout, Daalman, Sommer, & Korrelboom, 2012). These studies show

positive effects but stress the importance of further research to substantiate their findings.

1.2.4.3 Social and functional recovery.

In a review of the recovery literature, Mueser et al. (2002) suggest that "recovery refers not only to short-term and long-term relief from symptoms, but also to social success and personal accomplishment in areas that the person defines as important" (p. 1273). Thus, social and functional recovery generally refer to the process of getting one's life "back on track" after an episode of psychosis. Traditional psychiatric approaches define this as returning to full or part-time competitive employment or education. However, these definitions are often considered to be too narrow and, in contrast, consumer/survivor models put more emphasis on hope, peer support, meaningful outcomes, and personal experience. Indeed, service user literature suggests that "rebuilding life" and "reconnecting with the environment" are also important aspects of social and functional recovery from psychosis (Chadwick, 1997; Pitt et al., 2007, p. 57).

Despite debate over how it is conceptualised, improvements in functioning and quality of life feature as important components of recovery from both clinical and service user perspectives, irrespective of whether this is accompanied by symptom remission. In a review of service-based definitions of recovery, Lieberman, Kopelowicz, Ventura, and Gutkind (2002) describe "involvement in work and school" and "having friends with whom activities are shared on a regular basis" as important (p. 256). Similarly, user-based definitions include concepts such as "establishment of a fulfilling, meaningful life" and "living a satisfying, hopeful, and contributing life, even with the limitations caused by the illness" (Anthony, 1993, p. 14). The importance of social and functional outcome is also highlighted in the recovery statement of the American

Psychiatric Association (2005), who state that "the concept of recovery emphasises a person's capacity to have hope and lead a meaningful life, and suggests that treatment can be guided by attention to life goals and ambitions".

Although variable, social and functional outcome in psychosis is frequently reported as poor, with long-term follow-up studies suggesting that less than 50% of people with non-affective psychosis achieve a social recovery, and only 10-20% of people return to competitive employment (Harrison, Croudace, Mason, Glazebrook, & Medley, 1996; Jablensky et al., 1992; Johnstone, Macmillan, Frith, Benn, & Crow, 1990), despite the majority suggesting that they wish to work (Mueser, Salyers, & Mueser, 2001). Around 50% of people with bipolar disorder also fail to return to work and remain disabled (Tsai et al., 2001). Thus, many aspects of social functioning are affected by psychosis including employment, relationships and recreational activities (Birchwood, Smith, Cochrane, Wetton, & Copestake, 1990). Recent evidence suggests that EIP may have a positive impact on functional outcome (Fowler, Hodgekins, Howells, et al., 2009), but few studies include this area of recovery as a primary outcome and further research is necessary. The development of interventions targeting social and functional recovery from psychosis is a growing area of research. Current interventions include supported employment (Rinaldi et al., 2010), CBT (Fowler, Hodgekins, Painter, et al., 2009; Hodgekins & Fowler, 2010), and psychosocial interventions (Penn et al., 2011), all of which demonstrate positive results. More research into social disability in psychosis and the process of social recovery would be helpful in both informing intervention development and in identifying the appropriate phase of illness in which to intervene.

1.2.4.4 Summary.

As outlined above, recovery can be defined in a number of different ways, including symptom remission, emotional and psychological wellbeing, and social functioning. Undoubtedly there is an overlap between all of these domains. Indeed, research suggests that increased activity promotes other aspects of recovery via its positive effects of confidence and self-esteem; and potentially provides distraction from persistent or residual symptoms (Waddell & Burton, 2006). Nevertheless, much debate remains over how recovery is conceptualised. Clinical and psychiatric approaches tend to focus on recovery in terms of symptomatic improvement, and return to competitive employment and education; whereas service-user literature puts more emphasis on hope, meaningful outcomes, and personal experience. This difference in viewpoints has resulted in problems in defining the concept of recovery and problems in effectively measuring recovery as an outcome (see section 1.3 for further discussion).

Although functional recovery has been an area of increased interest over the past 20 years due to the Recovery Movement (Anthony, 1993), a focus on social recovery has only been identified as a key and primary aim of mental health policy in the UK within the past decade (Department of Health, 2001a). Social recovery focused interventions are now a key part of EIP services (Department of Health, 2001b). However, much of the literature on social and functional recovery occurred prior to the introduction of the EIP approach and is based on samples of chronic and hospitalised patients. There is thus a need for more research to be conducted into the assessment and process of social recovery from FEP since the implementation of EIP policy. This will be the focus of this thesis.

1.3 Defining and Measuring Social Recovery

One of the difficulties facing research into social recovery from psychosis is the use of appropriate measures to do so. Existing measures for assessing social functioning and recovery have a strong emphasis on work. For example, studies investigating the efficacy of supported employment interventions frequently use days in paid employment as their primary outcome (Mueser et al., 2001). Whilst engagement in full-time competitive work will always represent a key marker of social recovery, it is not the only marker of social improvement. Engagement in other domains of activity, such as education, household chores, voluntary work, and structured social activities, reflect realistic and meaningful recovery goals for many service users and also have wider economic benefits. These activities can have a positive impact on confidence and self-esteem and may be an important precursor to more formal involvement in economic activity such as work or education. In a longitudinal study, Wing and Brown (1970) showed that reduced time spent doing nothing, and increased social contact were the most reliable predictors of improvement in psychosis. However, few social functioning measures for use in psychosis measure daily activity and as such are insensitive to change on these domains.

Quality of life (QoL) measures attempt to tap into a broader range of activities than economic productivity, but these tools are not without their problems. Quality of life is a highly individual concept and QoL scales often fail to capture all aspects of life which are important to the individual (Higginson & Carr, 2001). Moreover, when used in psychosis, some QoL tools have a tendency to assess the impact of negative symptoms and the deficit syndrome, rather than quality of life per se (Heinrichs et al., 1984). A recent study showed that 17% of individuals who were in full-time employment were incorrectly identified as socially disabled using a QoL tool (Lin,

Wood, et al., 2011). Moreover, many QoL tools were developed for individuals with severe and enduring mental health problems. As such, their validity and reliability in FEP samples is unknown. In terms of face validity, some of the items are not relevant for individuals with FEP who do not suffer with the same deficit symptoms as their more chronic counterparts. For example, individuals with FEP may be able to cope with personal care but struggle with social and occupational activities. The need for more meaningful and appropriate outcome measures for recovery has been highlighted by several leading researchers and organisations in the field (Care Services Improvement Partnership, Royal College of Psychiatrists, & Social Care Institute for Excellence, 2007; Liberman et al., 2002; Shepherd, Boardman, & Slade, 2008). Further information about measures of social recovery used in existing studies with FEP samples is provided in section 1.4.2.

1.3.1 Time use as a measure of social disability and recovery.

Time use will be used as an index of social functioning and social recovery in the current study using a modified version of the Time Use Survey (TUS; Fowler, Hodgekins, Painter, et al., 2009; Hodgekins et al., in prep). Assessing how people spend their time is an important way of measuring participation in a range of activities which may have important economic, societal, and personal benefits (International Association for Time Use Research). As well as assessing time spent in employment and education, time use diaries and interviews capture the range of economic production and consumption activities that take place outside of the paid economy (Gershuny, 2011). This is particularly important when considering the increasing value placed on social capital (Putnam, 2000), a key feature of the Government's Big Society plans.

Time use may be a useful measure of social functioning and social recovery in psychosis. Indeed, time spent in structured activity has been associated with increased

mental wellbeing. In a longitudinal study, lower levels of depressive symptoms were exhibited in adolescents engaging in higher levels of structured leisure activities (Fletcher, Nickerson, & Wright, 2003). Psychological benefits have also been identified for young people engaging in extracurricular activities such as volunteering, organised sports, and special interest groups (Eccles & Barber, 1999).

The TUS was originally designed by the Office for National Statistics (ONS) for the UK 2000 Time Use Survey (Short, 2006), a study investigating how members of the general population in the UK spend their time. The modified TUS used in the current study (see Appendix A) consists of a semi-structured interview in which the participant is asked about how they have spent their time over the last month. Activities enquired about include: work, education, voluntary work, leisure, sports, socialising, resting, housework/chores, and childcare. See section 2.3.1.1 for more details about the TUS.

The TUS provides a direct and objective measure of the number of hours an individual is spending in structured activity. This is in contrast to other measures of social functioning for use in psychosis populations, which provide a more subjective assessment of the quality of an individual's life (Barry & Crosby, 1996). A further strength of the TUS is that it has been applied and validated in a normative community sample and thus allows the recovery of individuals with psychosis to be compared with societal norms. This comparative facility is something which is lacking in other outcome measures for psychosis (Liberman et al., 2002). As well as providing an objective outcome from a clinical perspective, time use also links to numerous consumer-defined components of recovery. Indeed, *connection* (i.e. rejoining the social world) and *purpose* (i.e. to have a meaningful role in society) are two key components of the recovery process highlighted in a narrative-based literature review of service user views on recovery (Davidson, 2003). Moreover, Harvey and Bellack (2009) suggest that

when assessing functional outcomes engagement in "everyday activities", including productive activities, residential and self-maintenance activities, and social relationships should be considered (p. 302).

1.4 Predictors of Social Recovery in FEP

A review of the current literature was conducted to explore predictors of social and functional recovery from FEP. This is important in understanding why some individuals remain socially disabled following an episode of psychosis and will inform the research questions outlined in this thesis.

1.4.1 Search strategy.

1.4.1.1 Data sources.

Recent literature (including studies published between 2000 and March 2012) was reviewed. This time period was selected due to EIP policy having been implemented since 2000. Relevant studies were identified by searching computerised databases (Academic Search Elite, Broadsearch, Google Scholar, PsychINFO, Science Direct, Web of Science). Five psychosis-related key terms and synonyms were used: early, first episode, psychosis, schizophrenia, psychotic disorders. These terms were cross-referenced with outcome-related and methodological key terms: outcome, functional, social, recovery, follow-up, longitudinal, cohort, predictors. Further studies were obtained by manual reference examination of published reports and hand searching of recent editions of relevant journals (e.g. Psychological Medicine, Schizophrenia Bulletin, Schizophrenia Research). Searches were restricted to articles from peer-reviewed journals (excluding unpublished theses and conference abstracts) and those printed in the English language.

1.4.1.2 Selection criteria.

The following inclusion criteria were applied to studies:

1. Longitudinal cohort studies recruited from FEP services (i.e. individuals making their first treatment contact for psychotic symptoms). Studies which based their inclusion criteria on first admissions to hospital were excluded unless this was the first treatment contact for psychotic symptoms.
2. Diagnosis must be made using a specified standardised diagnostic system (e.g. DSM, ICD).
3. The study must include a prospective follow-up of at least 12 months and include predictor variables measured at baseline.
4. The primary outcome of the study must be related to functional outcome, including social functioning, quality of life, and engagement in employment/education.

The following exclusion criteria were applied to studies:

1. Studies where the sample included organic aetiology of psychosis.
2. Randomised controlled trials as the primary aim of these studies is to examine the efficacy of an intervention, rather than predictors of outcome.

The search produced an initial pool of 1900 articles, which were reduced using a stepwise approach to screen the study title, abstract, and methods section for inclusion criteria (see Figure 1). This screening process produced a final pool of 15 studies that met inclusion requirements (see Table 1).

1.4.1.3 Evaluation of literature.

Once selected, studies were evaluated using the following criteria:

1. Was the measure of functional recovery reliable and valid in a FEP population?
2. What was the size of the relationship between predictors and outcome? Effect sizes used include Pearson's *r* for correlational studies (small = .1-.23;

medium = .24-.36; large = >.37); Cohen's *d* for between-group studies (small = 0.2; medium = 0.5; large = 0.8); and Cohen's f^2 for studies using multiple regression analyses (small = 0.02; medium = 0.15; large = 0.35).

3. Did the analysis control for other variables which may be associated with outcome?
4. Did the study have adequate power to detect effects?
5. Did the authors account for participants who dropped out of the study between baseline and follow-up assessments?

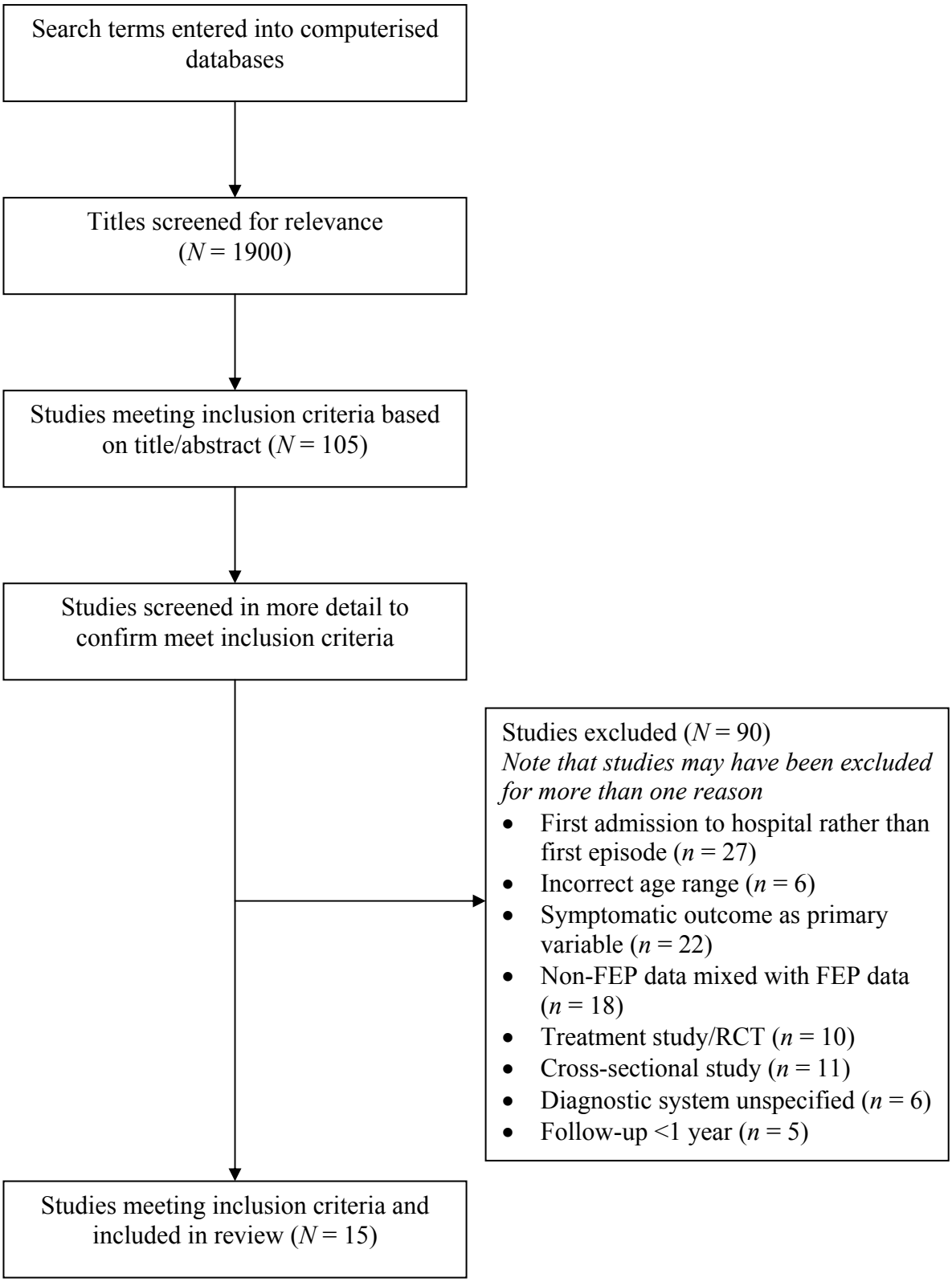

Figure 1

Flow diagram of the process of selecting articles for inclusion in the systematic review

Table 1

Summary of Studies Included in the Systematic Review

Study	Sample[1]	Length of follow-up	Measure of Functional Outcome (Analysis)	Predictor Variables[2]
1. Addington and Addington (2005)	*N* = 194 Recruited from FEP service in Canada (diagnosed using DSM criteria)	2 years	Quality of Life Scale (One-way ANOVA)	Premorbid function (PAS)
2. Barnes et al. (2008)	*N* = 98 Recruited from West London First Episode Psychosis study (diagnosed using DSM criteria)	1 year	Social Functioning Scale (Between-groups t-test)	DUP
3. González-Blanch et al. (2010)	*N* = 131 Recruited from FEP service in Spain (diagnosed using DSM criteria)	1 year	Engagement in part-time work/study (Between groups t-tests followed by logistic regression)	DUP Premorbid function (PAS) Symptoms (SAPS, SANS) Cognition (15 subtests grouped into 4 domains: verbal memory, executive function, motor dexterity, sustained attention)

Table 1 contd.

Study	Sample[1]	Length of follow-up	Measure of Functional Outcome (Analysis)	Predictor Variables[2]
4. Harrigan, McGorry, and Krstev (2003)	*N* = 354 Recruited from FEP service in Australia (diagnosed using DSM criteria)	1 year	Quality of Life Scale (Multiple regression)	DUP Premorbid function (PAS)
5. Keshavan et al. (2003)	*N* = 104 FEP recruited from inpatient/outpatient services (diagnosed using DSM criteria)	2 years	Global Assessment of Functioning (Correlations followed by multiple regression)	DUP Premorbid function (PAS) Cognition (CVLT, WAIS-R, WMS-R, WCST, Trail-making)
6. Leeson, Barnes, Hutton, Ron, and Joyce (2009)	*N* = 54 Recruited from West London First Episode Psychosis study (diagnosed using DSM criteria)	4 years	Social Functioning Scale (Multiple regression)	Cognition (NART, WAIS-R, CANTAB)
7. Lucas, Redoblado-Hodge, Shores, Brennan, and Harris. (2008)	*N* = 52 Recruited from FEP project in Australia (diagnosed using DSM criteria)	3 years	Role Functioning Scale (Correlations followed by multiple regression)	Premorbid function (PAS) Symptoms (PANSS) Cognition (WAIS-III, RCFT, RAVLT, WMS-III, Trail-making, CPT, WCST, COWAT)

Table 1 contd.

Study	Sample[1]	Length of follow-up	Measure of Functional Outcome (Analysis)	Predictor Variables[2]
8. Malla, Norman, Manchanda, and Townsend (2002)	*N* = 66 Recruited from FEP project in Canada (diagnosed using DSM criteria)	1 year	Social Relations and Daily Life Activities subscales of Wisconsin Quality of Life Scale (Correlations followed by multiple regression)	DUP Premorbid function (PAS) Symptoms (SAPS, SANS) Cognition (WAIS-III, NART, WMS-III, WCST, PASAT, CPT, WFT)
9. Meng et al. (2006)	*N* = 56 Recruited from FEP project in Switzerland, Germany, and Austria (diagnosed using DSM criteria)	1 year	Strauss-Carpenter Scale (Correlations followed by multiple regression)	DUP Symptoms (PANSS) Premorbid function (SCS)
10. Milev, Ho, Arndt, and Andreasen (2005)	*N* = 99 Recruited from FEP project in America (diagnosed using DSM criteria)	7 years	Psychiatric Status You Currently Have (Multiple regression)	Symptoms (SAPS, SANS) Cognition (27 subtests grouped into 5 domains: Verbal Memory, Processing Speed and Attention, Language Skills, Visuospatial Skills, Problem Solving)
11. Norman et al. (2007)	*N* = 163 Recruited from FEP service in Canada (diagnosed using DSM criteria)	3 years	Weeks in full-time employment or study over the past year (Correlations followed by multiple regression)	DUP Premorbid function (PAS)

Table 1 contd.

Study	Sample[1]	Length of follow-up	Measure of Functional Outcome (Analysis)	Predictor Variables[2]
12. Saravanan et al. (2010)	*N* = 115 FEP recruited from consecutive first contacts with mental health services in India (diagnosed using DSM criteria)	1 year	Global Assessment of Functioning (Multiple regression)	DUP Symptoms (BPRS) Insight
13. Simonsen et al. (2007)	*N* = 301 Recruited from FEP project in Norway/Denmark (diagnosed using DSM criteria)	1 year	Global Assessment of Functioning (Multiple regression)	DUP Premorbid functioning (PAS)
14. Thompson, McGorry, and Harrigan (2003)	*N* = 196 Recruited from FEP service in Australia (diagnosed using DSM criteria)	1 year	Quality of Life Scale (Multiple regression)	Recovery style

Table 1 contd.

Study	Sample[1]	Length of follow-up	Measure of Functional Outcome (Analysis)	Predictor Variables[2]
15. Yamazawa et al. (2008)	*N* = 34 FEP recruited from consecutive admissions into hospital (diagnosed using ICD criteria)	1 year	Social Functioning Scale (t-tests and correlations)	DUP Premorbid function (PAS) Cognition (Letter Cancellation Test, Word Fluency, Trail-Making, Digit Span)

Note. [1]Sample: FEP = First Episode Psychosis; DSM = Diagnostic and Statistical Manual; ICD = International Classification of Diseases; RDC = Research Diagnostic Criteria

[2]Predictor Variables: BPRS = Brief Psychiatric Rating Scale; CANTAB = Cambridge Neuropsychological Test Automated Battery; COWAT = Controlled Oral Word Association Test; CPT = Continuous Performance Test; CVLT = California Verbal Learning Test; DUP = Duration of Untreated Psychosis; GAF = Global Assessment of Functioning; NART = National Adult Reading Test; NES = Neurological Evaluation Scale; PANSS = Positive and Negative Syndrome Scale; PAS = Premorbid Adjustment Scale; PASAT = Paced Auditory Serial Addition Task; RAVLT = Rey Auditory Verbal Learning Test; RCFT = Rey Complex Figure Test, SADS = Schedule for Affective Disorders and Schizophrenia; SANS = Schedule for the Assessment of Negative Symptoms; SAPS = Schedule for the Assessment of Positive Symptoms; SCS = Strauss-Carpenter Scale; WAIS = Wechsler Adult Intelligence Scale; WCST = Wisconsin Card Sorting Test; WFT = Word Fluency Test; WMS = Wechsler Memory Scale

Table 2

Summary of Findings of Studies Included in the Systematic Review across Measures of Outcome (numbers refer to study numbers shown in Table 1)

Predictor variable	Social Recovery Outcome Measure							
	Global Functioning		Quality of Life		Social Functioning		Vocational Functioning	
	S	NS	S	NS	S	NS	S	NS
Duration of Untreated Psychosis	5, 12, 13	-	4	-	2, 8, 9	15	11	3
Premorbid Functioning	5, 13	-	1, 4	-	7, 8, 9, 15	-	3, 11	-
Psychotic Symptoms								
Positive	-	-	-	-	-	7, 8, 9, 10	-	3
Negative	12	-	-	-	7, 9, 10	8	3	-
Global	12	-	-	-	-	-	-	-
Cognition								
IQ	-	-	-	-	6, 7	8	-	-
Attention & Processing Speed	-	5	-	-	10, 15	6, 7, 8	3	-
Memory	5	-	-	-	8, 10, 15	6, 7	-	3
Executive Function	5	-	-	-	-	6, 7, 8, 10, 15	-	3
Visuospatial Skills	-	-	-	-	-	7, 10	-	-
Motor Skills	-	-	-	-	-	-	-	3
Psychological Factors								
Insight	12	-	-	-	-	-	-	-
Recovery Style	-	-	14	-	-	-	-	-

Note. S = significant; NS = non-significant

1.4.2 Measures of social recovery outcome used in the review.

The 15 studies included in this review used different tools to assess functional outcome. These will now be discussed in more detail, focusing in particular on whether they are appropriate for use in a FEP sample.

1.4.2.1 Global assessment of functioning.

Three studies used the Global Assessment of Functioning Scale (GAF; Spitzer, Williams, Gibbon, & First, 1995) to assess overall psychological, social, and occupational functioning. The GAF is a clinician-rated scale (1 to 100), with higher scores indicating superior functioning and scores below 50 indicating serious distress and dysfunction. Inter-rater reliability in psychotic samples has been reported as r = .80-.90 (Startup, Jackson, & Bendix, 2002). Despite being quick to administer and a commonly used outcome tool in research studies, the GAF has been criticised for its lack of ecological validity (Mausbach, Moore, Bowie, Cardenas, & Patterson, 2009). In addition, GAF categories often relate to the impact of symptoms on functioning, rather than focusing on activities individuals are able to do irrespective of their symptoms.

1.4.2.2 Quality of life.

Three studies used the Quality of Life Scale (QLS; Heinrichs et al., 1984). The QLS is a 21-item semi-structured interview designed to assess functional impairments associated with psychosis. It consists of four categories rated on a 6-point scale: Intrapsychic Foundations (e.g. sense of purpose, motivation), Interpersonal Relations (e.g. social contacts); Instrumental Role Functioning (e.g. employment, accomplishment), and Common Objects and Activities (e.g. participation in regular activity). Higher scores relate to increased quality of life. Although the scale is commonly used and has good psychometric properties (Cramer et al., 2000), it was originally designed for more chronic samples. As a result, its validity for use in FEP

samples is unknown. Moreover, research on the validity of quality of life as an outcome measure suggests it is a very subjective concept, with little correlation between self and observer ratings (Priebe, 2007). This needs to be taken into account when considering studies using these measures.

1.4.2.3 Social functioning.

Seven studies used social functioning as a measure of outcome. Social functioning relates to an individual's ability to interact within their society, including engagement in social relationships, and completion of activities of daily living. Three studies used the Social Functioning Scale (Birchwood et al., 1990), a 79-item self-report scale designed to assess global social functioning. The scale comprises lists of activities which respondents tick according to frequency of occurrence. As such, it is more inclusive than other functional outcome measures, and includes activities which may be more relevant to individuals with FEP. The SFS has been shown to be reliable, valid, and sensitive to change (Birchwood et al., 1990) and has been used successfully in FEP samples (Voges & Addington, 2005).

Other measures of social functioning include the Social Functioning subscale of the Strauss-Carpenter Scale (SCS; Strauss & Carpenter, 1972); the Social Relations and Activities of Daily Living subscales of the Wisconsin Quality of Life Scale (WQOL; Becker, Diamond, & Sainfort, 1993); the Psychiatric Status You Currently Have scale (PSYCH; Andreasen, 1989); and the Role Functioning Scale (RFS; Goodman, Sewell, Cooley, & Leavitt, 1993). All of these measures have good psychometric properties but were designed to assess functioning in individuals with severe and persistent mental illness and therefore may not be as relevant for individuals with FEP.

1.4.2.4 Vocational functioning.

Two studies used measures of vocational functioning to assess outcome. One study used a categorical approach to assess engagement in part- or full-time work or education, and another assessed weeks over the 1-year follow-up period that an individual was engaged in full-time employment or study (Norman et al., 2007). Although these measures are limited in the range of activities they assess, they could be argued to be more objective and therefore more reliable than other outcome tools. Moreover, vocational outcomes are commonly used in FEP studies, due to the increasing emphasis on vocational interventions in EIP services (International First Episode Vocational Recovery Group, 2010).

1.4.3 Predictors of outcome identified by the review.

Predictors of outcome identified by the review will now be discussed. See Table 2 for a summary of study findings across different measures of outcome.

1.4.3.1 Duration of untreated psychosis (DUP).

DUP is the length of time between an individual first experiencing psychotic symptoms and receiving treatment for those symptoms. Ten studies examined the effect of DUP on outcome, with mean DUP ranging from 26 to 185 weeks across studies. DUP varied in the way that it was assessed across studies, with some studies accounting for the prodromal phase (Keshavan et al., 2003) and others only measuring the onset of diagnosable psychotic symptoms. This accounts for the wide range in DUP length across studies but makes comparison between studies difficult.

Eight studies found that longer DUP was associated with poorer functional outcome at 1-, 2-, and 4-year follow-up, with effect sizes ranging from r = .23-.34. Seven studies used multiple regression analyses to examine whether DUP remained a significant predictor of outcome when controlling for other variables, including

psychotic symptoms, premorbid adjustment, cognitive function, and demographic characteristics. DUP remained a significant independent predictor in five of these studies, with effect sizes ranging from f^2 = 0.05-0.10 for the addition of DUP into stepwise regression models, and DUP accounting for approximately 5-6% of the variance in outcome. The one study where DUP did not remain a significant predictor (Malla, Norman et al., 2002) was only powered to detect large effects and thus this could be a type II error.

González-Blanch et al. (2010) reported no significant difference in DUP between individuals who had and had not achieved functional recovery at 1-year follow-up. Similarly, Yamazawa et al. (2008) found no significant difference in GAF or global SFS scores at 1-year follow-up between individuals with long and short DUP. However, both of these studies lacked the power to detect small effects. In addition, Yamazawa et al. (2008) do not provide an adequate description of how DUP was assessed; simply stating that a best estimate approach was used.

When taken together, these findings suggest that DUP is an important contributing factor when predicting poor functional outcome from psychosis, although the amount of independent variance it explains is relatively small and thus it should be considered in combination with other factors. Moreover, several studies had attrition rates as high as 30% (Harrigan et al., 2003; Keshavan et al., 2003; Malla, Norman, et al., 2002). This may be taken to suggest that there was a bias in the sample followed-up. However, some studies compared completers with non-completers and found no difference in baseline characteristics (Harrigan et al., 2003).

1.4.3.2 Premorbid functioning.

Assessments of premorbid functioning provide an indication of social, interpersonal, school, and work functioning in the period prior to the onset of psychotic

symptoms. Some argue that poor premorbid functioning is an early manifestation of psychotic illness (Häfner, Nowotny, Löffler, An der Heiden, & Maurer, 1995). Ten studies examined the effect of premorbid functioning on outcome. The majority of studies used the Premorbid Adjustment Scale (PAS; Cannon-Spoor, Potkin, & Wyatt, 1982) to assess social and academic functioning in childhood and adolescence. In all studies, better premorbid functioning was associated with improved functional outcome at 1-, 2-, 3- and 4-year follow-up, with effect sizes ranging from r = .38-.64 in correlational studies, and d = 0.54-1.06 in studies comparing groups with good and poor outcomes (Addington & Addington, 2005; González-Blanch et al., 2010; Yamazawa et al., 2008). Seven studies used hierarchical multiple regression analyses to examine whether premorbid functioning remained a significant predictor of outcome when controlling for other variables, including psychotic symptoms, DUP, cognitive function, and demographic characteristics. Premorbid functioning remained a significant predictor in all but two studies (Keshavan et al., 2003; Norman et al., 2007), with effect sizes ranging from f^2 = 0.11-0.27, and premorbid functioning explaining 10-17% of the variance in outcome.

The stability of findings across studies using different outcome measures and different follow-up periods suggests that premorbid functioning is an important predictor of functional outcome. However, methodological limitations of the studies reviewed need to be considered. Keshavan et al. (2003) only assessed premorbid functioning in a subsample of participants (n = 48), thus reducing the power of the study. Moreover, studies varied in whether they included childhood or adolescent premorbid functioning in their analyses, and thus it is unclear which aspects of premorbid function are particularly important. Simonsen et al. (2007) looked at each type of premorbid function separately and found that both poorer functioning in both

childhood and adolescence predicted poorer social recovery. Conversely, Lucas et al. (2008) highlighted premorbid function in adolescence as a significant predictor of outcome, although this study was only powered to detect large effects. Further studies are needed to examine this in more detail.

1.4.3.3 Psychotic symptoms.

Six studies examined the effect of baseline psychotic symptom severity on outcome. Psychotic symptoms were assessed using a range of measures, including the Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987), the Schedule for the Assessment of Positive Symptoms (SAPS; Andreasen, 1984), the Schedule for the Assessment of Negative Symptoms (SANS; Andreasen, 1981), and the Brief Psychiatric Rating Scale (BPRS; Overall & Gorham, 1962). Of the six studies, none found positive symptoms to be a specific predictor of functional outcome, although one study highlighted reductions in global symptoms over the first 6 months (assessed using the BPRS) as a significant predictor of improved GAF scores at 1-year follow-up (Saravanan et al., 2010). However, it should be noted that the GAF assesses the impact of symptoms on functioning and thus there is some overlap with constructs assessed by the BPRS.

Negative symptoms were found to be associated with functional outcome in five studies, with lower levels of negative symptoms at baseline being associated with better outcome at 1-, 4-, and 7-year follow-up, across different outcome measures. In addition, individuals defined as having made a functional recovery at 1-year follow-up had significantly lower scores on the SANS at baseline than individuals defined as having functional deficits at 1-year follow-up (d = 0.67; González-Blanch et al., 2010). All studies used multiple regression models and found that negative symptoms remained a predictor of outcome even when controlling for demographic variables and cognitive

function, with effect sizes of models including negative symptoms ranging from f^2 = 0.38-0.62. Only one study investigated the independent contribution of negative symptoms, suggesting they accounted for 11% of the variance in outcome at 7-year follow-up (Milev et al., 2005).

1.4.3.4 Cognition.

Seven studies examined the effect of cognition on outcome. All studies found baseline neuropsychological functioning to be associated with later functional outcome (r = .21-.75), although domains of cognition highlighted as predictors varied between studies. Three studies found that increased scores on tests of attention were associated with better outcome at 1-, 2-, and 7-year follow-up, with medium effect sizes (d = 0.55, r = .46) and attention explaining 7.2% of the variance in outcome. Increased verbal and working memory were also highlighted as predictors of improved 1-, 2-, and 7-year outcome in four studies, explaining 6-10% of the variance in GAF and social functioning scores, when controlling for premorbid function and symptoms. Only one study highlighted executive function as a predictor of outcome, explaining 8% of the variance in GAF scores at 1-year follow-up (Keshavan et al., 2003). None of the studies found motor or visuospatial skills to predict outcome.

Three studies examined general cognitive ability in contrast to performance on specific domains. Leeson et al. (2009) assessed 54 individuals with FEP using a full battery of neuropsychological tests, including an estimate of premorbid IQ using the National Adult Reading Test (NART). Following a multiple regression analysis, the results suggested that general IQ scores were a better predictor of global SFS scores at 4-year follow-up than measures of specific ability, accounting for 12% of the variance, although the effects of symptoms and premorbid function were not controlled for. In a stepwise regression, higher baseline scores on the verbal comprehension index of the

WAIS-III were also found to be predictive of better functioning at 3-year follow-up (f^2 = 0.19; Lucas et al, 2008). However, in another study, working memory was found to be a better predictor of social functioning at 1-year follow-up than baseline NART scores (Malla, Norman, et al., 2002).

It is important to consider that studies used different tools to assess cognitive function (see Table 1), with some using individual test scores in the analyses (e.g. Keshavan et al., 2003; Leeson et al., 2009), and others grouping tests into factor scores (González-Blanch et al., 2010; Milev et al., 2005). Thus comparability of findings is somewhat limited. In addition, many of the studies used large batteries, increasing the number of predictor variables. As a result, studies with sample sizes of less than 100 participants did not have adequate power to detect small or moderate effects. Not all studies reported medication levels or considered their potential influence on cognitive function (Keshavan et al., 2003; Malla, Norman, et al., 2002). However, Milev et al. (2005) compared individuals who had been prescribed medication and those who were neuroleptic naïve and found no difference in neuropsychological function. A further methodological consideration is the time of testing. The majority of studies conducted neuropsychological tests following stabilisation of psychotic symptoms. However, Keshavan et al. (2003) assessed participants during the acute episode, which may have affected the findings.

1.4.3.5 Psychological factors.

Out of the 15 studies, only two examined the effect of psychological factors on functional outcome. One study examined the effect of insight (Saravanan et al., 2010) and found that improvements in insight over the first 6 months post-episode, predicted improvements in functioning at 1-year follow-up on the GAF, when controlling for DUP and symptoms. The Schedule for the Assessment of Insight (SAI; David,

Buchanan, Reed, & Almeida, 1992) assesses awareness of illness, relabeling, and compliance; suggesting that changes in an individual's beliefs about their illness may have a positive effect on outcome. However, it must be remembered that this study was conducted on a sample in India, using translated versions of measures. Therefore the findings may not be generalisable to other countries and further research is warranted.

Thompson et al. (2003) examined the effect of recovery style on outcome, using the Recovery Style Questionnaire (Drayton et al., 1998), and found that recovery style at baseline explained 12% of QLS outcome variance at 1-year follow-up, after controlling for premorbid functioning. Individuals with a sealing over (avoidant) recovery style had a worse outcome than individuals with an integrated (accepting) recovery style, suggesting that incorporating psychosis into wider life experience and being accepting of oneself, may promote better recovery. As this is the only study which investigated recovery style and functional outcome, further research is needed. However, an integrative recovery style has since been associated with an increased likelihood of remission in individuals with schizophrenia spectrum disorders (Staring, van der Gaag, & Mulder, 2011).

1.4.4 Summary of findings from literature review.

The studies discussed in this review suggest that important predictors of functional outcome following an episode of psychosis include DUP, premorbid functioning, and neuropsychological performance (specifically premorbid IQ, attention, and memory). These findings are broadly consistent across different outcome measures and different lengths of follow-up. This suggests that some characteristics are stable and may be used in the early identification of individuals at risk of poor functional outcome. In addition, negative symptoms and psychological variables such as insight and recovery style have also been indicated as important considerations when predicting

outcome. Such factors may be amenable to change using psychological interventions. However, research in this area is currently limited due to the use of varied and sometimes inappropriate tools to assess functional outcome. Moreover, although several factors have been highlighted as predictors of outcome, the relative contribution of each variable remains unclear as few studies have examined the contribution of all variables in the same sample. Thus, further research is necessary in order to substantiate these findings. This is a focus of the current study.

1.5 Psychological Models of Social Recovery

Based on the above literature review, it is likely that social recovery following an episode of psychosis is influenced by many factors, occurring both before and after the onset of psychosis. A combination of these factors may be useful in formulating why some individuals experience delayed social recovery whilst others do not.

1.5.1 Pre-onset factors.

Retrospective studies of psychosis suggest that social decline occurs long before the emergence, detection, and treatment of psychotic symptoms (Häfner et al., 1999). Thus, early difficulties with functioning and relationships may be a key indicator of long-term social disability. Prospective longitudinal studies suggest that a longer DUP and problems with premorbid adjustment are significant independent predictors of poor functional outcome following FEP (Harrigan et al., 2003; Malla, Norman, et al., 2002). Neuropsychological deficits – specifically premorbid IQ, attention, and memory – have also been found to predict outcome (Leeson et al., 2009; Lucas et al., 2008). Such research suggests that even prior to the onset of frank psychotic symptoms; individuals may already be faced with numerous barriers to functional recovery.

The mechanism by which these pre-onset factors influence outcome is unclear. It has been suggested that DUP may impact upon outcome due to the toxic effect of

untreated psychosis on underlying neurological and psychological processes (Marshall et al., 2005), although much of the research into DUP has focused on its impact on psychotic symptomatology. Premorbid adjustment difficulties have been hypothesised to be indicative of a disruption to the normal developmental processes occurring during childhood and adolescence, resulting in a heightened vulnerability and/or reduced resilience (Häfner et al., 1995; Harrop & Trower, 2001). Gumley and Schwannauer (2006) suggest that this may influence both how an individual responds and adapts to psychosis, and how well they engage with treatment. Poor premorbid adjustment has also been linked to a course of psychosis characterised by greater severity of negative symptoms, which have been linked with poor outcome (MacBeth & Gumley, 2008). Finally, it has been proposed that neuropsychological deficits may influence functional recovery due to the direct impact of such deficits on the adaptive skills required for social and occupational functioning, e.g. social cognition, planning, and problem-solving (Green, 1996). However, further research is required to fully understand the mechanism by which poor social and functional outcome occurs and to understand how different predictors of outcome may interact.

1.5.2 Post-onset factors.

From a psychological perspective, mental illness has long been known to have an important and profound effect on an individual's identity and sense of self. Indeed, the emotional and psychological impact of psychosis has already been outlined in section 1.2.4.2. In particular, psychosis has been associated with feelings of shame which have been hypothesised to be linked to the development of social anxiety and depression (Birchwood et al., 2006). The experience of psychotic symptoms is often traumatic and can sometimes result in trauma-related phenomena, including flashbacks and emotional disturbance (McGorry et al., 1991). This can lead to what Gumley,

Schwannauer, MacBeth, and Read (2008) describe as "thwarted recovery" where the individual becomes very distressed and preoccupied with what has happened to them. The recovery model (Anthony, 1993; Warner, 2009) suggests that, in order to achieve recovery from severe mental illness, an individual must be able to make meaning from their experiences and maintain a hopeful and optimistic stance. Social inclusion, self-determination, supportive relationships, and positive coping strategies are all hypothesised to be important factors in promoting recovery (Anthony, 1993; Repper & Perkins, 2006; Sayce, 2001; Sells, Stayner, & Davidson, 2004). In addition, two recent prospective longitudinal studies have highlighted increased insight and an integrative recovery style as significant predictors of improved functional outcome following FEP (Saravanan et al., 2010; Thompson et al., 2003). External societal factors have also been hypothesised to be important, including the availability of roles in education and work within the local labour market (Warner, 1985). Local economic factors, government policy, and individual variations in cultural values may also affect social recovery. It is likely that these relationships are mediated by societal effects on personal psychological factors, such as feelings of stigmatisation, beliefs about self and others, and the experience of social anxiety.

1.6 Recovery: A Homogeneous or Heterogeneous Construct?

As outlined by outcome studies, some individuals make a good functional recovery from psychosis whereas others do not (Menezes et al., 2006). However, recovery from FEP currently tends to be treated as a homogenous construct, with research investigating predictors of outcome using group means on measures of functioning, or by comparing FEP samples with non-clinical comparison groups. Rather than all individuals developing and responding to psychosis in the same way, it is arguably more likely that cohorts of individuals with FEP are heterogeneous, consisting

of subgroups with different baseline levels of social disability and different recovery pathways. Moreover, predictor variables may influence these different subgroups in different ways. Identifying who recovers and who doesn't, as well as factors underlying different patterns of recovery, will be important in developing and implementing targeted recovery-focused interventions.

The notion of heterogeneous outcome has long been applied to symptomatic recovery from psychosis, with early studies identifying subgroups of individuals with different symptom recovery profiles, e.g. full recovery vs. treatment resistant psychosis (Strauss & Carpenter, 1977). Moreover, predictors of different types of symptomatic outcome have also been examined (Barnes & Durson, 2005), as well as targeted interventions (Garety et al., 2008). However, this approach has not yet been applied to functional outcomes. This is the aim of the current study. The typology of social recovery profiles will be examined using different cut-off scores on the TUS to define subtypes of social disability and recovery in a large cohort of individuals with FEP. In addition to this, latent class growth analysis (LCGA) will be applied to longitudinal data to examine different recovery trajectories. Before the aims of the study are outlined, the concept of LCGA will be introduced along with a review of other studies which have utilised this approach.

1.7 Latent Class Growth Analysis

LCGA is a statistical approach for identifying homogeneous subgroups – or latent classes – in larger, more heterogeneous samples. Thus it is an ideal approach for use in the current study. According to Jung and Wickrama (2008), the goal is to "classify individuals into distinct groups or categories based on individual response patterns so that individuals within a group are more similar than individuals between groups" (p. 303). The approach was developed in response to conventional methods of

analysing longitudinal data, which assume that individuals come from a single population and that predictor variables influence each member of the population in the same way. In contrast, many theoretical frameworks often categorise individuals into distinctive subpopulations (e.g. socioeconomic classes, age groups, etc) rather than referring to the population as a whole. Moreover, it is not always expected that all individuals in a given sample will change in the same direction across time (Raudenbush, 2001). Thus, for analyses in which the presence of subgroups is anticipated or the direction of change is expected to vary between individuals, LCGA is deemed more appropriate. LCGA has been applied in some studies in the field of mental health, including investigations into psychotic symptoms. These studies will now be reviewed.

1.7.1 Development of psychotic symptoms.

Three studies have examined the development of psychotic symptoms in large samples of adolescents recruited from the general population. Mackie, Castellanos-Ryan, and Conrod (2011) collected data on self-reported psychotic-like experiences (PLEs) in a group of 409 adolescents, recruited from London secondary schools, who scored high on four personality risk factors (hopelessness, anxiety-sensitivity, impulsivity, and sensation-seeking). Participants were assessed at 6 month intervals over a 2 year period. Using general growth mixture modelling (GGMM) – a variant of LCGA – three developmental classes of PLEs were identified: a "persistent" class (9%) who reported high levels of PLEs across the four time points; an "increasing" class (7%), who reported increasing levels of PLEs as the study progressed; and a "low" class (84%), who reported consistently low levels of PLEs throughout the study. The three classes were compared on demographic variables and environmental risk factors. There were no differences in gender or ethnicity between the three classes. However, the

persistent class scored higher on baseline measures of anxiety and depression, and reported more frequent victimisation than the low class. Adolescents in the increasing class showed increasing levels of cannabis use in line with increases in reported PLEs. These findings are taken to support the psychosis-proneness-persistence model (Cougnard et al., 2007) which suggests that environmental risk factors interact with vulnerability to psychosis, resulting in the persistence of psychotic symptoms.

Whilst the above study assessed individuals who may be at risk of experiencing psychotic symptoms due to personality traits, other studies have focused on more heterogeneous general population samples. Wigman et al. (2011) recruited a cohort of 2230 Dutch young people aged 10-11 years and assessed them three times over a period of 6 years on a range of measures, including thought problems on the Youth Self Report (Achenbach, 1991b) and the Child Behavior Checklist (Achenbach, 1991a) as an index of PLEs. Four developmental trajectories of PLEs were identified in the data. Similar to the analyses by Mackie et al. (2011), these included: a "low" class (82%), a "decreasing" class (9%), an "increasing" class (7%), and a "persistent" (2%) class. The persistent class was associated with cannabis use, childhood trauma, developmental problems, and ethnic minority status. Members of the persistent class were also more distressed by their experiences and were engaged in higher levels of mental health care at the end of the study compared to other individuals in other trajectories.

Similar to Wigman et al. (2011), Lin et al. (2011) conducted a longitudinal cohort study of 813 Australian 15-year olds over a 3 year period, assessing the presence of positive psychotic experiences using the Community Assessment of Psychic Experiences (Konings, Bak, Hanssen, van Os, & Krabbendam, 2006). Four latent classes were identified within the wider sample, including a "low" class (71%), a "moderate decreasing" class (24%), a "strong decreasing" class (4%), and a "persistent"

class (1%). Although this is broadly similar to the two studies outlined above, Lin et al. (2011) did not identify an increasing class within their sample. The four subgroups were compared on measures of coping, with the persistent class showing higher levels of emotion-focused coping (i.e. worry) than the other three classes, whereas individuals whose psychotic symptoms decreased exhibited higher levels of more adaptive task-focused coping (i.e. talking to someone). The authors suggest that a maladaptive coping style may interact with the presence of psychotic symptomatology to create a vicious cycle, leading to the persistence of psychotic symptoms. They propose that introducing more helpful ways of coping with psychotic symptoms and life events may be an important focus of EIP.

All three studies highlight consistent developmental trajectories of psychotic symptoms in adolescent populations and suggest that the majority of adolescents experience very low levels of psychotic symptoms. However, a significant minority experience either decreasing, increasing, or persistent patterns of symptomatology, associated with greater psychopathology (e.g. anxiety, depression) and an increased frequency of environmental risk factors (e.g. substance use, trauma). These studies suggest that it is the developmental trajectory, and particularly the persistence of psychotic symptoms, rather than their presence at one point in time, which may predict transition to a diagnosis of psychotic disorder. Thus, longitudinal studies of this type add an important dimension to the literature and can answer more complex research questions than cross-sectional designs. Indeed, it has previously been argued that cross-sectional designs do not adequately capture the fluctuating nature of psychopathology (Tschacher, Scheier, & Hashimoto, 1997). However, the longitudinal studies outlined above focus on symptom rather than functional trajectories, and on events and experiences occurring prior to the onset of psychosis. More research is needed to

examine the development and persistence of functional impairment over time, both before and after the onset of psychosis.

1.7.2 Trajectories of recovery following the onset of psychosis.

Peer and Spaulding (2007) used growth mixture modelling to examine heterogeneity in psychosocial functioning during psychiatric rehabilitation. One hundred and fifty-two inpatients with diagnosed schizophrenia spectrum disorders were followed up over the first 18 months of a psychiatric rehabilitation program. Psychosocial functioning was assessed monthly using clinical observations and ratings of an individual's functioning on the ward over six domains (daily schedule competence, social interest, neatness, irritability, psychoticism, and motor retardation). The analysis identified two latent classes: a "higher psychosocial functioning" class (67%) and a "lower psychosocial functioning" class (33%). The two subgroups were compared on baseline variables using t-tests. This revealed that the lower class had had significantly more hospital admissions prior to engaging with the rehabilitation program. They also had a younger age of onset, more negative symptoms, and poorer baseline neuropsychological performance than the high functioning group. The finding that baseline variables predicted later outcome is important, suggesting that individuals at risk of social disability could be highlighted at an early stage.

Whilst informative, Peer and Spaulding's study focused on a chronic and treatment resistant sample, and thus is not necessarily representative of the wider population of individuals with psychosis. Indeed, the mean length of illness of participants in the study was approximately 20 years. Moreover, the rehabilitation program under investigation was based on social learning principles, i.e. using positive reinforcement strategies when patients exhibit rehabilitative behaviours. This approach is quite different to early intervention strategies which are more ecologically valid,

taking place within the individual's own community. In addition, the assessment of functioning is based on behavioural observations and will be restricted by the nature of the inpatient environment. There is a need for a similar study to be conducted in a FEP sample to examine whether comparable findings emerge.

1.7.3 Summary.

In all of the studies outlined above, each heterogeneous cohort was found to be made up of homogenous subgroups. Persistence of symptomatology appeared to be important in predicting poor long-term outcome. In addition, variables assessed at baseline (e.g. trauma, developmental problems) were often predictive of outcome, suggesting that it may be possible to identify individuals at risk of poor long-term outcome at an early stage. The majority of studies using the LCGA approach within the field of mental health have focused on symptom trajectories. The focus of this study is to examine trajectories of social functioning over time using the TUS, and to investigate potential predictors of trajectory membership using baseline variables. Detecting individuals who may be at risk of long-term social disability will be important in providing targeted interventions to aid social recovery.

1.8 Summary of Literature and Rationale for Further Research

Psychosis has a profound effect on an individual's social and occupational functioning. Although social and functional recovery from psychosis is more promising since the advent of EIP services, a significant proportion of individuals remain socially disabled following FEP (Menezes et al., 2006). Problems with measuring social and functional recovery lead to variation in the rates of social disability and recovery reported within the literature. Indeed, measures of social functioning are often confounded with psychotic symptoms and most were designed for use with individuals with chronic schizophrenia, rather than those in the early stages of psychosis. Further

research is needed using a more valid and accurate assessment of functioning to examine the frequency of social disability in individuals presenting to EIP services, as well as rates and patterns of social recovery over time.

Factors predicting social disability and social recovery in FEP have been discussed in this chapter, including factors occurring both before and after the onset of psychosis. However, as outlined above, studies investigating predictors of recovery use measures of social functioning which are not appropriate within this client group. Moreover, current research focuses on cohorts of individuals with FEP as homogeneous as opposed to heterogeneous samples. It may be the case that FEP is more of an umbrella category, made up of distinct subgroups with different baseline levels of social disability as well as different longitudinal patterns of social recovery. This thesis will examine this concept in more detail, attempting to identify such subgroups, as well factors predicting membership to subgroups with poor longitudinal patterns of social recovery. This will be important in identifying individuals who may be at risk of long-term social disability and thus in developing targeted preventative interventions.

1.9 Research Questions

1. What is the frequency of social disability, defined using weekly hours engaged in structured activity, in individuals with FEP presenting to EIP services across the UK?
2. Which factors predict baseline levels of social disability in FEP?
3. How many individuals with FEP experience a change in their weekly hours of structured activity in the first 12 months of Early Intervention service provision?
4. Which factors predict change in time use over the first 12 months of EIP service provision?

5. How many individuals with FEP make a good social recovery in the first 12 months of EIP service provision and how many remain socially disabled?
6. Which factors predict whether an individual makes a social recovery in the first 12 months of EIP service provision following FEP?
7. Do different trajectories of social recovery exist in the first 12 months following FEP? Which factors predict different recovery trajectories?

CHAPTER TWO

2. Method

2.1 Design

The study was of longitudinal design, with one group of participants assessed at three time points: at baseline upon entry into the project and again at 6- and 12-month follow-up. This design is appropriate for the research questions which investigate the frequency of social disability in FEP; whether there are different patterns of social recovery over time; and which variables predict social disability and recovery.

Social recovery was assessed at all three time points using the Time Use Survey (TUS) to measure weekly hours in structured activity (the rationale for choosing this measure over more traditional assessment tools was discussed in section 1.3.1). Predictor variables were assessed at baseline only. Baseline levels of social disability were defined using cut-off scores on the TUS, defined by comparing clinical and non-clinical samples using the Jacobson, Folette, and Revenstorf (1984) formula for clinically significant change, and Receiver Operating Characteristic (ROC) curves. Change in time use over a 12 month period of early intervention was then examined. Subgroups of individuals with different patterns or trajectories of social recovery were identified within the larger sample using two approaches: transition between clinical and non-clinical cut-off scores on the TUS; and trajectories of social recovery defined using latent class growth analysis (LCGA). Differences between the subgroups on baseline variables were examined using Analysis of Variance (ANOVA). Ordinal and multinomial regression analyses were conducted to examine which baseline variables predicted baseline social disability and longitudinal patterns of social recovery.

2.2 Participants

2.2.1 Sample.

Data from individuals participating in an existing project, the National EDEN study, were used in the current study. A description of the National EDEN study is provided below before focusing on the sample included in the current study. For more information see Birchwood et al. (submitted).

2.2.1.1 National EDEN.

National EDEN is a national evaluation of EIP services across the UK (services in: Birmingham, Norwich, Cambridge, Cornwall, Bristol, and Lancashire), funded by the Department of Health (Birchwood et al., submitted). The aim of National EDEN was to evaluate the implementation, effectiveness, and cost-effectiveness of the first 12 months of care provided by EIP services in the UK. Consecutive patients accepted into each EIP service from August 2005 to April 2009 were approached and invited to take part in the study. Recruitment into each EIP service, and thus inclusion criteria for the study, corresponded to criteria laid out in the EIP service specification defined by the Department of Health (2001b). These criteria included: the presence of a first episode of non-affective psychosis conforming to ICD-10 diagnostic categories F20-29; a presenting age of between 14 to 35 years; and no prior receipt of drug treatment for psychosis. There were no specific exclusion criteria. One thousand nine hundred and fifty-two young people with psychosis entered EIP services over the period of recruitment into National EDEN. Of these, 1027 people (53%) gave informed consent to participate in the study and were assessed at baseline. Eight hundred and twenty-five participants (80%) were reassessed at the 6-month follow-up, and 788 participants (77%) were reassessed at the 12-month follow-up. A breakdown of recruitment and follow-up rates for each EIP service is shown in Table 3.

Table 3

Recruitment and Follow-up Rates into the National EDEN Study by Site – N (%)

	Total accepted into EIP service	Consented into National EDEN	6 month follow-up	12 month follow-up
Birmingham and Solihull	580	348 (60%)	252 (72%)	252 (72%)
Lancashire and Wirral	629	254 (40%)	205 (81%)	194 (76%)
Norwich and King's Lynn	316	170 (54%)	141 (83%)	135 (79%)
Cambridge and Peterborough	220	129 (59%)	103 (80%)	93 (72%)
Cornwall	207	126 (61%)	124 (98%)	117 (93%)
Total	1952	1027 (53%)	825 (80%)	791 (77%)

2.2.1.2 Current study sample.

Individuals included in the current study were participants in the National EDEN study who completed the Time Use Survey (TUS) at baseline. This consisted of a subsample of 878 participants, 85% of the total National EDEN sample. Participants who completed the TUS at baseline did not differ from participants who did not complete the TUS in terms of age of onset of psychosis, diagnosis, DUP, gender, ethnicity, and work status (see Table 4). Of the 878 participants completing the TUS at baseline, 673 (77%) completed the TUS at 6 month follow-up and 623 (71%) completed the TUS at 12 month follow-up. More details about the study sample are provided in the Results chapter.

Table 4

Baseline Characteristics in the Whole National EDEN sample (N = 1027) and Participants Completing the TUS at Baseline (N = 878)

	National EDEN sample (N = 1027)	Participants completing TUS at baseline (N = 878)
Age of onset – mean (*SD*)	21.33 (4.98)	21.25 (4.97)
Duration of untreated psychosis > 4 months – *n* (%)	433 (42%)	368 (42%)
Diagnosis – *n* (%)		
Psychosis	852 (83%)	720 (82%)
Schizophrenia	103 (10%)	97 (11%)
Bipolar/Schizoaffective Disorder	72 (7%)	61 (7%)
Gender – *n* (%)		
Male	709 (69%)	606 (69%)
Female	318 (31%)	272 (31%)
Ethnicity – *n* (%)		
White	750 (73%)	632 (72%)
Asian	157 (15%)	140 (16 %)
Black Caribbean	71 (10%)	62 (7%)
Mixed Ethnicity	49 (5%)	44 (5%)
Not in education, employment or training (NEET) – *n* (%)	596 (58%)	518 (59%)

2.2.1.3 Samples providing normative and comparison data on the TUS.

TUS data from a non-clinical sample obtained from the Office for National Statistics, and from a sample of individuals with at-risk mental state (ARMS) were compared with TUS data from the FEP sample and used to create cut-off scores for

social disability (see section 2.6.2.1). These samples will now be described in more detail.

2.2.1.3.1 Non-clinical sample.

TUS data from an age-matched sub-sample (N = 5686) of individuals participating in the ONS UK 2000 Time Use Survey (Short, 2006) was used to obtain a non-clinical comparison group for the current study. The ONS 2000 Time Use Survey was a national study assessing how people in the UK spend their time. A total of 11,864 households participated in the study, completing the Time Use Survey interview and daily diaries. Households were selected at random using postcodes to ensure an equal representation of areas across the UK. Data was obtained with permission from the ONS website (www.statistics.gov).

2.2.1.3.2 At-risk mental state (ARMS) sample.

TUS data for the ARMS sample (N = 199) were taken from the Early Detection and Intervention Evaluation (EDIE-II) study (see Morrison et al., 2011 for more details). EDIE-II was a multi-centre randomised controlled trial of CBT for individuals with at-risk mental states, funded by the Medical Research Council. The aim of EDIE-II was to evaluate the efficacy of psychological therapy in preventing or delaying the onset of psychosis. Individuals were defined as meeting ARMS criteria if they had a first-degree relative with psychosis or were experiencing low-level psychotic-like symptoms, assessed using the Comprehensive Assessment of At-risk Mental State (CAARMS; Yung et al., 2002).

2.2.2 Sample size.

2.2.2.1 Analysis of variance (ANOVA).

ANOVAs were used to examine differences in baseline predictor variables between subgroups of individuals with FEP with different patterns and trajectories of

social recovery. A power calculation using G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007) revealed that to achieve 80% power with a significance level of .05 and an estimated medium effect size, a minimum total sample size of and 159 for three subgroups (53 participants per group); and 180 participants for four subgroups (45 participants per group) was required. Therefore the study was adequately powered. A medium effect size was chosen due to the findings of the literature review outlined in section 1.4.

2.2.2.2 Ordinal and multinomial regression.

Ordinal and multinomial regression was used in the current study to examine predictors of different patterns or trajectories of social recovery in individuals with FEP. This statistical technique was chosen as group membership was, in most cases, an ordered categorical variable (i.e. from poorer recovery to better recovery). Where group membership was considered a nominal variable (i.e. categorical but with no ordering), multinomial regression was used.

Sample sizes required for ordinal and multinomial regression is a matter of some debate. Some researchers argue for a sample size with at least 30 participants per predictor variable (Pedhazur & Schmelkin, 1991), whereas others suggest a minimum sample of 500 (Long, 1997) is required. Taylor, West, and Aiken (2006) provided more concrete recommendations after using simulation techniques to examine the effect of sample size on power in logistic regression with differing numbers of categories. They found that to achieve 80% power, a logistic model with three categories required a sample size ranging from 249 to 461, depending on the shape of the distribution of the outcome variable; and a logistic model with five categories required a sample size ranging from 225 to 377, also depending on the shape of the distribution of the outcome variable.

In the current study, several ordinal regression analyses were conducted with up to four categories and 12 predictor variables. With its large sample size, the current study meets all of the criteria outlined above, even where distributions were skewed, and was thus adequately powered to conduct ordinal and multinomial regression analyses.

2.2.2.3 Latent class growth analysis (LGCA).

LCGA is a semi-parametric technique for identifying distinct latent classes, or homogenous subpopulations, within longitudinal data collected from a larger heterogeneous population (Jung & Wickrama, 2008). LCGA was therefore used in the current study to examine different trajectories of social recovery in individuals with FEP using longitudinal TUS data.

Large sample sizes are required to conduct LCGA, although the exact method of determining power and sample size is still under debate. Nagin (2005) suggests that a sample size of at least $N = 300$ is required in order to successfully conduct LCGA. Smaller sample sizes are thought to limit the power of the analysis and impact upon the number of identifiable trajectories (Andruff, Carraro, Thompson, Gaudreau, & Louvet, 2009). With its large sample size, the current study was adequately powered to conduct LCGA.

2.3 Measures

Participants in National EDEN completed a large battery of self-report and interview measures assessing a range of areas including: help-seeking behaviour and the care pathway into EIP services; premorbid adjustment; clinical status over the 12-month period; relapse, recovery, and social and occupational functioning over the 12-month period; and service provision. A subsample of these measures were included in the

current study in order to answer the study research questions. These measures will now be described in more detail, along with the rationale for their selection.

2.3.1 Social Recovery.

2.3.1.1 Time Use Survey (TUS; Short, 2006).

Social recovery was assessed in terms of weekly hours spent engaged in structured activity, measured using the TUS. The TUS was chosen as an index of social recovery as measuring time use is an important way of measuring participation in a range of activities which may have significant economic, societal, and personal benefits (Gershuny, 2011). Time spent engaged in structured activity has also previously been shown to be associated with increased mental wellbeing (Fletcher et al., 2003). Moreover, engaging in activity gives meaning to people's lives, and this concept is central to service-user definitions of recovery (Davidson, 2003). Further discussion regarding the choice of this measure over more traditional assessment tools is outlined in section 1.3.1.

The TUS is a semi-structured interview in which the participant is asked about how they have spent their time over the last month. Activities enquired about include: work, education, voluntary work, leisure, sports, hobbies, socialising, resting, housework/chores, and childcare. The TUS provides a direct and objective measure of the average number of hours per week an individual is spending in activity. It was developed by the Office for National Statistics (Short, 2006) and used in a national survey to examine how members of the population of the UK spend their time. As such, normative data is available for the measure. The TUS has also been successfully used with a sample of individuals with psychosis (Fowler, Hodgekins, Painter, et al., 2009).

The TUS provides a composite score of hours per week spent in Structured Activity. Structured Activity is defined as everyday activities which are productive and

may have wider economic and psychosocial benefits (i.e. paid/voluntary work, education, childcare and chores, and structured social activities). As outlined above, these activities have been linked to increased wellbeing (Fletcher et al., 2003). Hours in structured activity assessed using the TUS have been shown to be positively correlated with existing measures of functioning (Hodgekins et al., in prep), including the Quality of Life Scale (QLS; Heinrichs et al., 1984), $r = .43$, $p < .001$; the Social and Occupational Functioning Assessment Scale (SOFAS; American Psychiatric Association, 1994), $r = .31$, $p < .01$; and Jolley et al's (2006) Time Budget, $r = .57$, $p < .001$. Hours in structured activity were not associated with positive, negative, or general symptoms measured by the Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987). This is a strength of the TUS as scores on some functioning assessment tools have previously been shown to be confounded by negative symptoms (Barry & Crosby, 1996).

Previous research using the TUS in a randomised controlled trial of CBT for social recovery in early psychosis has suggested that the minimal clinically important difference (i.e. the smallest difference in score which is perceived to be beneficial) on the TUS is 8 hours per week (Fowler, Hodgekins, Painter, et al., 2009). This has been agreed to have face validity in focus groups with both clinicians and service users and also equates to one full-time working day (Hodgekins et al., in prep). This figure was used in order to assess whether change had occurred over the study period. See Appendix A for a copy of the TUS and examples of activities included within the definition of structured activity.

2.3.2 Predictor Variables.

2.3.2.1 Demographic characteristics

Demographic characteristics including age of onset of psychosis, gender, and ethnicity, were collected for all participants in the National EDEN study. These variables were included as predictors of outcome in the analyses.

2.3.2.2 Duration of Untreated Psychosis (DUP; Larsen, McGlashan, Johannessen, & Vibe-Hansen, 1996).

DUP is a measure of the amount of time, in days, between the onset of positive psychotic symptoms (defined using a cut-off score of 4 on the Positive and Negative Syndrome Scale) and the start of treatment (defined as the prescription of antipsychotic medication). For the current study, DUP was assessed retrospectively upon entry into the EIP service using information collected from medical notes and interviews with participants at each site. This method of assessing DUP is a standard procedure used in research (Harrigan et al., 2003). Longer DUP has previously been shown to be associated with poorer functional and symptomatic outcome (Norman et al., 2007) and thus DUP was included as a predictor variable in the current study. In the analyses, DUP was considered as a categorical variable, using a cut-off of 4 months (M. Marshall, personal communication, December 9, 2011) to define those with short (< 4 months) and long (> 4 months) DUP. This decision was taken due to findings of previous research indicating a non-linear relationship between DUP and outcome (Singh, 2007).

2.3.2.3 Premorbid Adjustment Scale (PAS; Cannon-Spoor et al., 1982).

The PAS is a structured interview designed to assess an individual's level of functioning prior to the onset of a psychotic episode. It contains a 28-item rating scale that measures social isolation, peer relationships, functioning outside of the family, and school performance during four age periods (up to 11 years, 12–15 years, 16–18 years

and 19 years and above), as well as social–sexual aspects of life starting at age 15. All PAS ratings are based on interviews with service-users and their family members. Each item is scored on a Likert scale of 0–6, where lower ratings indicate healthy functioning and higher ratings suggest problematic development. Scores for each of the subscales are calculated by dividing the obtained score by the total possible score for that section. Scores range from 0.0 to 1.0, where lower numbers represent a higher level of functioning.

The PAS has been used extensively in research and has been shown to have good internal and inter-rater reliability, with Cronbach's alphas of subscales ranging from .81-.93, and an intra-class correlation of .77 (van Mastrigt & Addington, 2002). Poorer premorbid functioning has previously been found to be associated with poorer functional outcome (Keshavan et al., 2003; Norman et al., 2007) and thus PAS scores for childhood (up to age 11), early adolescence (12-15 years), and late adolescence (16-18 years) were included as predictor variables in the current study. Adulthood PAS scores were not included in the analyses as these developmental periods coincided with the onset of psychosis.

2.3.2.4 Positive and Negative Syndrome Scales (PANSS; Kay, 1991).

The PANSS is a semi-structured interview assessing the frequency and severity of psychotic symptomatology over three subtypes: positive (e.g. hallucinations), negative (e.g. emotional withdrawal), and general (e.g. depression) symptoms. Symptoms are rated by trained interviewers on a 7-point scale of increasing severity, from 1 (absent) to 7 (extreme). In the current study, symptoms were rated over the past 72 hours in order to assess the recent frequency and severity of individual's psychotic symptoms. The PANSS is one of the most widely used instruments in schizophrenia research (Van den Oord et al., 2006). Moderate to high inter-rater reliability (intra-class

correlation = .60-.80) and internal consistency (Cronbach's alphas = .60-.92) have been demonstrated for the scale by Kay et al. (1987) and independently by Peralta and Cuesta (1994), although the latter and others argue that the factor structure of the scale may be more complex than suggested by the original authors (van der Gaag et al., 2006). High levels of negative symptoms have previously been linked with poor functional outcomes in psychosis (Milev et al., 2005). Positive, negative, and general psychotic symptom levels at baseline were therefore included as predictor variables in the current study.

2.3.2.5 Calgary Depression Scale (CDS; Addington, Addington, & Maticka-Tyndale, 1993).

The CDS is a 9-item semi-structured interview designed to assess symptoms of depression in individuals with schizophrenia, separate to positive, negative, and expyramidial symptoms. Symptoms are rated by trained interviewers on a 4-point scale of increasing severity, from 0 (absent) to 3 (severe). The frequency and severity of symptoms are rated over the past 2 weeks. Scores range from 0 to 36, with higher scores indicating more severe depressive symptoms. A cut-off score of 6 has been shown to have 82% specificity and 85% sensitivity in predicting the presence of a major depressive episode (Addington et al., 1993). The CDS is widely used in psychosis research and has been shown by Addington et al. (1993) to have good inter-rater and internal reliability (intra-class correlation = .90, Cronbach's alpha = .79). Other researchers have also examined the psychometric properties of the scale with similar results (Collins, Remington, Coulter, & Birkett, 1996). Levels of depression are high in individuals with FEP and may impact upon recovery (Addington, Addington, & Patten, 1998; Romm et al., 2010). Thus, depression assessed using the CDS was included as a predictor variable in the current study.

2.4 Procedure

Research staff at each site involved in National EDEN were responsible for recruiting participants and collecting data at all time points. Researchers were graduate psychologists who received extensive training in all assessments. Concordance of ratings on the interview-based assessments was checked by the research team on a regular basis using tapes to ensure high inter-rater reliability. Data collection was completed in 2009.

As data used in the current research were collected as part of National EDEN, participants were not required to participate in anything additional for the purpose of this study. The author of this thesis was involved in data collection for the National EDEN project at the Norwich site and was given approval by the National EDEN grant holders and Principal Investigators to use the data for the analyses outlined in this thesis (see Appendix B).

2.5 Ethical Considerations

2.5.1 Ethical approval and informed consent.

National EDEN was granted ethical approval both centrally by Birmingham Research Ethics Committee and locally by each of the research sites, including Norfolk Research Ethics Committee. Participants from the National EDEN project provided informed consent to take part in the project and for their data to be used in the current study. The information sheet explained the rationale for the study and exactly what would be required of participants. It also explained that participants could withdraw from the study at any time, at which point their data would be destroyed. This would not affect current or future involvement with services. Consent was taken by researchers at each site who also conducted the assessments and interviews. See Appendix C for

letters of consent from ethics committee and study information sheets and consent forms.

2.5.2 Data storage and confidentiality.

Each participant was allocated a code so that their responses to questionnaires and assessments could be matched without using their names. Raw data were kept in a locked filing cabinet and electronic data were stored on a password protected network. Participants were informed that all of their responses were confidential, unless something was disclosed that raised concerns about the personal safety of the participant or the safety of others. If any concerns did arise, the participant was always informed about who was to be contacted and what was going to happen. The confidentiality policy was also included in the participant information sheet. Storage of all data complied with the terms of the Data Protection Act (1998).

2.5.3 Risks and benefits of participation.

All participants were paid £20 for completing National EDEN assessments. They were also informed that their participation had wider benefits for EIP services and service users in terms of the research questions asked by the study. All participants were invited to receive information on the outcome of the National EDEN study. In terms of risk, some of the assessments involved asking for personal information which could have been distressing to the participant. Interviews were conducted by graduate psychologists who received extensive training and were experienced in conducting assessments with this client group and had an awareness of the potential sensitivity of the issues being discussed. Researchers received regular supervision on these issues from Clinical Psychologists working in EIP services. In addition, all participants were under the care of an EIP service and thus any distress could be appropriately managed

within this context. These processes were consistent across all sites participating in the research.

2.6 Data Analysis Plan

2.6.1 Initial treatment of the data.

Raw data were screened and cleaned prior to analyses. The data set was screened for missing data and outliers. Individuals scoring above 168 hours per week on the TUS were considered as outliers as this exceeds the number of hours in a week (n = 8, <1%). TUS scores for these individuals were changed to the next highest score in the dataset plus one, as recommended by Field (2009).

Where participants who had endorsed an activity on the TUS (e.g. work) but had not specified the hours per week engaged in that activity, prorating was used to replace missing responses. This involved replacing missing variables with the median number of hours for the sample on that particular activity. This was considered a valid procedure to use as only a small number (< 5%) of missing data points were prorated (Tabachnick & Fidell, 2001). Prorating did not significantly alter mean scores on the TUS (see Appendix D).

Missing data analyses were conducted to examine patterns of missing data on baseline predictor variables to check whether data were missing at random. Mean scores on the TUS were compared between participants with and without missing data on predictor variables to examine whether missingness was related to the dependent variable (Tabachnick & Fidell, 2001). See Appendix D for more information on this analysis.

2.6.2 Analyses of the data.

All data were analysed using SPSS for Windows, version 16 (SPSS, 2007) and Mplus version 4.0 (Muthén & Muthén, 1998). In the first stage of the analysis,

descriptive statistics and data distributions were calculated for all measures and examined for normality of spread to ensure that the assumptions of the statistical tests being used were met. This process is described further in the Results chapter. Analysis plans will now be outlined for each research question.

2.6.2.1 Research Question 1: What is the frequency of social disability, defined using weekly hours engaged in structured activity, in individuals with FEP presenting to EIP services across the UK?

As a first stage of the analysis, cut-off scores were calculated on the TUS in order to define clinical levels of social disability. This was done by applying Jacobson, Folette, and Revenstorf's (1984) formula for clinically significant change to TUS data from the FEP sample; data from a sample of individuals with at-risk mental state (ARMS); and normative data on the TUS acquired from the Office for National Statistics. This formula provides a cut-off point on the TUS above which individuals fall within the non-clinical range and below which individuals fall within the clinical range:

$$\frac{(\text{mean}_{clin} \times \text{SD}_{norm}) + (\text{mean}_{norm} \times \text{SD}_{clin})}{\text{SD}_{norm} + \text{SD}_{clin}}$$

A Receiver Operating Characteristic (ROC) curve analysis was also conducted to examine the accuracy of the TUS in discriminating between clinical and non-clinical samples and to obtain the cut-off point at which optimal sensitivity and specificity were achieved (Akobeng, 2006; Deyo & Centor, 1986). Further cut-offs were then defined by comparing FEP and ARMS samples.

After defining cut-off scores on the TUS, the FEP sample was split into subgroups according to levels of social disability using the cut-off scores. The frequency of social disability in the sample was then examined.

2.6.2.2 Research Question 2: Which factors predict baseline levels of social disability in FEP?

The social disability subgroups defined by the previous phase of the analyses were compared on baseline predictor variables using one-way ANOVAs. Post-hoc Tukey's HSD tests were conducted to interpret significant main effects. Following this, ordinal regression was used to examine predictors of social disability subgroup. Social disability subgroup (severe social disability, social disability, at risk of social disability, or no social disability) was the dependent variable. Explanatory variables included: gender, ethnicity, DUP, age of onset of psychosis, PANSS positive, negative, and general symptoms, depression, and premorbid adjustment in childhood, early adolescence, and late adolescence. These were selected on the basis of previous research (see section 1.4). Odds ratios were calculated for significant predictors by calculating the exponent of the regression coefficient.

2.6.2.3 Research Question 3: How many individuals with FEP experience a change in weekly hours of structured activity in the first 12 months EIP service provision?

Change in time use between baseline and follow-up assessment points were calculated. The minimal clinically important difference (MCID; Wells et al., 2001) score of 8 hours per week on the TUS was used to assess whether change in time use had occurred. A change of less than 8 hours could be due to measurement error and was also not deemed clinically important (Hodgekins et al., in prep). Participants were categorised according to their change profile over time (increasing, decreasing, stable,

and variable; see section 3.7.1 for how these profiles were defined). The frequency of different change profiles was then examined.

2.6.2.4 Research Question 4: Which factors predict change in time use over the first 12 months of EIP service provision?

The change subgroups defined by the previous phase of the analyses were compared on baseline predictor variables using one-way ANOVAs. Post-hoc Tukey's HSD tests were conducted to interpret significant main effects. Following this, multinomial regression was used to examine predictors of social disability subgroup, comparing the increasing subgroup with each of the other change subgroups. Change subgroup (increasing, decreasing, stable, or variable) was the dependent variable. Explanatory variables included: gender, ethnicity, DUP, age of onset of psychosis, PANSS positive, negative, and general symptoms, depression, and premorbid adjustment in childhood, early adolescence, and late adolescence. Baseline social disability subgroup was also included in the analysis as a predictor.

2.6.2.5 Research Question 5: How many individuals with FEP make a good social recovery in the first 12 months of EIP service provision and how many remain socially disabled?

Social recovery was defined using baseline social disability groups and change profiles over the 12 month study period. Change over the 12 months was examined to see whether it had resulted in transition between social disability levels. Individuals were deemed to have made a recovery if they either remained within the non-clinical range, or made transition from the clinical to non-clinical range using the cut-off scores defined in section 2.6.2.1. A partial recovery was defined as remaining in or making transition to the at-risk range. A lack of recovery was defined as remaining within the clinical range or making transition from the non-clinical range to the clinical range (i.e.

a reduction in time use). These decisions were informed by existing literature discussing definitions of recovery (e.g. Harvey & Bellack, 2009).

2.6.2.6 Research Question 6: Which factors predict whether individuals make a social recovery in the first 12 months of EIP service provision following FEP?

Individuals with different types of social recovery were compared on baseline predictor variables using one-way ANOVAs. Post-hoc Tukey's HSD tests were conducted to interpret significant main effects. Following this, ordinal regression was used to examine predictors of recovery type. Social recovery type defined in the previous analysis (no social recovery, partial social recovery, full social recovery) was the dependent variable. Explanatory variables included: gender, ethnicity, DUP, age of onset of psychosis, PANSS positive, negative, and general symptoms, depression, and premorbid adjustment in childhood, early adolescence, and late adolescence. Odds ratios were calculated for significant predictors by calculating the exponent of the regression coefficient.

2.6.2.7 Research Question 7: Do different trajectories of social recovery exist in the first 12 months following FEP? Which factors predict different trajectories?

Latent Class Growth Analysis (LCGA) was used to examine recovery trajectories within the longitudinal data. LCGA is a semi-parametric technique for identifying distinct latent classes, or homogenous subpopulations, within longitudinal data collected from a larger heterogeneous population (Jung & Wickrama, 2008). The analyses were conducted using the statistical programming software, Mplus (Muthén & Muthén, 1998). The modelling followed a two-step approach as outlined in Jung and Wickrama (2008). First, a single growth curve was fitted to the data to examine whether time use remained stable or changed over time. Once change over time was identified, models with varying numbers of recovery trajectories (or latent classes) were fitted to

the data to examine which provided the best fit, starting with a two-class model and increasing the number of classes until the model which best fitted the data was identified. The goodness-of-fit of a model can be ascertained using a range of criteria (Andruff et al., 2009). These are outlined in Table 5.

Determining the most appropriate number of classes depends on a combination of factors in addition to statistical fit indices, including parsimony, theoretical justification, and interpretability (Jung & Wickrama, 2008). Checks on convergence were also conducted to ensure that solutions were global rather than local. LCGA is at risk of producing local solutions, particularly in more complex models (i.e. those with more classes), due to its iterative nature and use of maximum likelihood estimation (Andruff et al., 2009). Local solutions occur when a model terminates prematurely, on a local maximum solution, rather than on the global maximum solution (Nylund, Asparouhov, & Muthén, 2007). The use of random starting values and increasing the number of iterations within the analysis also reduces the likelihood of local solutions (Jung & Wickrama, 2008). However, further checks on convergence were conducted using the OPTSEED syntax in MPlus (Muthén & Muthén, 1998). This allows replication of the analysis using the best loglikelihood values. If model estimates are replicated using this approach, it is likely that the initial solution was global, not local, thus increasing the stability and reliability of the findings.

Individuals with different social recovery trajectories were compared on baseline predictor variables using one-way ANOVAs. Post-hoc Tukey's HSD tests were conducted to interpret significant main effects. Following this, ordinal regression was used to examine predictors of recovery trajectory. Social recovery trajectory (low stable, moderate/increasing, high/decreasing) was the dependent variable. Explanatory variables included: gender, ethnicity, DUP, age of onset of psychosis, PANSS positive,

negative, and general symptoms, depression, and premorbid adjustment in childhood, early adolescence, and late adolescence. Odds ratios were calculated for significant predictors by calculating the exponent of the regression coefficient.

Table 5

Summary Table of Model Fit Criteria for LCGA

Fit Index	Description	Value indicating good fit
Bayesian Information Criterion (BIC) value	Fit index used to compare competing models with different numbers of trajectories.	The best fitting model will have a lower BIC value compared to other, poorer fitting models.
Entropy	A measure of how clearly distinguishable the classes are.	Entropy values should be close to 1 (suggests each individual has a high probability of being in just one class)
Average posterior probabilities	An approximation of the internal reliability for each class.	Average posterior probabilities should be greater than .70
Class proportions	The proportion of the total sample within each class.	Should be > 5% for each class
Lo-Mendell-Rubin (LMR) test	A statistical test used to compare models with different numbers of classes.	LMR *p*-value should be significant (i.e. <.05).

CHAPTER THREE

3. Results

3.1 Overview

This chapter will report the results of the statistical analyses outlined in the data analysis plan (section 2.6). First, the data screening process is outlined before descriptive data are provided for the sample and test assumptions are considered. Following this, the data are considered in relation to the research questions. Clinical and non-clinical cut-off scores for the Time Use Survey (TUS) are calculated and baseline characteristics of subgroups with different baseline levels of time use are examined using ANOVAs, chi-square tests, and ordinal regression. Changes in scores on the TUS over the 12 month time period are examined, as well as baseline predictors of change. Definitions of recovery are then established using baseline categories and change scores, before predictors of different recovery types are examined. Finally, results of the latent class growth modelling analyses are outlined, including a description of the best-fitting model and baseline predictors of class membership.

3.2 Data Screening and Missing Data

As a first stage of the analysis, data were screened and cleaned. Missing data were prorated as described in section 2.6.1. Individuals scoring above 168 hours per week on the TUS were considered as outliers as this exceeds the number of hours in a week (n = 8, <1%). TUS scores for these individuals were changed to the next highest score in the dataset plus one, which was 140 hours (Field, 2009).

3.2.1 Missing TUS data.

Of the 1027 participants recruited into the National EDEN study and assessed at baseline, 878 (85%) completed the TUS and were included in the current study. Of these 878 participants, 673 (77%) completed the TUS at 6 month follow-up and 623

(71%) completed the TUS at 12 month follow-up. Comparisons on baseline variables between individuals with and without baseline TUS data were conducted and revealed some differences. Participants with baseline TUS data (N = 878) had higher baseline negative symptoms scores on the PANSS than participants without baseline TUS data (N = 149), $t(819) = 2.40$, $p = .02$. Moreover, participants who dropped out of the study at 6 or 12 month follow-up had lower baseline negative symptoms, $t(819) = -2.46$, $p = .01$; lower general symptoms on the PANSS, $t(825) = -3.07$, $p = .002$; and higher GAF scores, $t(844) = 3.13$, $p = .002$, than individuals who remained in the study. This suggests that individuals whose data were included in the analyses came from a more disabled group. The implications of this will be considered in the Discussion chapter of this thesis.

3.2.2 Missing data on predictor variables.

Rates of missing data on predictor variables were calculated for the 878 participants completing the TUS at baseline. Rates of missing data varied from 1.5% (Duration of Untreated Psychosis) to 25% (Premorbid Adjustment in Late Adolescence). For individual predictor variables, there was no difference in baseline TUS scores between participants who had data for the predictor variable and those who did not (see Appendix D). Sixty-five percent of participants had complete data on all variables. There was no difference in baseline TUS scores between participants with complete data on all variable and those who did not. Missing data were therefore considered to be missing at random (i.e. unrelated to the dependent variable) and was excluded listwise from the analyses (Tabachnick & Fidell, 2001).

3.4 Descriptive Data

3.4.1 Descriptive statistics for the Time Use Survey and baseline predictor variables.

Demographic characteristics of the study sample have been shown in section 2.2.1.2. Descriptive statistics for the TUS are shown in Table 6 and descriptive statistics for baseline predictor variables are shown in Table 7. Correlations between study variables are shown in Table 8.

Table 6

Descriptive Data for the Time Use Survey

	N	Min-Max	Median	Mean *(SD)*	Skewness *(SE)*
TUS Baseline	878	0-140	15.00	25.17 (26.22)	1.70 (0.08)
TUS 6 months	673	0-140	24.00	30.82 (25.28)	1.22 (0.09)
TUS 12 months	623	0-136	26.50	32.49 (26.97)	1.19 (0.10)

Table 7

Descriptive Data for Baseline Predictor Variables

	N	Min-Max	Median	Mean *(SD)*	Skewness *(SE)*
PANSS Positive Symptoms	836	7-33	15.00	15.16 (5.98)	0.54 (0.09)
PANSS Negative Symptoms	821	7-43	14.00	14.98 (6.56)	0.93 (0.09)
PANSS General Symptoms	827	16-79	31.00	32.90 (10.08)	0.80 (0.09)
Calgary Depression Scale	845	0-26	5.00	6.29 (5.37)	0.82 (0.08)
Premorbid Adjustment					
Childhood	811	0-0.88	0.21	0.23 (0.18)	0.72 (0.09)
Early Adolescence	780	0-0.77	0.27	0.29 (0.17)	0.51 (0.09)
Late Adolescence	657	0-0.93	0.30	0.31 (0.19)	0.64 (0.10)
Global Assessment of Functioning	846	8-95	50.00	50.52 (17.16)	0.20 (0.08)

Note. PANSS = Positive and Negative Syndrome Scale

Table 8

Correlations between Study Variables

	TUS baseline	TUS 6 month	TUS 12 month	PANSS Positive	PANSS Negative	PANSS General	CDS	PAS <11 yrs	PAS 12-15 yrs	PAS 16-18yrs	GAF
TUS baseline	1										
TUS 6 month	.56***	1									
TUS 12 month	.41***	.57***	1								
PANSS Positive	-.06	-.07	-.04	1							
PANSS Negative	-.21***	-.21***	-.23***	.31***	1						
PANSS General	-.15***	-.09*	-.08*	.68***	.57***	1					
CDS	-.02	.00	-.05	.33***	.19***	.50***	1				
PAS <11 yrs	.03	-.04	-.02	.14***	.12***	.15***	.16***	1			
PAS 12-15 yrs	-.12**	-.16***	-.13**	.14***	.27***	.20***	.19***	.66***	1		
PAS 16-18 yrs	-.23***	-.21***	-.23***	.17***	.35***	.22***	.14***	.48***	.68***	1	
GAF	.25***	.19***	.23***	-.45***	-.37***	-.46***	-.30***	-.16***	-.23***	-.21***	1

Note. TUS = Time Use Survey, PANSS = Positive and Negative Syndrome Scales, CDS = Calgary Depression Scale, PAS = Premorbid Adjustment Scale, GAF = Global Assessment of Functioning; *p <.05, **p <.01, ***p <.001

3.4.2 Normality of the distributions and assumptions of statistical analyses.

3.4.2.1 TUS data.

Komologov-Smirnov tests showed the distributions of scores on the TUS to be significantly different from normal at all time points (see Appendix E for the normality test result tables). Observation of histograms and z-scores of skewness confirmed that the data were positively skewed. Data on the TUS were resistant to transformation using both log and square root techniques (see Appendix E).

When using TUS scores to define social disability and recovery, two approaches were used. First, continuous TUS data were converted to a categorical variable using cut-off scores, thus overcoming the extreme skewness of the data and making assumptions of normality irrelevant (MacCallum, Zhang, Preacher, & Rucker, 2002). The use of cut-off scores also enabled recovery to be determined in terms of transition between clinical and non-clinical ranges, increasing clinical utility of the scale. As reducing a continuous variable into a categorical variable can result in the loss of useful information (MacCallum et al., 2002), this approach was compared with a second approach in which continuous TUS data were analysed using LCGA to identify smaller more homogeneous classes within the larger heterogeneous sample. As LCGA is a semi-parametric technique, it does not require data to be normally distributed (Jung & Wickrama, 2008). Nevertheless, an estimation approach robust to non-normality was chosen when conducting these analyses.

3.4.2.2 Baseline predictors.

Komologov-Smirnov tests showed the distributions of scores on all predictor variables to be significantly different from normal (see Appendix E for the normality test result tables). Observation of histograms and z-scores of skewness confirmed that

all data were positively skewed. Data were resistant to transformation using both log and square root techniques (see Appendix E). Although the assumptions of the test were violated, ANOVA techniques have been shown to be robust to violations of test assumptions, particularly where sample sizes are large (Kirk, 1995). One-way ANOVAs were therefore used to analyse between-group differences on predictor variables. For each ANOVA, the homogeneity of variance of predictor variables between groups was examined using Levene's test. In addition, parallel non-parametric analyses in the form of Kruskal-Wallis tests revealed the same findings (see Appendix F).

3.5 Research Question 1: What is the frequency of social disability, defined using weekly hours engaged in structured activity, in individuals with FEP presenting to EIP services across the UK?

Levels of social disability were examined in the FEP sample using baseline TUS data. In order to do this, continuous TUS scores were converted into an ordinal categorical variable depending on the level of social disability. Cut-off scores are often applied to clinical measures in order to improve the ease of interpretation and to impose a threshold over or under which clinical cases can be identified (Mazumdar & Glassman, 2000). Cut-off scores were calculated using TUS data from a normative sample. This process will now be described in more detail.

3.5.1 Defining clinical and non-clinical cut-off scores for the Time Use Survey.

Normative data is available for the TUS from the Office for National Statistics (ONS) UK 2000 Time Use Survey providing data on hours per week spent engaged in Structured Activity by an age-matched non-clinical sample. A sample of individuals with at-risk mental state (ARMS) also completed the TUS (Morrison et al., 2011) providing data on hours per week spent engaged in Structured Activity by individuals at

risk of developing psychosis. Data from these samples are described in Table 9 and were used to establish clinical and non-clinical cut-off scores for the TUS.

Table 9

Descriptive Statistics for Weekly Hours in Structured Activity on TUS in Non-clinical and At-risk Mental State Samples

	N	Min-Max	Median	Mean (SD)	Skewness (SE)
Non-clinical (UK 2000 Time Use Survey)	5686	0.00 – 140.00	61.83	63.49 (25.89)	0.19 (0.03)
At-risk mental state (EDIE-II)	199	1.31 – 139.19	29.91	35.61 (29.68)	1.31 (0.17)
First Episode Psychosis (National EDEN study)	878	0-140	15.00	25.17 (26.22)	1.70 (0.08)

3.5.1.1 Non-clinical cut-off scores.

Cut-off scores between the clinical and non-clinical samples were examined using two different approaches: clinically significant change (Jacobson et al., 1984) and Receiver Operating Characteristic (ROC) curve analysis (Altman & Bland, 1994). The results of these analyses will now be described in more detail.

3.5.1.1.1 Clinically significant change.

Clinically significant change between the clinical and non-clinical samples was calculated using the following formula:

$$\frac{(\text{mean}_{clin} \times \text{SD}_{norm}) + (\text{mean}_{norm} \times \text{SD}_{clin})}{\text{SD}_{norm} + \text{SD}_{clin}}$$

$$\frac{(25.17 \times 25.89) + (63.49 \times 26.22)}{25.89 + 26.22}$$

This approach produced a cut-off score between the clinical and non-clinical groups of 44.45 hours, suggesting that when individuals score above this point they are in the non-clinical range. However, this method has been suggested to be inappropriate when the distributions of the clinical and non-clinical samples have different variances and skewness, as is the case with the TUS data. Therefore, ROC analysis was conducted to examine the specificity and sensitivity of different cut-off points.

3.5.1.1.2 Receiver Operating Characteristic (ROC) curve analysis.

A ROC curve (Figure 2) was plotted to examine the ability of the TUS to accurately discriminate between clinical and non-clinical samples and to determine the cut-off point at which optimal sensitivity and specificity are achieved. The area under the curve was .86 (95% CI = .85 to .88) suggesting that the TUS has good accuracy at discriminating between clinical and non-clinical samples. The optimal cut-off point suggested by the Youden Index (Youden, 1950) was 45 hours per week (sensitivity = .81, specificity = .79). Thus, anyone scoring below this cut-off can be considered to be scoring in the clinical range and anyone scoring above this cut-off can be considered to be scoring in the non-clinical range.

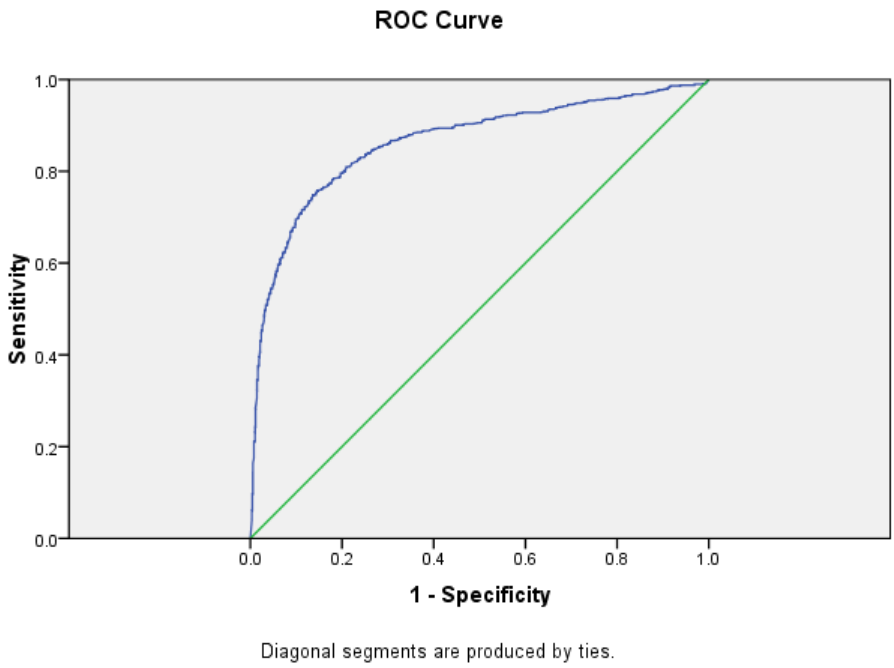

Figure 2

ROC curve for sensitivity and specificity of the TUS

3.5.1.2 Defining cut-off scores for severity of social disability within the clinical group.

The majority of the FEP group scored below the clinical cut-off of 45 hours per week on the TUS. A lower cut-off may be useful in determining those with more severe levels of social disability. Indeed, a dichotomous split of continuous data can result in the loss of information and thus creating an ordinal variable with different levels of social disability would reduce the likelihood of this (Altman & Royston, 2006). Moreover, the Youden Index regards specificity and sensitivity as equally important, whereas in clinical terms, increasing the specificity of cut-off scores would reduce the likelihood of falsely identifying individuals as socially disabled.

3.5.1.2.1 At-risk of social disability.

Clinically significant change between the ARMS and FEP groups was calculated, using the formula outlined in section 3.5.1.1.1. This produced a cut-off score of 30 hours per week, suggesting that when individuals score above 30 hours (but below 45 hours) they are in the at-risk range. This is consistent with a median split of the ARMS group. In discriminating clinical and non-clinical samples, a cut-off of 30 hours per week has a sensitivity of 68% and a specificity of 91%.

3.5.1.2.2 Severe social disability.

A further cut-off of 15 hours per week was chosen to define individuals with severe levels of social disability, and is consistent with a median split of the FEP. This cut-off score is almost two standard deviations from the non-clinical mean ($z = 1.87$), suggesting a severely disabled group. In discriminating clinical and non-clinical samples, a cut-off score of 15 hours per week has a sensitivity of 50% and a specificity of 97%.

3.5.2 Levels of social disability in FEP.

In order to determine baseline levels of social disability in individuals with FEP, the sample was split into social disability subgroups by applying the cut-off scores described above to the baseline TUS data. Individuals with TUS scores of 15 hours per week or less were defined as a *Severe Social Disability (Severe SD)* group. Individuals with TUS scores of more than 15 hours per week but less than or equal to 30 hours per week were defined as a *Social Disability (SD)* group. In line with the mean of the ARMS sample, individuals with TUS scores of above 30 but less than 45 hours per week were defined as an *At-risk of Social Disability (At-risk SD)* group. In line with the non-clinical mean, individuals with TUS scores of 45 hours per week or above were defined as a *No Social Disability (No SD)* group. See Table 10 for more details.

Table 10

Baseline Social Disability Subgroups

Subgroup	*n* (%) of total sample	Mean hours per week in Structured Activity on TUS at baseline (*SD*)
Severe Social Disability (Severe SD)	436 (49.7%)	6.17 (4.22)
Social Disability (SD)	159 (18.1%)	22.85 (4.25)
At-risk of Social Disability (At-risk SD)	117 (13.3%)	37.16 (4.43)
No Social Disability (No SD)	166 (18.9%)	68.86 (24.36)

3.5.3 Summary.

There are high levels of social disability in FEP, with over 80% of individuals scoring below the non-clinical cut-off. Moreover, over 65% of individuals with FEP were spending less than 30 hours per week engaged in structured activity. However, a small proportion of individuals (18.9%) did not experience social disability, scoring within the non-clinical range. The next section will examine factors associated with social disability in FEP.

3.6. Research Question 2: Which factors predict baseline levels of social disability in FEP?

3.6.1 Comparing subgroups on baseline predictor variables.

The four subgroups outlined above (Severe SD, SD, At-risk SD, and No SD) were compared on demographic characteristics and baseline predictor variables. Descriptive statistics are shown in Table 11. Exploratory ANOVAs were conducted to examine differences in continuous predictor variables between the four subgroups. Post hoc Tukey's HSD tests were conducted to interpret significant main effects. As nine

ANOVAs were conducted, a Bonferroni adjustment (.05/9 = .006) was applied to the level of significance to avoid Type I errors (Field, 2009). Chi-square tests were used to examine group differences on categorical variables.

3.6.1.1 Age of onset.

When applying the Bonferroni adjustment, there was no significant main effect of group on age of onset of psychosis, F (3, 837) = 3.55, p = .01, suggesting a comparable age of onset between groups.

3.6.1.2 Gender.

There was a significant association between social disability group and gender, χ^2 (3) = 13.97, p = .003. Further investigation of this relationship by examining the standardised residuals of individual cells showed that there were more males in the Severe SD subgroup than in other subgroups.

3.6.1.3 Ethnicity.

There was a significant association between social disability group and ethnicity, χ^2 (9) = 29.48, p = .001. Further investigation of this relationship by examining the standardised residuals of individual cells showed that there were significantly more individuals with Black African-Caribbean and Mixed Ethnicity in the SD subgroup than in other subgroups. In addition, there were significantly less individuals with Asian ethnicity in the No SD subgroup than in other subgroups.

3.6.1.4 Duration of untreated psychosis.

There was no significant association between social disability group and length of DUP, χ^2 (3) = 2.14, p = .54, suggesting comparable DUPs between different social disability groups.

3.6.1.5 Psychotic symptoms.

There was no significant main effect of group on Positive PANSS symptoms scores, F (3, 832) = 2.29, p = .08. However, there was a significant main effect of group on Negative PANSS symptoms scores, F (3, 817) = 14.73, p<.001 and General PANSS symptoms scores, F (3, 823) = 8.61, p<.001. Post hoc comparisons using Tukey's HSD tests indicated that the Severe SD subgroup had significantly higher levels of negative and general symptoms at baseline compared to the SD, At-risk SD, and No SD subgroups.

3.6.1.6 Depression.

There was no significant main effect of group on Calgary Depression Scale scores, F (3, 841) = 1.52, p = .21, with all subgroups scoring around the cut-off score for a major depressive episode.

3.6.1.7 Global Assessment of Functioning.

There was a significant main effect of group on GAF scores, F (3, 842) = 30.87, p<.001. Post hoc comparisons using Tukey's HSD tests indicated that the Severe SD subgroup had significantly lower functioning at baseline than the SD, At-risk SD, and No SD subgroups.

3.6.1.8 Premorbid adjustment.

There was no significant main effect of group on Childhood (up to age 11) PAS scores, F (3, 807) = 0.80, p = .50. However, there was a significant main effect of group on Early Adolescence (12-15yrs) PAS scores, F (3, 776) = 4.20, p = .006, and Late Adolescence (16-18yrs) PAS scores, F (3. 653) = 15.40, p <.001. Post hoc comparisons using Tukey's HSD tests indicated that the Severe SD subgroup had significantly poorer premorbid adjustment at age 16-18 years than all other subgroups. The Severe SD subgroup also had significantly poorer premorbid adjustment at age 12-15 years than

the No SD subgroup. This suggests that social disability may have been present in this group even before the onset of psychosis.

Table 11

Descriptive Statistics for Baseline Predictor Variables for Baseline Social Disability Subgroups – Mean (SD)

	Severe Social Disability (n = 436)	Social Disability (n = 159)	At-risk of Social Disability (n = 117)	No Social Disability (n = 166)
Age of onset	21.19 (4.73)	21.01 (4.76)	20.38 (5.01)	22.27 (5.60)
Male Gender *n* (%)	327 (75%)[a]	101 (64%)[b]	74 (63%)[b]	105 (63%)[b]
Ethnicity *n* (%)				
White	305 (70%)	102 (64%)	90 (77%)	139 (84%)
Asian	79 (18%)[a]	24 (15%)[a]	19 (16%)[a]	14 (8%)[b]
Black African-	34 (8%)[a]	18 (11%)[b]	5 (4%)[a]	6 (4%)[b]
Caribbean	18 (4%)[a]	15 (10%)[b]	3 (3%)[a]	7 (4%)[a]
Mixed Ethnicity				
DUP > 4 months *n* (%)	184 (42%)	60 (38%)	49 (43%)	75 (46%)
PANSS Positive	15.66 (6.10)	15.05 (6.16)	14.49 (5.77)	14.42 (5.52)
PANSS Negative	16.42 (6.73)[a]	14.15 (6.38)[b]	13.95 (6.47)[b]	12.80 (5.46)[b]
PANSS General	34.59 (10.35)[a]	31.80 (10.83)[b]	31.77 (9.17)[b]	30.31 (8.36)[b]
Calgary Depression Scale	6.65 (5.41)	5.68 (5.77)	6.25 (5.70)	5.94 (4.56)
GAF	45.45 (15.34)[a]	52.29 (17.66)[b]	55.57 (15.88)[b]	58.59 (17.70)[b]
Premorbid Adjustment				
Childhood	0.23 (0.17)	0.23 (0.20)	0.21 (0.19)	0.25 (0.17)
Early Adolescence	0.31 (0.27)[a]	0.27 (0.17)	0.28 (0.17)	0.25 (0.16)[b]
Late Adolescence	0.36 (0.20)[a]	0.29 (0.18)[b]	0.25 (0.17)[b]	0.25 (0.16)[b]

Note. Different superscript letters refer to significant differences ($p < .05$) between groups on post hoc tests.

3.6.2 Predictors of social disability.

Baseline predictor variables were entered into an ordinal regression model with baseline social disability group as the dependent variable. A negative log-log link function was used as a high proportion of the sample fell into the lower category. The assumption of proportional odds was met, indicating that the effects of any explanatory variables were consistent across different thresholds, i.e. from the lowest group (Severe SD) to the three higher groups (SD, At-risk SD, No SD), from the two lower groups (Severe SD, SD) to the two higher groups (At-risk SD, No SD), from the three lower groups (Severe SD, SD, At-risk SD) to the highest group (No SD). Including explanatory variables in the model significantly improved the fit of the model to the data, χ^2 (13) = 72.96, p <.001. As is shown in Table 12, group membership was predicted by gender and premorbid adjustment in late adolescence.

3.6.2.1 Gender.

When comparing females to males, the change in odds of being in a less socially disabled group as opposed to a more socially disabled group is 0.75. This suggests that males are less likely than females to be in higher functioning groups.

3.6.2.2 Late adolescence premorbid adjustment.

As premorbid adjustment scores increase by one unit (indicating poorer premorbid adjustment), the change in odds of being in a less socially disabled group as opposed to a more socially disabled group is 0.17. This suggests that the poorer an individual's premorbid adjustment between 16-18 years, the less likely they are to be in higher functioning groups.

Table 12

Proportional Odds Model for Baseline Social Disability Subgroup

Variable	Parameter	*B*	*SE*	Odds Ratio
Threshold	Severe Social Disability	-1.14	0.51	-
	Social Disability	-0.49	0.50	-
	At-risk of Social Disability	0.11	0.50	-
Age of onset of psychosis	Age at onset (in years)	0.01	0.01	1.01
Positive Symptoms	PANSS Positive Score	0.01	0.02	1.01
Negative Symptoms	PANSS Negative Score	-0.02	0.02	0.98
General Symptoms	PANSS General Score	-0.02	0.02	0.98
Depression	CDS Score	-0.01	0.02	0.99
Premorbid Adjustment (up to 11 years)	Childhood PAS score	0.84	0.45	2.31
Premorbid Adjustment (12 to 15 years)	Early Adolescence PAS score	0.08	0.56	1.08
Premorbid Adjustment (16 to 18 years)	Late Adolescence PAS score	-1.78	0.49	0.17***
Gender	Females vs. Males	-0.29	0.13	0.75*
Ethnicity (base = White British)	Asian	-0.26	0.19	0.77
	Black African Caribbean	-0.34	0.26	0.71
	Mixed Ethnicity	0.18	0.26	1.19
Duration Untreated Psychosis	Short (< 4 months) vs. Long (> 4 months)	-0.19	0.12	0.83

Nagelkerke pseudo R^2 = 13.1%, *p <.05, **p <.01, ***p <.001

3.6.3 Summary.

The ANOVA analyses outlined above suggest that between-group differences mostly relate to the Severe SD group. This group have higher levels of baseline negative and general symptoms, and poorer baseline functioning. The Severe SD group also have significantly poorer premorbid adjustment than other groups, suggesting the emergence of difficulties even prior to the onset of their psychosis. Chi-square tests suggested that there were more males and ethnic minorities in the Severe SD and SD subgroups than in other subgroups. Age of onset and levels of baseline depression and positive psychotic symptoms were comparable across all four groups. These findings were supported by the ordinal regression analysis which suggest that male gender and poor premorbid adjustment in late adolescence predict social disability in FEP.

3.7 Research Question 3: How many individuals with FEP experience a change in their weekly hours of structured activity in the first 12 months of EIP service provision?

3.7.1 Calculating change in TUS.

Change in TUS scores over the 12 month study period was examined by calculating change scores at baseline to 6 months, 6 months to 12 months, and baseline to 12 months for each participant. Based on previous research (Fowler, Hodgekins, Painter, et al., 2009; Hodgekins et al., in prep), a minimum change of 8 hours between time points was required in order for change to have occurred. Percentages of participants showing change at each time point are shown in Table 13.

Table 13

Frequency of Change in TUS scores over 12 month Study Period

	Decrease (≥ 8hrs)	No change (< 8hrs)	Increase (≥ 8hrs)
Baseline – 6 months (N = 673)	20.7%	40.0%	39.4%
6 months – 12 months (N = 623)	29.8%	37.5%	32.7%
Baseline – 12 months (N = 600)	20.9%	33.1%	46.1%

3.7.2. Defining change profile groups.

Participants were categorised according to their change profile over time. Participants displaying a consistent decrease in TUS scores over the 12 months (i.e. decreasing at both baseline to 6 months, and 6 months to 12 months) were defined as a *Decreasing* group. Participants displaying a consistent increase in TUS scores over the 12 months (i.e. increasing at both baseline to 6 months, and 6 months to 12 months) were defined as an *Increasing* group. Participants whose TUS scores fluctuated (i.e. both increased and decreased) over the 12 months were defined as a *Fluctuating* group. Participants whose TUS scores remained stable over the 12 months (i.e. no change at either baseline to 6 months, or 6 months to 12 months) were defined as a *Stable* group. See Table 14 for more details.

Table 14

Change Profile Subgroups

Subgroup	*n* (%) of total sample	Mean hours in Structured Activity (*SD*)		
		Baseline	6 months	12 months
Decreasing	138 (18.1%)	50.47 (31.81)	28.08 (22.32)	20.05 (20.54)
Stable	182 (23.8%)	18.55 (20.14)	18.53 (20.03)	19.78 (21.69)
Fluctuating	171 (22.4%)	25.41 (24.46)	40.37 (26.52)	30.11 (24.79)
Increasing	273 (35.7%)	16.35 (18.57)	33.17 (25.51)	46.52 (27.08)

3.7.3 Summary.

These findings suggest that change in time use within the first year of early intervention is heterogeneous, with most individuals improving, comparable numbers fluctuating or remaining stable, and a minority worsening. This supports the notion of different types of social recovery within FEP. The next section will examine predictors of change in time use.

3.8 Research Question 4: Which factors predict change in time use over the first 12 months of EIP service provision?

3.8.1 Comparing groups with different change profiles on baseline variables.

The four subgroups (Decreasing, Stable, Fluctuating, and Increasing) were compared on demographic characteristics and baseline predictor variables. Descriptive statistics are shown in Table 15. Exploratory ANOVAs were conducted to examine differences in continuous predictor variables between the four subgroups. Post hoc Tukey's HSD tests were conducted to interpret significant main effects. As nine ANOVAs were conducted, a Bonferroni adjustment (.05/9 = .006) was applied to the level of significance to avoid Type I errors (Field, 2009). Chi-square tests were used to examine group differences on categorical variables.

3.8.1.1 Age of onset.

There was no significant main effect of group on age of onset of psychosis, F (3, 727) = 2.66, p = .06, indicating that age did not influence whether individuals experienced a change in their time use over the 12 month study period.

3.8.1.2 Gender.

There was a significant association between group and gender, χ^2 (3) = 9.39, p = .03. Further investigation of this relationship by examining the standardised residuals of individual cells showed that there were significantly less males in the Fluctuating subgroup than in other subgroups, suggesting that women's time use was more likely to fluctuate over time.

3.8.1.3 Ethnicity.

There was no significant association between group and ethnicity, χ^2 (9) = 10.14, p = .34, suggesting that ethnicity did not influence whether individuals experienced a change in their time use over the 12 month study period.

3.8.1.4 Duration of untreated psychosis.

There was no significant association between social disability group and length of DUP, χ^2 (3) = 1.96, p = .58, indicating that DUP did not influence whether individuals experienced a change in their time use over the 12 month study period.

3.8.1.5 Psychotic symptoms.

There was no significant main effect of group on Positive PANSS symptoms scores, F (3, 723) = 2.48, p = .06, or General PANSS symptoms scores, F (3, 718) = 2.78, p = .04. However, there was a significant main effect of group on Negative PANSS symptoms scores, F (3, 714) = 4.91, p =.002. Post hoc comparisons using Tukey's HSD tests indicated that the Stable subgroup had significantly higher levels of negative symptoms at baseline compared to the other three subgroups, suggesting that

change in time use was less likely for individuals with more baseline negative symptoms.

3.8.1.6 Depression.

There was no significant main effect of group on Calgary Depression Scale scores, F (3, 732) = 1.60, p = .19, with all subgroups scoring around the cut-off score for a major depressive episode.

3.8.1.7 Global Assessment of Functioning.

There was a significant main effect of group on GAF scores, F (3, 732) = 5.13, p = .002. Post hoc comparisons using Tukey's HSD tests indicated that the Decreasing group had significantly lower functioning at baseline than the Stable, and Fluctuating subgroups. This suggests that individuals with poor baseline functioning on the GAF were more likely to experience a reduction in their time use over the 12 month study period.

3.8.1.8 Premorbid adjustment.

There was no significant main effect of group on Childhood (up to age 11) PAS scores, F (3, 711) = 0.31, p = .82, Early Adolescence (12-15yrs) PAS scores, F (3, 687) = 1.32, p = .27, or Late Adolescence (16-18yrs) PAS scores, F (3, 582) = 3.02, p = .03, indicating that DUP did not influence whether individuals experienced a change in their time use over the 12 month study period.

Table 15

Descriptive Statistics for Baseline Predictor Variables for TUS Change Profile Subgroups – Mean (SD)

	Decreasing Group (n = 138)	Stable Group (n = 182)	Fluctuating Group (n = 171)	Increasing Group (n = 273)
Age of onset	20.76 (4.96)	20.61 (4.33)	21.72 (5.37)	21.73 (5.21)
Male Gender *n* (%)	103 (75%)[a]	137 (75%)[a]	106 (62%)[b]	186 (68%)[a]
Ethnicity *n* (%)				
White	96 (69%)	124 (68%)	126 (74%)	210 (77%)
Asian	26 (19%)	34 (19%)	24 (14%)	32 (12%)
Black African-	12 (9%)	15 (8%)	11 (6%)	15 (5%)
Caribbean	4 (3%)	9 (5%)	10 (6%)	16 (6%)
Mixed Ethnicity				
DUP > 4 months *n* (%)	63 (46%)	80 (45%)	68 (40%)	109 (40%)
PANSS Positive	14.07 (5.54)	14.72 (5.51)	15.57 (5.91)	15.55 (6.19)
PANSS Negative	14.10 (6.29)[a]	16.75 (6.93)[b]	14.77 (6.73)[a]	14.83 (6.18)[a]
PANSS General	30.70 (9.04)	33.06 (9.65)	33.37 (10.33)	33.70 (10.26)
Calgary Depression Scale	5.53 (4.79)	6.24 (5.42)	6.70 (5.49)	6.67 (5.48)
GAF	54.50 (17.25)[a]	47.46 (16.79)[b]	48.72 (16.24)[b]	51.33 (17.47)
Premorbid Adjustment				
Childhood	0.23 (0.17)	0.24 (0.19)	0.23 (0.17)	0.23 (0.18)
Early Adolescence	0.27 (0.17)	0.31 (0.17)	0.29 (0.18)	0.28 (0.17)
Late Adolescence	0.27 (0.18)	0.34 (0.19)	0.32 (0.19)	0.30 (0.19)

Note. Different superscript letters refer to significant differences ($p < .05$) between groups on post hoc tests.

3.8.2 Predicting TUS change profile from baseline variables.

As the assumption of proportional odds required for ordinal regression was violated, baseline predictor variables were entered into a multinomial regression model with change group (Decreasing, Stable, Fluctuating, Increasing) as the dependent variable. Baseline social disability group was also included in the model as a covariate as this may influence whether individuals make a change over time. The Increasing subgroup was chosen as the reference category for the regression analysis as this subgroup was thought to reflect the best functional outcome. Results of the regression model are shown in Table 16.

3.8.2.1 Decreasing vs. increasing group.

Membership in the decreasing vs. increasing group was predicted by gender, ethnicity, and baseline social disability group. Males were twice as likely as females to be in the decreasing vs. the increasing group, indicating that males were less likely to experience a positive change in their time use. Individuals of Asian ethnicity were three times as likely as individuals describing themselves as White to be in the decreasing vs. the increasing group. Individuals of Black African-Caribbean ethnicity were four and a half times as likely as individuals describing themselves as White to be in the decreasing vs. the increasing group. These findings suggest that individuals from ethnic minorities were less likely to experience a positive change in their time use than White individuals following 12 months of EIP service provision. Individuals in the Severe SD, SD, and At-risk SD baseline subgroups were significantly less likely to be in the decreasing vs. the increasing group, suggesting that these groups were more likely to experience a positive change in their time use. This may be because there is more scope for change in individuals with low baseline levels of time use.

3.8.2.2 Stable vs. increasing group.

Membership in the stable vs. increasing group was predicted by baseline negative symptoms, gender, DUP, and baseline social disability group. As baseline negative symptoms increase by one unit, the change in odds of being in the no change vs. increasing group is 1.07, suggesting that individuals with higher levels of baseline negative symptoms were less likely to experience a positive change in their time use over the 12 month study period. Males were twice as likely as females to be in the Stable vs. Increasing group, again indicating that males have a poorer recovery profile. Individuals with short DUP (< 4 months) were half as likely as individuals with long DUP (> 4 months) to be in the no change vs. increasing group, suggesting that a longer DUP reduces the likelihood of positive change in time use. Individuals in the Severe SD subgroup at baseline were half as likely to be in the no change vs. the increasing group compared to the No SD subgroup. As outlined above, this may be because there is more scope for change in the Severe SD subgroup.

3.8.2.3 Fluctuating vs. increasing group.

Membership in the Fluctuating vs. Increasing subgroup was predicted by late adolescence premorbid adjustment and baseline social disability group. As late adolescence PAS scores increase by one unit (indicating poorer premorbid adjustment), the change in odds of being in the Fluctuating vs. Increasing group is 6.88, suggesting that individuals with poorer premorbid adjustment in late adolescence are more likely to experience fluctuations in their time use rather than a consistent increase. This may reflect a vulnerability to social disability.

Table 16

Results of Multinomial Regression Analysis for Change Profile on TUS

	B	*SE*	Odds Ratio
Decreasing Group vs. Increasing Group			
Intercept	2.75	1.00	
Age of onset of psychosis	-0.06	0.04	0.94
Positive Symptoms	-0.01	0.04	0.98
Negative Symptoms	0.06	0.03	1.07
General Symptoms	-0.01	0.03	0.99
Depression	-0.01	0.04	0.99
Premorbid Adjustment (up to 11 years)	-0.19	1.16	0.82
Premorbid Adjustment (12 to 15 years)	-0.17	1.43	0.84
Premorbid Adjustment (16 to 18 years)	0.29	1.27	1.34
Gender (Males vs. Females)	0.73	0.36	2.08*
Ethnicity (base = White British)			
Asian	1.16	0.47	3.20***
Black African-Caribbean	1.52	0.63	4.58***
Mixed Ethnicity	-0.78	0.75	0.46
Duration Untreated Psychosis	-0.53	0.32	0.59
Baseline Social Disability (base = No Social Disability)			
Severe Social Disability	-4.90	0.58	0.01***
Social Disability	-2.19	0.46	0.11***
At-risk of Social Disability	-1.69	0.48	0.19***
Stable vs. Increasing Group			
Intercept	1.01	0.89	
Age of onset of psychosis	-0.03	0.03	0.97
Positive Symptoms	-0.03	0.03	0.97
Negative Symptoms	0.06	0.03	1.07**
General Symptoms	-0.01	0.02	0.99
Depression	-0.01	0.03	0.99
Premorbid Adjustment (up to 11 years)	0.47	0.99	1.59
Premorbid Adjustment (12 to 15 years)	0.63	1.23	1.87
Premorbid Adjustment (16 to 18 years)	-0.40	0.98	0.67
Gender (Males vs. Females)	0.72	0.30	2.05*
Ethnicity (base = White British)			
Asian	0.36	0.38	1.43
Black African-Caribbean	0.42	0.54	1.52
Mixed Ethnicity	-0.67	0.57	0.51
Duration Untreated Psychosis (Short vs. Long)	-0.58	0.26	0.56*
Baseline Social Disability (base = No Social Disability)			
Severe Social Disability	-0.88	0.43	0.42*
Social Disability	-0.52	0.48	0.60
At-risk of Social Disability	-0.84	0.55	0.45

Table 16 continued.

	B	*SE*	Odds Ratio
Fluctuating vs. Increasing Group			
Intercept	-0.48	0.82	
Age of onset of psychosis	0.03	0.03	1.04
Positive Symptoms	0.01	0.03	1.01
Negative Symptoms	0.01	0.03	1.01
General Symptoms	-0.01	0.02	0.99
Depression	-0.01	0.03	0.99
Premorbid Adjustment (up to 11 years)	0.82	0.99	2.27
Premorbid Adjustment (12 to 15 years)	-1.22	1.22	0.30
Premorbid Adjustment (16 to 18 years)	1.93	0.95	6.88*
Gender (Males vs. Females)	-0.22	0.26	0.80
Ethnicity (base = White British)			
Asian	0.10	0.39	1.11
Black African-Caribbean	0.37	0.53	1.45
Mixed Ethnicity	-0.23	0.52	0.79
Duration Untreated Psychosis	0.04	0.26	1.04
Baseline Social Disability (base = No Social Disability)			
Severe Social Disability	-1.31	0.40	0.27***
Social Disability	-0.75	0.44	0.47
At-risk of Social Disability	-0.52	0.48	0.59

Note. Nagelkerke pseudo R^2 = 34.4%. Model χ^2 = 197.06, p <.001.
*p <.05, **p <.01, ***p <.001

3.8.3 Summary.

The results suggest that being male, having an ethnic minority status, and a DUP longer than 4 months may be associated with a decrease or no change in time use. Moreover, high baseline levels of negative symptoms and poor premorbid adjustment in late adolescence may also reduce the likelihood of a positive change in time use following entry into an EIP service. Although change in time use reflects some aspects of social recovery, recovery also depends on the level of functioning achieved by the end of the 12 month study period. For example, individuals whose time use is stable, fluctuates, or decreases but remains within the No SD range could arguably still be considered as recovered, whereas an individual whose time use increases but remains within the disabled range would not. This will be considered in more detail in the next section.

3.9 Research Question 5: How many individuals with FEP make a good social recovery in the first 12 months of EIP service provision and how many remain socially disabled?

3.9.1 Recovery types.

Three different recovery types were defined using baseline social disability groups (from section 3.5) and change profiles over the 12 month study period (from section 3.7). These will now be described in more detail (and see Table 17). See Appendix G for a table illustrating how individuals were categorised into the different recovery types.

3.9.1.1 No Social Recovery (NSR).

This group included: (1) individuals who were in the Severe SD or SD subgroups at baseline and who remained in these groups over the 12 month period (n = 281); (2) individuals who were in the At-risk SD or No SD subgroups at baseline but whose TUS scores decreased over the 12 month period such that they fell into the clinical range by the end of the 12 months (n = 56); (3) individuals whose TUS scores fluctuated over the study period but who scored within the clinical range at the end of the 12 months (n = 92).

3.9.1.2 Partial Social Recovery (PSR).

This group included: (1) individuals who were in the At-risk SD subgroup at baseline and who remained in this group over the 12 month study period (n = 18); (2) individuals who were in the Severe SD or SD subgroups at baseline but whose TUS scores increased over the 12 month period such that they fell into the at-risk range by the end of the 12 months (n = 61); (3) individuals who were in the No SD subgroup at baseline but whose TUS scores decreased over the 12 month period such that they fell into the At-risk range by the end of the 12 months (n = 13); (4) individuals whose TUS

scores fluctuated over the study period but who scored within the At-risk range at the end of the 12 months (n = 35).

3.9.1.3 Full Social Recovery (FSR).

This group included: (1) individuals who were in the No SD subgroup at baseline and who remained in this group over the 12 month study period (n = 90); (2) individuals who were in the Severe SD, SD, or At-risk SD subgroups at baseline but whose TUS scores increased over the 12 month period such that they fell into the non-clinical range by the end of the 12 months (n = 97); (3) individuals whose TUS scores fluctuated over the study period but who scored within the non-clinical range at the end of the 12 months (n = 21).

Table 17

Social Recovery Subgroups

Subgroup	*n* (%) of total sample	Mean hours in Structured Activity (*SD*)		
		Baseline	6 months	12 months
No Social Recovery (NSR)	429 (56.2%)	15.93 (19.65)	17.73 (15.27)	13.08 (8.60)
Partial Social Recovery (PSR)	127 (16.6%)	27.90 (22.44)	35.85 (19.35)	38.05 (5.00)
Full Social Recovery (FSR)	208 (27.2%)	42.18 (30.97)	55.75 (26.19)	67.54 (21.76)

3.9.2 Summary.

Recovery following the first year of early intervention service provision is variable, with about one-third of individuals achieving a full social recovery (i.e. scoring within the non-clinical range on the TUS). However, over 50% of individuals

remain socially disabled at the end of 12 months EIP service provision. The next section will examine predictors of social recovery.

3.10 Research Question 6: Which factors predict whether an individual makes a social recovery in the first 12 months of EIP service provision following FEP?

3.10.1 Comparing recovery types on baseline variables.

The three recovery types were compared on demographic characteristics and baseline predictor variables. Descriptive statistics are shown in Table 18. Exploratory ANOVAs were conducted to examine differences in continuous predictor variables between the four subgroups. Post hoc Tukey's HSD tests were conducted to interpret significant main effects. As nine ANOVAs were conducted, a Bonferroni adjustment (.05/9 = .006) was applied to the level of significance to avoid Type I errors (Field, 2009). Chi-square tests were used to examine group differences on categorical variables.

3.10.1.1 Age of onset.

There was a significant main effect of group on age of onset of psychosis, F (2, 728) = 10.02, $p < .001$. Post hoc comparisons using Tukey's HSD tests indicated that the NSR and PSR groups had a significantly younger age of onset of their psychoses than the FSR group. This suggests that an older age of onset is indicative of a better outcome.

3.10.1.2 Gender.

There was a significant association between recovery group and gender, χ^2 (2) = 19.12, $p = <.001$. Further investigation of this relationship by examining the standardised residuals of individual cells showed that there were significantly more females in the FSR subgroup than in other subgroups. In line with other findings in this study, this suggests that females are more likely than males to have a better outcome.

3.10.1.3 Ethnicity.

There was a significant association between recovery group and ethnicity, χ^2 (6) = 16.28, p = .01. Further investigation of this relationship by examining the standardised residuals of individual cells showed that there were significantly less individuals of Asian ethnicity in the FSR subgroup than in other subgroups. This suggests that individuals of Asian ethnicity were less likely to have a good recovery outcome.

3.10.1.4 Duration of untreated psychosis.

There was no significant association between recovery group and length of DUP, χ^2 (2) = 3.17, p = .20, indicating comparable DUP lengths between all three recovery groups.

3.10.1.5 Psychotic symptoms.

There was no significant main effect of group on Positive PANSS symptoms scores, F (2, 724) = 4.76, p = .01, or General PANSS symptoms scores, F (2, 719) = 3.75, p = .02. However, there was a significant main effect of group on Negative PANSS symptoms scores, F (2, 715) = 16.99, p = < .001. Post hoc comparisons using Tukey's HSD tests indicated that the NSR group had significantly higher levels of negative symptoms at baseline compared to the FSR group. This suggests that higher baseline levels of negative symptoms are associated with a poorer social recovery outcome.

3.10.1.6 Depression.

There was no significant main effect of group on Calgary Depression Scale scores, F (2, 733) = 0.45, p = .64, with all groups scoring around the cut-off score for a major depressive episode.

3.10.1.7 Global Assessment of Functioning.

There was a significant main effect of group on GAF scores, F (2, 733) = 30.19, p < 001. Post hoc comparisons using Tukey's HSD tests indicated that the NSR group had significantly lower functioning at baseline than the PSR and FSR groups. This indicates that lower baseline functioning assessed by the GAF was associated with poorer social recovery outcome over the 12 month study period.

3.10.1.8 Premorbid adjustment.

There was no significant main effect of group on Childhood (up to age 11) PAS scores, F (2, 712) = 1.70, p = .18. However, there was a significant main effect of group on Early Adolescence (12-15yrs) PAS scores, F (2, 688) = 9.85, p <.001; and Late Adolescence (16-18yrs) PAS scores, F (2, 583) = 15.60, p = <.001. Post hoc comparisons using Tukey's HSD tests indicated that the NSR group had significantly poorer premorbid adjustment at age 12-15 years than the FSR group. The NSR group also had significantly poorer premorbid adjustment at age 16-18 years than both the PSR and FSR groups. Similar to previous findings in this study, this suggests that poor premorbid functioning in adolescence, before the onset of psychosis, was associated with a poorer social recovery outcome 12 months after entry into an EIP service.

Table 18

Descriptive Statistics for Baseline Predictor Variables for Social Recovery Subgroups – Mean (SD)

	No Social Recovery (*n* = 429)	Partial Social Recovery (*n* = 127)	Full Social Recovery (*n* = 208)
Age of onset	20.70 (4.74)[a]	21.15 (4.76)[a]	22.63 (5.53)[b]
Male Gender *n* (%)	324 (76%)[a]	86 (68%)[a]	122 (59%)[b]
Ethnicity *n* (%)			
White	291 (68%)	97 (76%)	168 (81%)
Asian	80 (18%)[a]	17 (13%)[a]	19 (9%)[b]
Black African-	37 (9%)	6 (5%)	10 (5%)
Caribbean	21 (5%)	7 (6%)	11 (5%)
Mixed Ethnicity			
DUP > 4 months *n* (%)	191 (45%)	50 (39%)	79 (38%)
PANSS Positive	15.43 (5.84)	15.71 (6.15)	14.02 (5.65)
PANSS Negative	16.29 (6.80)[a]	14.73 (6.09)	13.06 (5.77)[b]
PANSS General	33.71 (9.85)	33.02 (10.21)	31.34 (9.91)
Calgary Depression Scale	6.48 (5.42)	5.96 (5.42)	6.38 (5.21)
GAF	46.43 (16.06)[a]	52.65 (15.67)[b]	57.20 (17.83)[b]
Premorbid Adjustment			
Childhood	0.24 (0.18)	0.21 (0.19)	0.23 (0.17)
Early Adolescence	0.31 (0.17)[a]	0.27 (0.18)	0.25 (0.16)[b]
Late Adolescence	0.35 (0.19)[a]	0.29 (0.21)[b]	0.25 (0.15)[c]

Note. Different superscript letters refer to significant differences ($p < .05$) between groups on post hoc tests.

3.10.2 Predicting recovery type from baseline variables.

Baseline predictor variables were entered into an ordinal regression model with change group as the dependent variable. Baseline social disability group was also included in the model. The assumption of proportional odds was met, indicating that the effects of any explanatory variables were consistent across different thresholds (i.e. from the lowest group to the two higher groups, from the two lower groups to the highest group). Including explanatory variables in the model significantly improved the fit of the model to the data, χ^2 (16) = 146.42, p <.001. As is shown in Table 19, group membership was predicted by age of onset, baseline negative symptoms, gender, ethnicity, DUP, and baseline social disability group.

3.10.2.2 Age of onset.

As age of onset of psychosis increase by one unit, the change in odds of making a better recovery is 1.04. This suggests that the later an individual's age of onset, the more likely they are to make a Partial or Full recovery.

3.10.2.3 Negative symptoms.

As baseline negative symptoms increase by one unit, the change in odds of making a better recovery is 0.97. This suggests that individuals with higher levels of baseline negative symptoms are less likely to make a Partial or Full social recovery.

3.10.2.4 Gender.

When comparing females to males, the change in odds of making a better social recovery is 0.65. This suggests that males are less likely than females to make a Partial or Full social recovery supporting results from previous analyses in this study.

3.10.2.5 Ethnicity.

When comparing individuals with White ethnicity to individuals with Black African-Caribbean ethnicity, the change in odds of making a better social recovery is

0.50. This suggests that individuals with Black African-Caribbean ethnicity are half as likely to make a partial or full social recovery than individuals who describe their ethnicity as White.

3.10.2.6 DUP.

When comparing individuals with long DUP (> 4 months) and individuals with short DUP (< 4 months), the change in odds of making a better recovery is 1.31. This suggests that individuals with a shorter DUP are more likely to make a Full or Partial recovery than individuals with a long DUP.

3.10.2.7 Baseline social disability group.

Individuals in the Severe SD and SD subgroups at baseline were less likely to make a Full or Partial recovery than individuals in the No SD group at baseline. This finding suggests that social disability upon entry into EIP services may be indicative of long-term outcome.

3.10.3 Summary.

The results suggest that being male, having an ethnic minority status, and a DUP longer than 4 months may be associated with a poorer social recovery. Moreover, high baseline levels of negative symptoms and a younger age of onset of psychosis may also reduce the likelihood of a Partial or Full social recovery. The between-group comparisons using ANOVA suggested that the NSR group had poorer premorbid adjustment in early and late adolescence compared to PSR and FSR groups, although this finding was not supported by the regression analysis. However, baseline social disability predicted recovery group and earlier analyses suggest that poor premorbid adjustment predicts higher baseline levels of social disability.

Table 19

Proportional Odds Model for Social Recovery Subgroup

Variable	Parameter	*B*	*SE*	Odds Ratio
Threshold	No Social Recovery	0.18	0.41	-
	Partial Social Recovery	0.91	0.42	-
Age of onset of psychosis	Age at onset (in years)	0.04	0.01	1.04**
Positive Symptoms	PANSS Positive Score	-0.02	0.02	0.98
Negative Symptoms	PANSS Negative Score	-0.03	0.02	0.97*
General Symptoms	PANSS General Score	0.02	0.01	1.02
Depression	CDS Score	-0.02	0.02	0.98
Premorbid Adjustment (up to 11 years)	Childhood PAS score	0.23	0.54	1.26
Premorbid Adjustment (12 to 15 years)	Early Adolescence PAS score	-0.49	0.67	0.61
Premorbid Adjustment (16 to 18 years)	Late Adolescence PAS score	-0.67	0.58	0.51
Gender	Males vs. Females	-0.43	0.15	0.65**
Ethnicity (base = White British)	Asian	-0.39	0.23	0.68
	Black African Caribbean	-0.69	0.34	0.50*
	Mixed Ethnicity	0.18	0.30	1.20
Duration of Untreated Psychosis	Short (< 4 months) vs. Long (> 4 months)	0.27	0.14	1.31*
Baseline Social Disability Group (base = No Social Disability)	Severe Social Disability	-1.44	0.18	0.24***
	Social Disability	-1.08	0.20	0.34***
	At-risk of Social Disability	-0.33	0.20	0.72

Note. Nagelkerke pseudo R^2 = 29.1%, *p <.05, **p <.01, ***p <.001

3.11 Research Question 7: Do different trajectories of social recovery exist over the first 12 months following FEP? Which factors predict different recovery trajectories?

As a final stage of the analyses, Latent Class Growth Analysis (LCGA) was used as an alternative approach to examine social recovery trajectories in FEP. This approach used continuous TUS data rather than splitting the data into ordinal categories. It could be argued that this is more appropriate as converting continuous data into categories may result in the loss of information (Altman & Royston, 2006). The results of this analysis will now be outlined and compared to the analyses outlined above which used ordinal categories derived from cut-off scores on the TUS.

3.11.1 General changes in TUS scores over time.

Prior to specifying latent classes, change in time use over time (baseline, 6 months, and 12 months) was analysed using a single-class growth model (see Figure 3). This model showed an acceptable model fit, with $\chi^2(1) = 6.82$, $p = .001$, and a CFI of 0.98. The unstandardised mean intercept was 25.37 (95% CI = 23.49, 27.25) and the unstandardised mean slope was 6.36 (95% CI = 4.59, 8.12), indicating that time use increased over time in the sample as a whole. However, inspection of individual growth curves suggested significant variation within the sample (see Figure 4).

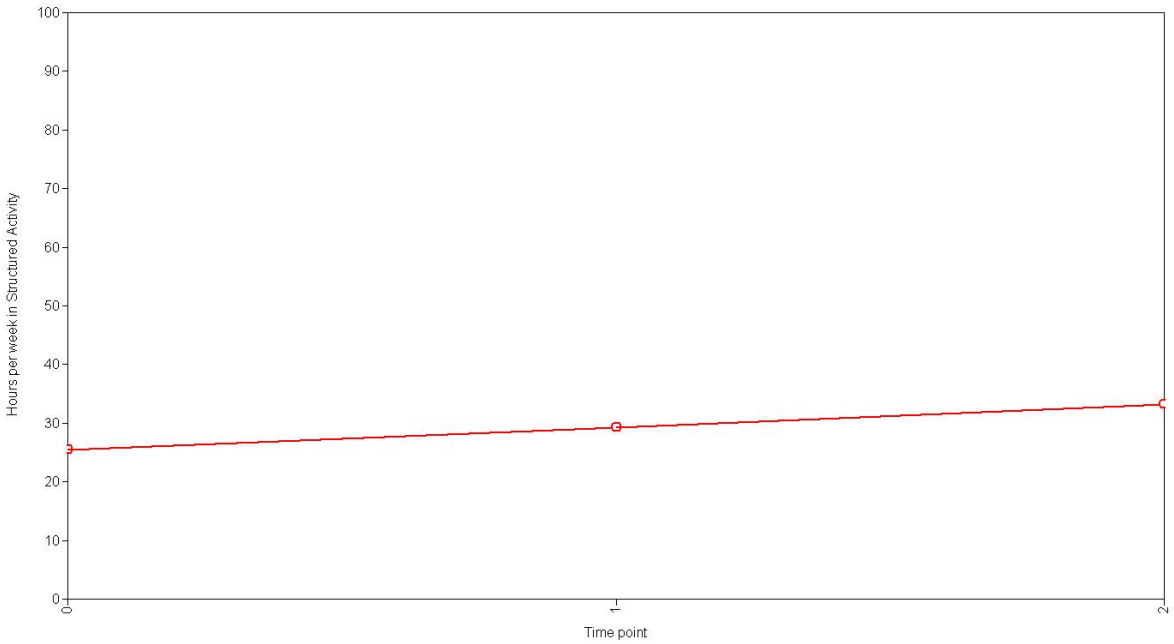

Figure 3

Single growth model illustrating mean trajectory of Structured Activity on the TUS over 12 months

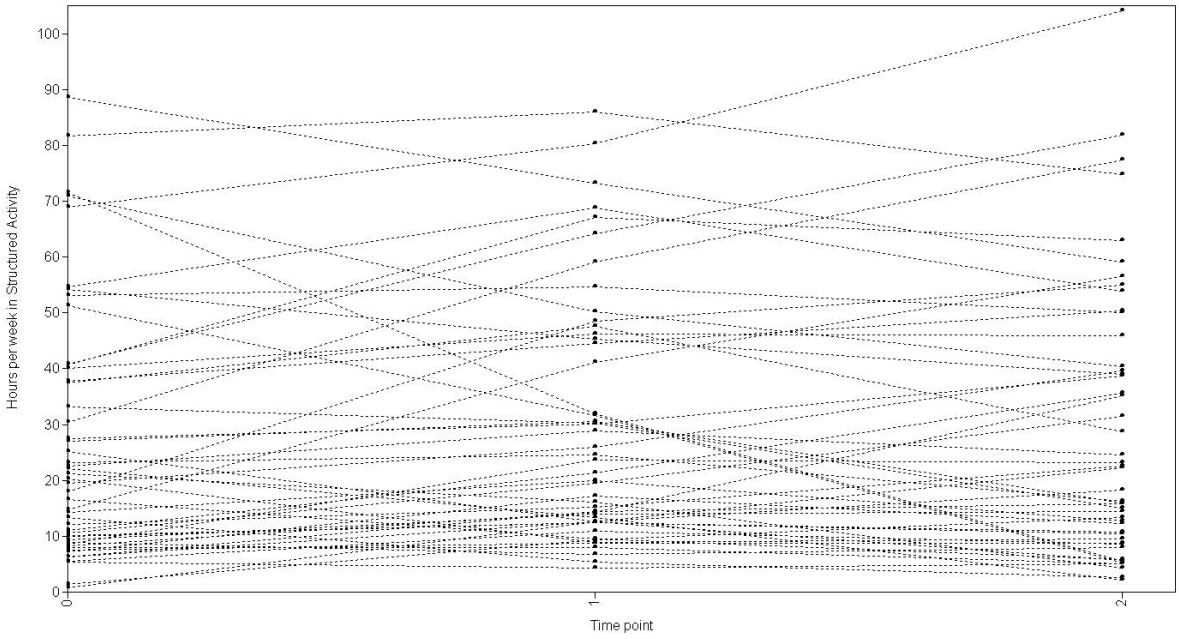

Figure 4

Subsample of 50 individual trajectories of Structured Activity on the TUS over 12 months

3.11.2 Examining different trajectories of time use.

Several subsequent LCGA models were executed with increasing numbers of classes to investigate the presence of different trajectories of social recovery. Model fit for each LCGA is shown in Table 20. A model with three classes described the data well. This model was significantly better than a model with two classes and showed a satisfactory entropy value (Andruff et al., 2009). In addition, the Bayesian Information Criterion (BIC; defined in Table 5) value decreased when increasing the number of classes from two to three. Average class probabilities for the three class model were high (see Table 21), indicating that participants were correctly assigned to their respective latent classes. Convergence checks were conducted on the three class model to ensure that it was not a local solution (Jung & Wickrama, 2008). Model estimates were replicated, suggesting a global solution and increasing the stability of the findings.

Although the BIC value reduced further for models with four and more classes, these models were not of significantly better fit than a model with three classes. In addition, models with four and more classes included classes consisting of less than 5% of the sample. Thus, a three class model was chosen as the best fitting model and is illustrated in Figure 5.

Table 20

Criteria for Deciding the Number of Classes within the Repeated Measures of Time Use

Number of classes	Entropy	BIC	LMR-LRT statistic	LMR-LRT *p* value
2	.89	18809.33	508.57	<.001
3	.80	18652.52	168.28	.05
4	.86	18582.12	86.00	.32
5	.87	18506.09	91.36	.10
6	.87	18452.27	70.76	.27
7	.89	18396.47	65.22	.32
8	.87	18379.97	61.23	.37
9	.88	18355.05	22.35	.72
10	.85	18350.88	23.89	.49

Note. BIC = Bayesian Information Criterion; LMR-LRT = Lo-Mendell-Rubin Likelihood Ratio Test

Table 21

Average Posterior Probabilities for each Class in a Three Class LCGA Model

	Class 1	Class 2	Class 3
Class 1	.94		
Class 2		.84	
Class 3			.91

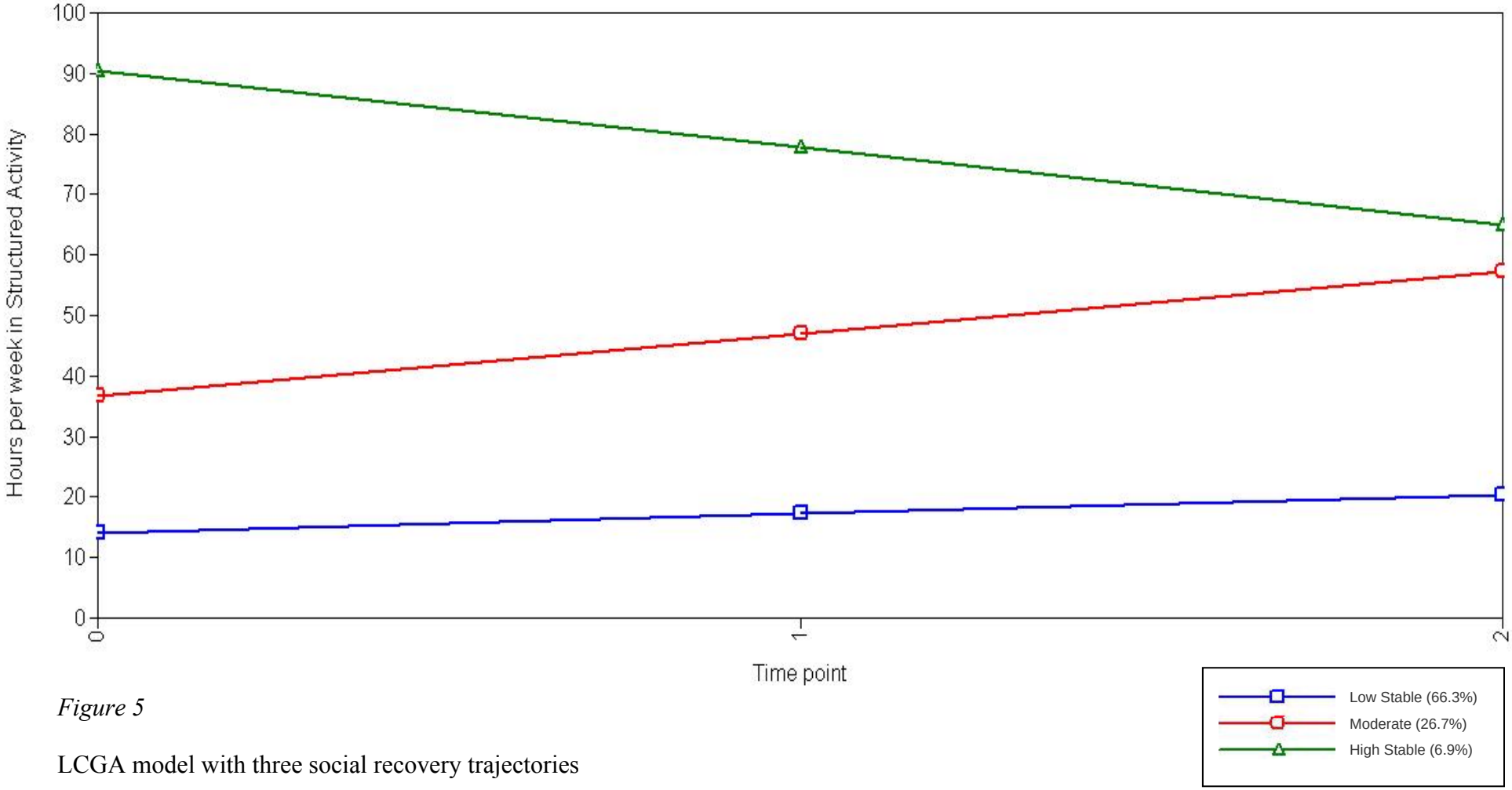

Figure 5

LCGA model with three social recovery trajectories

3.11.3 Description of classes.

The three groups included in the three class model represented different trajectories of social recovery. Each class will now be described in more detail.

3.11.3.1 Class 1 – low stable time use.

The first class contained the largest number of participants (*n* = 507, 66.3% of the sample) and was characterised by a low intercept (unstandardised mean intercept = 14.00) and a shallow positive slope (unstandardised mean slope = 3.18). This class was labelled the Low Stable group, reflecting individuals with high levels of social disability at baseline which then remained stable over the study period.

3.11.3.2 Class 2 – moderate/increasing time use.

The second class (*n* = 204, 26.7% of the sample) was characterised by a moderate intercept (unstandardised mean intercept = 36.64) and a positive slope (unstandardised mean slope = 10.29). This class was labelled the Moderate/Increasing group, reflecting individuals with a moderate level of social disability at baseline which then remained stable or slightly improved over the study period.

3.11.3.3 Class 3 – high/decreasing time use.

The third class (*n* = 53, 6.9% of the sample) was characterised by a high intercept (unstandardised mean intercept = 90.53) and a negative slope (unstandardised mean slope = -12.78). This class was labelled the High/Decreasing group, reflecting individuals who were not socially disabled at baseline and who maintained their level of functioning over the study period, but with a slight decrease.

3.11.4 Comparing LCGA with groups defined using cut-off scores.

Membership in recovery groups defined using cut-offs outlined in section 3.9 was compared with membership in the recovery classes defined by the LCGA. Results are shown in Table 22. The results suggest an overlap between the two approaches, but

also some differences. The Low Stable group (66.3%) defined by LCGA is larger than the No Recovery subgroup (56.2%) and also includes a substantial proportion of individuals defined as having a Partial Recovery using cut-off scores. Moreover, many of the individuals defined as having a Full Recovery using cut-off scores fall into the Moderate/Increasing category in the LCGA. Thus, the LCGA findings suggest a higher level of social disability in individuals with FEP than findings from the analyses using cut-off scores. However, both approaches suggest that time use remains relatively stable over the 12 month study period and thus that baseline levels of functioning (i.e. upon entry into EIP services) may be important in predicting long-term course.

Table 22

Comparing Social Recovery Types Defined from TUS Cut-off Scores vs. LCGA

	Recovery classes (from LCGA)			
	Low Stable	Moderate/ Increasing	High/ Decreasing	*Total*
Recovery subtypes (from cut-off scores)				
No Social Recovery	402	21	6	*429*
Partial Social Recovery	81	38	8	*127*
Full Social Recovery	24	145	39	*208*
Total	*507*	*204*	*53*	*764*

3.11.5 Comparing classes on baseline variables.

The three classes (Low Stable, Moderate/Increasing, and High/Decreasing) were compared on demographic characteristics and baseline predictor variables. Descriptive statistics are shown in Table 23. Exploratory ANOVAs were conducted to examine differences in continuous predictor variables between the four subgroups. Post hoc

Tukey's HSD tests were conducted to interpret significant main effects. As nine ANOVAs were conducted, a Bonferroni adjustment (.05/9 = .006) was applied to the level of significance to avoid Type I errors (Field, 2009). Chi-square tests were used to examine group differences on categorical variables.

3.11.1.1 Age of onset.

There was a significant main effect of social recovery class on age of onset of psychosis, F (2, 728) = 13.58, $p < .001$. Post hoc comparisons using Tukey's HSD tests indicated that the Low Stable group had a younger age of onset than the Moderate/Increasing and the High/Decreasing groups. The Moderate/Increasing group also had a younger age of onset than the High/Decreasing group. In line with previous findings in this study this suggests that an older age of onset of psychosis may be associated with a better outcome.

3.11.1.2 Gender.

There was a significant association between social recovery class and gender, χ^2 (2) = 21.00, p = <.001. Further investigation of this relationship by examining the standardised residuals of individual cells showed that there were significantly more females in the Moderate/Increasing and High/Decreasing subgroups than in the Low Stable subgroup. This suggests that females may have a better outcome than males.

3.11.1.3 Ethnicity.

There was a significant association between social recovery class and ethnicity, χ^2 (6) = 21.97, $p < .001$. Further investigation of this relationship by examining the standardised residuals of individual cells showed that there were significantly more individuals of Asian and Black African-Caribbean ethnicity in the Low Stable subgroup than in other subgroups. In line with previous findings in this study this suggests that

individuals from ethnic minorities may have a poorer outcome than individuals describing their ethnicity as White.

3.11.1.4 Duration of untreated psychosis.

There was no significant association between recovery group and length of DUP, χ^2 (2) = 3.64, p = .16, indicating comparable DUP lengths between all three recovery groups.

3.11.1.5 Psychotic symptoms.

There was a significant main effect of social recovery class on Positive PANSS symptoms scores, F (2, 724) = 6.04, p = .002; Negative PANSS symptoms scores, F (2, 715) = 18.92, p = < .001; and General PANSS symptoms scores, F (2, 719) = 5.73, p = .003. Post hoc comparisons using Tukey's HSD tests indicated that the Low Stable class had significantly higher levels of positive and general psychotic symptoms at baseline compared to the Moderate/Increasing class. The Low Stable class also had significantly higher levels of negative symptoms at baseline compared to the Moderate/Increasing and High/Decreasing classes. These findings suggest that higher baseline levels of psychotic symptoms were associated with a poorer social recovery outcome.

3.11.1.6 Depression.

There was no significant main effect of social recovery class on Calgary Depression Scale scores, F (2, 733) = 1.33, p = .27, with all classes scoring around the cut-off score for a major depressive episode.

3.11.1.7 Global Assessment of Functioning.

There was a significant main effect of social recovery class on GAF scores, F (2, 733) = 35.25, p < 001. Post hoc comparisons using Tukey's HSD tests indicated that the Low Stable class had significantly lower functioning at baseline than the Moderate/Increasing, and High/Decreasing classes. This indicates that lower baseline

functioning assessed by the GAF is associated with poorer social recovery outcome over the 12 month study period.

3.11.1.8 Premorbid adjustment.

There was no significant main effect of social recovery class on Childhood (up to age 11) PAS scores, F (2, 712) = 2.05, p = .13. However, there was a significant main effect of group on Early Adolescence (12-15yrs) PAS scores, F (2, 688) = 9.42, p <.001; and Late Adolescence (16-18yrs) PAS scores, F (2, 583) = 21.10, p = <.001. Post hoc comparisons using Tukey's HSD tests indicated that the Low Stable class had significantly poorer premorbid adjustment at age 12-15 years than the Moderate/Increasing class. The Low Stable class also had significantly poorer premorbid adjustment at age 16-18 years than both the Moderate/Increasing and High/Decreasing classes. Similar to previous findings in this study, this suggests that poor premorbid functioning in adolescence, before the onset of psychosis, was associated with a poorer social recovery outcome 12 months after entry into an EIP service.

Table 23

Descriptive Statistics for Baseline Predictor Variables for Social Recovery Classes – Mean (SD)

	Low Stable (n = 507)	Moderate/Increasing (n = 204)	High/Decreasing (n = 53)
Age of onset	20.75 (4.67)[a]	21.88 (5.32)[b]	24.30 (5.97)[c]
Male Gender *n* (%)	378 (75%)[a]	128 (63%)[b]	26 (49%)[b]
Ethnicity *n* (%)			
White	346 (68%)	169 (83%)	41 (77%)
Asian	93 (18%)[a]	17 (8%)[b]	6 (11%)[b]
Black African-	44 (9%)[a]	7 (4%)[b]	2 (4%)[b]
Caribbean	24 (5%)	11 (5%)	4 (8%)
Mixed Ethnicity			
DUP > 4 months *n* (%)	217 (43%)	76 (38%)	27 (51%)
PANSS Positive	15.63 (5.85)[a]	13.98 (5.93)[b]	14.35 (5.23)
PANSS Negative	16.16 (6.73)[a]	13.45 (5.95)[b]	12.00 (4.59)[b]
PANSS General	33.84 (9.91)[a]	31.28 (10.37)[b]	30.94 (7.67)
Calgary Depression Scale	6.47 (5.44)	5.91 (5.16)	7.13 (5.31)
GAF	46.81 (15.73)[a]	58.01 (17.60)[b]	55.31 (17.84)[b]
Premorbid Adjustment			
Childhood	0.24 (0.18)	0.21 (0.18)	0.26 (0.18)
Early Adolescence	0.31 (0.17)[a]	0.25 (0.17)[b]	0.25 (0.16)
Late Adolescence	0.35 (0.19)[a]	0.24 (0.17)[b]	0.23 (0.15)[b]

Note. Different superscript letters refer to significant differences ($p < .05$) between groups on post hoc tests.

3.11.6 Predicting class membership from baseline variables.

Baseline predictor variables were entered into an ordinal regression model with change group as the dependent variable. The assumption of proportional odds was met, indicating that the effects of any explanatory variables were consistent across different thresholds, i.e. from the lowest group (Low Stable) to the two higher groups (Moderate/Increasing, High/Decreasing) and from the two lower groups (Low Stable, Moderate/Increasing) to the highest group (High/Decreasing). Including explanatory variables in the model significantly improved the fit of the model to the data, χ^2 (13) = 91.30, p <.001. As is shown in Table 24, social recovery class membership was predicted by age of onset, baseline negative symptoms, premorbid adjustment, gender, and ethnicity.

3.11.6.1 Age of onset.

As age of onset of psychosis increase by one unit, the change in odds of having a better social recovery profile is 1.06. This suggests that the later an individual's age of onset, the more likely they are to have a Moderate/Increasing or High/Decreasing social recovery profile, and thus a better outcome.

3.11.6.2 Negative symptoms.

As baseline negative symptoms increase by one unit, the change in odds of having a better social recovery profile is 0.95. This suggests that individuals with higher levels of baseline negative symptoms are less likely to have a Moderate/Increasing or High/Decreasing recovery profile, and thus a worse outcome.

3.11.6.3 Late adolescence premorbid adjustment.

As premorbid adjustment scores increase by one unit (indicating poorer premorbid adjustment), the change in odds of having a better social recovery profile is 0.07. This suggests that the poorer an individual's premorbid adjustment between 16-18

years, the less likely they are to have a Moderate/Increasing or High/Decreasing recovery profile, and thus a worse outcome.

3.11.6.4 Gender.

When comparing females to males, the change in odds of making a better recovery is 0.58. This suggests that males are less likely than females to have a Moderate/Increasing or High/Decreasing recovery profile, and thus a worse outcome.

3.11.6.5 Ethnicity.

When comparing individuals with White ethnicity to individuals with Asian ethnicity, the change in odds of making a better recovery is 0.54. This suggests that individuals with Asian ethnicity are less likely to have a Moderate/Increasing or High/Decreasing recovery profile than individuals who describe their ethnicity as White. When comparing individuals with White ethnicity to individuals with Black African-Caribbean ethnicity, the change in odds of making a better recovery is 0.28. This suggests that individuals with Black African-Caribbean ethnicity are less likely to have a Moderate/Increasing or High/Decreasing recovery profile than individuals who describe their ethnicity as White. In line with previous findings in this study, this suggests that individuals with ethnic minority status are more likely to have a poorer social recovery over the study period.

3.11.7 Summary.

The results suggest that being male and having an ethnic minority status may be associated with a poorer social recovery profile. Moreover, high baseline levels of negative symptoms, poor premorbid adjustment at 16-18 years, and a younger age of onset of psychosis may also reduce the likelihood of having a better social recovery profile. These findings are consistent with those outlined in section 3.10, where recovery groups were defined using cut-off scores.

Table 24

Proportional Odds Model for Social Recovery Class

Variable	Parameter	*B*	*SE*	Odds Ratio
Threshold	Low Stable	0.04	0.60	-
	Moderate/Increasing	2.23	0.62	-
Age of onset of psychosis	Age at onset (in years)	0.06	0.02	1.06**
Positive Symptoms	PANSS Positive Score	-0.05	0.03	0.95
Negative Symptoms	PANSS Negative Score	-0.05	0.02	0.95*
General Symptoms	PANSS General Score	0.01	0.02	1.01
Depression	CDS Score	-0.01	0.02	0.99
Premorbid Adjustment (up to 11 years)	Childhood PAS score	1.50	0.78	4.48
Premorbid Adjustment (12 to 15 years)	Early Adolescence PAS score	-0.58	0.98	0.56
Premorbid Adjustment (16 to 18 years)	Late Adolescence PAS score	-2.68	0.84	0.07***
Gender	Males vs. Females	-0.55	0.21	0.58*
Ethnicity (base = White British)	Asian	-0.62	0.32	0.54*
	Black African Caribbean	-1.26	0.49	0.28**
	Mixed Ethnicity	0.34	0.42	1.40
Duration of Untreated Psychosis	Short (< 4 months) vs. Long (> 4 months)	0.05	0.21	1.05

Note. Nagelkerke pseudo R^2 = 20.0 %, *p <.05, **p <.01, ***p <.001

3.12 Summary of Findings

The analyses outlined in this chapter suggest a high baseline level of social disability in individuals with FEP presenting to EIP services, with over 80% of the sample engaging in less than 45 hours per week of structured activity, assessed using the TUS. Baseline social disability was predicted by poor premorbid adjustment in late adolescence (16-18 years) and male gender.

Change in time use over the first year of early intervention was heterogeneous, with one-third of individuals making a positive change in their time spent in structured activity, whilst others' time use decreased, remained the same, or fluctuated. When controlling for baseline social disability, an increase in time use (compared to a decrease or no change) was predicted by older age of onset, lower baseline negative symptoms, female gender, and a DUP of less than 4 months. Individuals with better premorbid adjustment in late adolescence were more likely to increase their weekly hours in structured activity, as opposed to experiencing a fluctuating pattern of time use.

Social recovery over the first year of early intervention was also heterogeneous, with just under one-third of individuals making a full social recovery. However, more than half of individuals remained socially disabled by the end of the first year, engaging in less than 30 hours structured activity per week. When controlling for baseline social disability, full or partial social recovery was predicted by female gender, non-ethnic minority status, and a short DUP (< 4 months). Lower baseline levels of negative symptoms and a younger age of onset also predicted better social recovery.

Social recovery classes defined using LCGA were similar to those defined using cut-off scores, although the Low Stable class was slightly larger than the No Social Recovery type, indicating higher levels of social disability in FEP when using this approach. Predictors of social recovery class in the LCGA analysis were consistent with

predictors of recovery type defined using cut-off scores, with the exception of DUP which did not predict social recovery class. Premorbid adjustment in late adolescence was an additional predictor of social recovery when using LCGA.

Overall, factors indicated by the analyses to be associated with social disability and/or poor social recovery are: male gender, ethnic minority status (specifically Asian and African-Caribbean ethnicity), long DUP (> 4 months), young age of onset of psychosis, poor premorbid adjustment in late adolescence (16-18 years), and high baseline levels of negative symptoms. The presence of social disability at baseline is also a predictor of poor social recovery after 12 months of EIP service provision.

CHAPTER FOUR

4. Discussion

4.1 Overview

This thesis aimed to: (1) investigate the prevalence of social disability in a cohort of individuals with FEP; (2) investigate the existence of different social recovery pathways over the first 12 months of EIP service provision; and (3) examine factors predicting social disability and social recovery in individuals with FEP. Although previous studies have examined social functioning in individuals with FEP, most have used assessments of social functioning or quality of life which were not designed for use in FEP samples, and are often confounded by psychotic symptoms. This study is the first to use a measure of time use as an index of social disability and social recovery in FEP. A further novel feature of this research is the identification of subgroups with different patterns of social recovery within a cohort of individuals with FEP, rather than examining the mean of the sample as a whole.

This final chapter will review the findings of the current study, initially considering them in relation to the research questions posed in the introduction, before discussing the theoretical implications and how the findings fit within the existing literature. Clinical implications of the findings will then be examined. Finally, strengths and weaknesses of the study methodology will be outlined, as well as possibilities for future research.

4.2 Evaluation of the Study Findings in Relation to Research Questions

4.2.1 Research Question 1: What is the frequency of social disability, defined using weekly hours engaged in structured activity, in individuals with FEP presenting to EIP services across the UK?

The findings suggest that a large proportion of individuals with FEP experience a high level of social disability. Indeed, almost 50% of participants scored in the Severe Social Disability (Severe SD) range on the TUS, indicative of less than 15 hours per week spent engaged in structured activity. A further 18% and 13% scored in the Social Disability (SD) and At-risk of Social Disability (At-risk SD) ranges respectively. Thus, only 19% of individuals with FEP scored within the non-clinical range on the TUS upon presentation to EIP services. As baseline assessments in the National EDEN study occurred during the first 3 months of being accepted into the EIP service, it is unknown whether this low level of structured time use predates the onset of the psychosis or is a response to the acute phase of the illness.

These findings are in line with studies suggesting that individuals with FEP have poor social functioning and reduced quality of life, and thus that social disability is not unique to individuals with more chronic psychosis and schizophrenia (Addington et al., 2003; MacDonald et al., 2000; Turner et al., 2009). To some extent these findings support the idea that social disability is a core feature of psychosis, rather than simply being an epiphenomenon. However, it could also be the case that social disability in FEP is a response to the experience of psychosis. Indeed, many individuals lose their job, drop out of school or college, and reduce contact with friends in order to cope with the acute phase of the illness. Nevertheless, the findings also suggest that a proportion of individuals with FEP do not experience any social disability, despite experiencing psychotic symptoms, or at least that any early social disability quickly resolves within the first 3 months of EIP service provision. Understanding differences between those who do and do not experience social disability in FEP will be important in developing and targeting interventions.

4.2.2 Research Question 2: Which factors predict baseline levels of social disability in FEP?

Comparisons on baseline variables between individuals with different levels of social disability at entry to EIP services showed that individuals with Severe SD had significantly lower functioning assessed by the GAF than the other three groups. This perhaps highlights the validity of the TUS in assessing social functioning. The Severe SD group also had a significantly higher proportion of males; higher scores on the negative and general symptoms scales of the PANSS; and significantly poorer premorbid adjustment in late adolescence (16-18 years) compared to the other three groups. Moreover, the Severe SD group had significantly poorer premorbid adjustment in early adolescence compared to the NSD subgroup. Finally, there were significantly more individuals with Black African-Caribbean and Mixed ethnicity in the SD subgroup, and significantly fewer individuals with Asian ethnicity in the NSD group compared to other groups. There were no group differences in age of onset of psychosis, positive symptoms, DUP, depression, or premorbid adjustment in childhood.

When entering all of the baseline explanatory variables into an ordinal regression analysis, gender and premorbid adjustment in late adolescence were the only two variables which predicted social disability subgroup, accounting for 13% of the variance. Female gender and better premorbid adjustment between 16-18 years predicted membership in less socially disabled groups. The finding that negative symptoms and ethnicity were not predictors of social disability subgroup may suggest that group differences on these variables can be explained by premorbid adjustment. Indeed, previous research suggests that poor premorbid adjustment is associated with higher levels of negative symptoms (MacBeth & Gumley, 2008). Moreover, premorbid

adjustment may be poorer in ethnic minorities due to higher rates of deprivation and social disadvantage (Sharpley, Hutchinson, McKenzie, & Murray, 2001).

The finding that premorbid adjustment predicts social disability in FEP is in line with other studies examining functional outcome (Häfner et al., 1999; Kelley, Gilbertson, Mouton, & van Kammen, 1992; MacBeth & Gumley, 2008), providing further evidence for this variable as a potential risk factor and also highlighting the validity of the TUS as a measure of social functioning. Males have also previously been shown to have poorer outcomes (Cotton et al., 2009). The finding that positive symptoms did not predict social disability supports the hypothesis that functional and symptomatic outcomes from psychosis are somewhat independent (Harvey & Bellack, 2009). It also suggests that social disability is not purely a response to cope with psychotic symptoms. However, levels of positive psychotic symptoms were relatively low across social disability subgroups. This may be because the baseline assessments in National EDEN took place in the first 3 months following acceptance into an EIP service. It is possible that acute psychotic symptoms were in remission by this time. Indeed, psychotic symptoms are often responsive early in the course of illness, whereas improvements in functioning can take longer to achieve (Harvey & Bellack, 2009).

4.2.3 Research Question 3: How many individuals with FEP experience a change in their weekly hours of structured activity in the first 12 months of EIP service provision?

The findings suggest that changes in time use, and thus functioning, are variable over the first 12 months of EIP service provision. The majority of participants experienced a change in their time use over the 12 month study period, with only 24% reporting stable scores on the TUS (i.e. a change of less than 8 hours per week). These findings suggest that functioning is a malleable construct, challenging traditional views

that functional disability is stable over the lifetime in schizophrenia (Liberman et al., 2002). However, it should be noted that stability in time use does not necessarily reflect disability, as individuals whose structured activity remains stable within the non-clinical range would be considered to have a good outcome. A large proportion of participants (36%) experienced a consistent increase in their time use, a positive outcome for EIP services. However, 18% experienced a decrease and the remaining 22% had a fluctuating profile, with TUS scores both increasing and decreasing over time. Understanding differences between individuals with different change profiles will be important in developing and targeting interventions.

4.2.4 Research Question 4: Which factors predict change in time use over the first 12 months of EIP service provision?

Comparisons on baseline variables between individuals with different social functioning change profiles revealed that there were significantly more females in the fluctuating subgroup than in other groups. The stable subgroup had significantly higher baseline levels of negative symptoms compared to the other three groups.

When entering all of the baseline explanatory variables into a multinomial regression and controlling for baseline social disability subgroup, males were more likely than females to be in the decreasing or stable groups versus the increasing group. Individuals with Black African-Caribbean or Asian ethnicity were more likely than individuals describing their ethnicity as White to be in the decreasing group versus the increasing group. High levels of negative symptoms and a DUP longer than 4 months also increased the likelihood of being in the stable group as opposed to the increasing group. Membership in the fluctuating versus increasing group was predicted by poorer premorbid adjustment in late adolescence.

These findings suggest that as well as being more likely to have more severe social disability upon entry to EIP services, males are more likely than females to experience a stable or deteriorating course of social functioning, further supporting the literature that males have poorer outcomes than females with FEP (Cotton et al., 2009). Individuals in ethnic minorities (specifically Asian and Black African-Caribbean ethnicities) were also more likely to experience a deterioration rather than an improvement in weekly hours spent in structured activity over the 12 months compared to individuals describing their ethnicity as White. Previous research has highlighted poorer symptomatic outcomes in individuals with Black African-Caribbean ethnicity (Bhugra et al., 1997), but functional outcome has been less well researched. Higher baseline levels of negative symptoms were associated with an increased likelihood of no change in functioning, possibly suggesting a stable or chronic course. Negative symptoms have previously been postulated as a barrier to the recovery process (Kirkpatrick et al., 2006). Individuals with longer DUPs were also more likely to have stable than increasing time use. Although DUP is traditionally associated with poorer symptomatic recovery, it has been suggested that it may also be predictive of functional outcome (Marshall et al., 2005). Poor premorbid functioning in adolescence was associated with an increased likelihood of a fluctuating versus an increasing profile of functioning. Although fluctuation in time use suggests malleability rather than a stable course, it may also be suggestive of an underlying vulnerability to social disability, potentially indicating difficulties in sustaining improvements in functioning over time.

4.2.5 Research Question 5: How many individuals make a good social recovery in the first 12 months of EIP service provision following FEP and how many remain socially disabled?

Almost 17% of individuals made a partial social recovery (PSR) and 27% made a full social recovery (FSR) in the first 12 months of EIP service provision following FEP. However, over half of all participants (56%) remained socially disabled at the end of the study period. This supports the hypothesis that social recovery from FEP is heterogeneous.

These findings are in line with literature suggesting that functional recovery takes longer to achieve than symptomatic recovery, and that many individuals remain socially disabled following FEP (Harvey & Bellack, 2009; Menezes et al., 2006). However, this is the first study to show this using a measure of time use and using cut-off scores derived from a non-clinical comparison group. The finding that most individuals with FEP remain at a level of functioning where they are engaging in less than 30 hours of structured activity per week – less than half the weekly hours of an age-matched non-clinical sample – emphasises the level of disability in this group. Moreover, the majority of individuals in the No Social Recovery (NSR) subgroup were socially disabled at the baseline assessment and remained in this category over the 12 months (n = 281, 66%). This suggests that for a significant subgroup, poor functioning occurs in the very early stages of psychosis and remains stable over the first 12 months. Understanding differences between individuals with different types of recovery will be important in developing and targeting interventions.

4.2.6 Research Question 6: Which factors predict whether an individual makes a social recovery in the first 12 months of EIP service provision following FEP?

Comparisons on baseline variables between individuals with different types of social recovery revealed that the FSR subgroup had an older age of onset of their psychosis than the NSR and PSR subgroups. There were also more females and fewer individuals with Asian Ethnicity in the FSR subgroup than the other two groups. Individuals in the NSR subgroup had higher baseline negative symptoms scores on the PANSS than individuals in the FSR subgroup, and lower GAF scores than the PSR and FSR subgroups. Premorbid functioning in late adolescence was significantly different in all three subgroups, with the NSR group having poorest premorbid adjustment, followed by the PSR group, and the FSR group reporting the best premorbid adjustment. The NSR subgroup also had poorer premorbid adjustment in early adolescence (12-15 years) than the FSR group. There were no differences in depression or childhood premorbid adjustment between the three groups.

When entering all of the baseline variables into an ordinal regression and controlling for baseline social disability subgroup, females were more likely than males to make a better social recovery. An older age of onset of psychosis also predicted better social recovery, as did fewer negative symptoms at baseline. Individuals with a DUP shorter than 4 months were more likely to achieve a better social recovery than individuals with a DUP longer than 4 months. Individuals with Black African-Caribbean ethnicity were less likely to make a social recovery than individuals describing their ethnicity as White. Moreover, individuals defined as having Severe SD (i.e. less than 15 hours per week in structured activity) or SD (15-30 hours per week in structured activity) at baseline were less likely to make a social recovery than

individuals with NSD (i.e. more than 45 hours per week in structured activity) at baseline. Premorbid adjustment in adolescence did not predict social recovery. However, this could be explained by the finding that poor premorbid adjustment in adolescence was a significant predictor of baseline social disability.

These findings suggest that individuals engaging in less than 30 hours per week of structured activity upon entry into EIP services may be at risk of a poor social outcome. Those with a younger age of onset may also be at risk of poorer outcome. Age of onset has previously been suggested to be a risk factor for poor outcome, due to the impact that the psychotic episode may have on identity and on the development of social and interpersonal skills (Ballageer, Malla, Manchanda, Takhar, & Haricharan, 2005; Harrop & Trower, 2001). As highlighted in previous analyses in this thesis, long DUP, high levels of baseline negative symptoms, male gender, and Black African-Caribbean ethnicity may be further risk factors for poor functional outcome, supporting existing literature (Cotton et al., 2009; Marshall et al., 2005; Milev et al., 2005; Morgan et al., 2006).

4.2.7 Research Question 7: Do different trajectories of social recovery exist in the first 12 months following FEP? Which factors predict different recovery trajectories?

Latent class growth analysis (LCGA) was used as an alternative approach to define social recovery trajectories in individuals with FEP. The findings were broadly consistent with the analyses using cut-off scores on the TUS, with a three-class model providing the best fit to the data. The low stable class corresponded to the NSR subgroup; the moderate/increasing class corresponded to the PSR subgroup, and the high/decreasing subgroup corresponded to the FSR subgroup. This supports the findings

from research question 5, suggesting that a large subgroup of individuals with FEP remain socially disabled in the 12 months after entry into an EIP service.

When comparing classes on baseline variables, similar variables outlined in section 4.2.6 differentiated between groups with different recovery trajectories. Individuals in the low stable class had a younger age of onset of their psychosis, higher baseline positive, negative, and general symptoms scores on the PANSS, lower GAF scores, and poorer premorbid adjustment in late adolescence than the other classes. There were also more males in the low stable class compared to the other two classes, and more individuals with Asian and Black African-Caribbean ethnicity. Results of an ordinal regression analysis were similar to those outlined in section 4.2.6, with an older age of onset, fewer baseline negative symptoms, better late adolescent premorbid adjustment, female gender, and White ethnicity predicting better social recovery over the 12 month study period.

4.2.8 Summary.

This section has summarised the findings of the current study in relation to the study research questions. Overall, the findings suggest that a large proportion of individuals with FEP presenting to EIP services display a high level of social disability which does not improve over the first 12 months of service provision. However, there is also a significant minority who do not display social disability, scoring above the non-clinical cut-off on the TUS. Factors predicting baseline social disability and poor social recovery over time include male gender, poor adolescent premorbid adjustment, high levels of baseline negative symptoms, Black African-Caribbean or Asian ethnicity, a younger age of onset, and a DUP longer than 4 months. The next section will attempt to interpret these findings and fit them into a theoretical framework underpinned by existing literature.

4.3 Interpretation of Findings and Theoretical Implications

4.3.1 Is social recovery from FEP homogeneous or heterogeneous?

The findings of this study indicate that recovery from FEP is heterogeneous, with some individuals experiencing a good social recovery and others remaining socially disabled even after the first 12 months of EIP service provision. There was also a third group who made a partial social recovery, scoring within the at-risk range on the TUS by the end of the study period. The proportion of individuals making a full recovery (i.e. scoring within the non-clinical range on the TUS) was 27.2%, with a further 16.6% meeting criteria for a partial recovery. Thus, 43.8% of individuals were engaged in more than 30 hours per week of structured activity at the end of the 12 month study period. This is compared to 32.2% at baseline.

These rates are slightly better to those outlined in previous studies of FEP cohorts using alternative definitions and outcome measures. Indeed, Robinson, Woerner, McMeniman, Mendelowitz, and Bilder (2004) report 25.5% of FEP patients as functionally recovered after 5 years, defining recovery as fulfilling age-appropriate role expectations and performing activities of daily living without supervision. Similarly, Wunderink et al. (2009) report 26.4% of FEP patients as functionally recovered after 2 years, with recovery defined as not experiencing any disability on any of the seven functional roles outlined in the Groningen Social Disabilities Schedule (self-care, housekeeping, family relationships, partner relationships, community integration, relationship with peers, vocational role). Strakowski et al. (1998) define recovery as 8 weeks of functioning consistently at the premorbid level, and report a 35% recovery rate after 12 months following the first admission into hospital. However, it must be remembered that premorbid functioning may not be that functional when compared to non-clinical groups. Singh et al. (2007) define functional recovery as

being in education, employment, or training, but they do not assess the number of hours. Using these criteria they describe 42.2% recovery rates after 12 months of EIP service provision.

Functional outcomes from FEP are more promising than studies of individuals with more chronic presentations of psychosis prior to the introduction of EIP, with rates of approximately 15% of individuals returning to competitive employment (Fowler, Hodgekins, Howells, et al., 2009). However, functional recovery rates haven't consistently been reported in these samples as symptomatic outcomes were traditionally viewed as the primary outcome. Moreover, it is only relatively recently that functional recovery from psychosis has been considered a real possibility (Lieberman et al., 2008). Although promising, the results of the current study still suggest that functional recovery from FEP may be more difficult to achieve than symptomatic recovery, with previous research suggesting that over 50% of FEP patients make a symptomatic recovery (Menezes et al., 2006; Wunderink et al., 2009). Perhaps this is because psychotic symptoms are the main focus of treatment in the acute phase. More targeted intervention may be required to improve social recovery from early psychosis.

As well as social recovery being heterogeneous, social disability in the initial stages of FEP is also variable, with a significant subgroup (19%) experiencing no social disability at baseline. Generally, TUS scores remained fairly stable over time, with good functioning at baseline predicting good functioning at 12 months. Part of the role of EIP is to help individuals maintain their premorbid level of functioning (Birchwood et al., 2002) and the findings suggest that this occurs. However, individuals with poor premorbid functioning may require additional assistance. Identifying factors which predict baseline social disability, as well as factors predicting who recovers and who

does not, will be important in uncovering potential mechanisms of change for use in intervention development. This will be discussed in the next section.

4.3.2 Factors predicting baseline social disability.

This section will consider variables highlighted as predictors of baseline social disability, which included gender and adolescent premorbid adjustment.

4.3.2.1 Gender.

Males were more likely than females to be socially disabled at baseline assessment. This finding supports previous research highlighting superior functioning in women compared to men both prior to the onset of psychosis (Morgan, Castle, & Jablensky, 2008; Seeman, 1986), and upon entry into EIP services (Cotton et al., 2009). However, premorbid functioning cannot account for all of the gender difference as gender remained a predictor of baseline TUS scores, even when controlling for PAS scores. An alternative hypothesis comes from research showing that women are more likely to receive diagnoses of affective rather than non-affective psychoses (Køster, Lajer, Lindhardt, & Rosenbaum, 2008). Indeed, the impact of illness on functioning has been found to be more benign in bipolar disorder compared to non-affective psychosis (Jarbin, Ott, & Von Knorring, 2003; Macmillan et al., 2007).

In some studies, women's onset of psychosis has been found to occur later than men's, and thus is hypothesised to be less disruptive to the development of social and interpersonal skills (Häfner et al., 1998). This has also been attributed to differences in brain structure and the impact of hormones on brain development (Castle, Abel, Takei, & Murray, 1995). In terms of other hypotheses for the gender difference in functional deficits, higher levels of negative symptoms and comorbid substance use have been reported by males (Thorup et al., 2007), both of which may have a detrimental impact on functioning. It has also been suggested that females with psychosis may have closer

social networks than males and make better use of them, thus reducing social isolation and buffering against social disability (Preston, Orr, Date, Nolan, & Castle, 2002; Seeman, 1986). Further research is necessary to unpick the mechanisms underlying gender differences in more detail. However, it will be important to consider the impact of gender in relation to access and engagement with services.

4.3.2.2 Premorbid adjustment.

Poor premorbid adjustment between the ages of 16-18 years predicted social disability at baseline. This finding supports other studies linking premorbid adjustment difficulties with poor functioning. However, there has been debate over the exact developmental stage at which premorbid adjustment may impact upon functioning in psychosis, with some studies indicating childhood (Simonsen et al., 2007), and others indicating adolescence (Lucas et al., 2008). Measures of functioning used in previous studies have not been validated for use in FEP samples and are also confounded by psychotic symptoms. Thus, the current study adds to the literature by using a more targeted measure of social functioning and examining the role of premorbid functioning at different developmental stages.

Individuals with poor premorbid adjustment between 16-18 years were more likely to be socially disabled upon entry into EIP services. Poor premorbid adjustment in early adolescence (12-15 years) also differentiated between individuals with SSD and NSD, but PAS scores for this developmental period did not predict outcome in the regression analyses. This may be because individuals with poor premorbid adjustment in late adolescence also had poor premorbid adjustment in early adolescence. Either way, adolescence, but not childhood, is implicated by the current study as an important developmental period in relation to social disability in FEP. This is perhaps unsurprising when considering the developmental tasks of adolescence, including separation and

individuation, and the fact that this is a key time for social development (Harrop & Trower, 2001).

The findings suggest that functional impairment occurs even before the onset of psychosis and that at least for some, the social disability observed in FEP may be premorbid rather than a consequence of psychosis itself. It is unknown whether the onset of psychosis resulted in an additional drop in functioning in individuals with premorbid adjustment difficulties, due to further problems adjusting to the illness, or if time spent engaged in structured activity was low in this group even prior to the emergence of positive psychotic symptoms as a feature of the prodromal phase. Indeed, it has previously been suggested that disability following FEP might simply be a continuation of poor premorbid functioning (Harvey & Bellack, 2009). Investigating the trajectory of time use in the prodromal phase of psychosis would be an interesting area of further research.

It is notable that not all individuals were socially disabled at baseline, with 19% of participants engaging in more than 45 hours of structured activity per week. Individuals in this subgroup were more likely to have good premorbid adjustment. This suggests that good premorbid adjustment may be protective against social disability following the onset of psychosis. The reasons for this require further investigation but a potential explanation is that good premorbid adjustment in adolescence confers a certain degree of resilience, buffering against the impact of a psychotic episode. Indeed, previous research suggests that good premorbid adjustment may result in the development of *social competence*, defined as an individual's ability or capacity to solve life problems and achieve instrumental and affiliative goals (Mueser, Bellack, Morrison, & Wixted, 1990). In addition to social adjustment, good academic premorbid adjustment is also likely to provide a sense of mastery over one's life, such that

psychosis may be less likely to result in an internalised sense of inferiority and thus have a lesser impact on self-esteem (Romm et al., 2011).

Poor premorbid adjustment in adolescence has also been hypothesised to reflect an unfolding neurodevelopmental component to psychosis, resulting in an earlier age of onset, higher levels of negative symptoms, and a more chronic course (Häfner et al., 1999; Häfner et al., 1995). Whilst difficulties with social competence may reflect underlying cognitive deficits occurring a this stage, these difficulties may also be the product of early relationships (MacBeth, Schwannauer, & Gumley, 2008), such that an individual has underdeveloped mentalisation abilities and social skills; perceives interpersonal relationships as threatening; and uses avoidance as a way of coping with this. Moreover, the attachment literature suggests that difficult relationships in early childhood (e.g. parental depression, separation, abuse) and indeed relationships over the life course may influence brain development (Cozolino, 2006; Schore, 2001). What is most likely is a complex interplay between these processes, with underlying neurodevelopmental anomalies resulting in interpersonal difficulties, which are then maintained by avoidance and adverse experiences.

4.3.3 Factors predicting change in time use and social recovery.

4.3.3.1 Baseline social disability.

Individuals with high levels of baseline social disability (defined as engaging in less than 30 hours per week of structured activity) were more likely to experience an increase in their time use over the 12 month study period compared to individuals with no social disability at baseline, possibly because their time use was so low to start off with and thus there was more scope for change. Nevertheless, individuals who were defined as socially disabled at baseline were less likely to make a good social recovery over the 12 month study period than individuals scoring in the non-clinical range on the

TUS. Therefore, although experiencing an increase in time use, this often did not result in a recovery in terms of making transition to the non-clinical range.

These findings suggest that social functioning in the early stages of FEP is predictive of later outcome, meaning that early social disability can remain. Although the best predictor of outcome is often the baseline score (Pocock, Assmann, Enos, & Kasten, 2002), it is important to consider how baseline levels of structured activity may impact upon later outcome. Individuals with better baseline functioning may have been less affected by the psychotic episode and thus have less of a gap to fill in terms of returning to premorbid levels of functioning. Indeed, a central tenet of EIP is to retain people in their social and occupational activities as it is harder to reengage with these after dropping out (Birchwood et al., 2002).

As outlined above, premorbid adjustment in late adolescence predicted baseline levels of social disability. Thus, it may be the case that social disability in the early stages of psychosis is indicative of a history of poor functioning, thus making recovery more difficult for the reasons outlined in section 4.3.2.2 . Indeed, it should be remembered that although recovery is sometimes defined as a return to premorbid functioning (Harvey & Bellack, 2009), at least for some people premorbid functioning may have been quite poor.

4.3.3.2 Gender.

Males were less likely than females to experience an increase in their time use over the study period. Males were also more likely to remain socially disabled at the end of the first 12 months of EIP service provision, even when controlling for baseline social disability. As well as research highlighting gender differences in functioning upon presentation to services (outlined in section 4.3.2.1), existing research suggests that males have poorer outcomes, both in terms of symptoms and functioning, than

females (Cotton et al., 2009) and the current findings are in line with this. Indeed, female gender has been argued to be one of the most powerful predictors of good outcome (Rosen & Garety, 2005). The exact mechanisms underlying this gender difference are unknown. However, it is hypothesised that males have more difficulties both seeking help and engaging with services than females, meaning that interventions may be less effective (Seeman, 1986). Moreover, insight has been found to be better in females than in males (Karow et al., 2008). Thus, it may be that females have a more integrative recovery style whereas males are more likely to adopt a sealing over approach. This hypothesis has yet to be examined in FEP, although evidence suggests that females exhibit more distress in relation to their illness than males which may be suggestive of a less avoidant coping style (Cotton et al., 2009). As outlined previously, better social adjustment in females and better use of social networks may also buffer against the impact of psychosis on social roles (Usall, Haro, Ochoa, Márquez, & Araya, 2002). Systemic factors have also been considered, with the suggestion that it is more socially acceptable for women to have mental health problems and thus stigma may be less for females, contributing to a more positive recovery (Anderson & Holder, 1989). However, this hypothesis has yet to be substantiated and social attitudes towards mental illness have arguably changed over the last 25 years.

4.3.3.3 Ethnicity.

Individuals with Black African-Caribbean or Asian ethnicity were more likely than individuals describing their ethnicity as White to experience a decrease in their TUS scores over the 12 month study period. Black African-Caribbean individuals were also less likely to achieve a social recovery than White individuals. Ethnicity has previously been linked to symptomatic outcome from psychosis, with migrant and ethnic minority groups having a higher incidence of psychotic illness and being more

likely to enter services via hospital admissions or criminal justice routes (Morgan et al., 2006). How ethnicity influences social recovery is less well researched, although poor premorbid adjustment and higher levels of unemployment have been highlighted in this group (Bhugra & Bhui, 2001; Bhugra et al., 1997). The current study is one of the first large cohort studies to examine the influence of ethnicity on social recovery from FEP.

It seems unlikely that ethnicity influenced social recovery due to an increased severity of psychotic symptoms, as positive symptoms scores on the PANSS were comparable across all social recovery subgroups and PANSS scores were also included as a covariate in the regression analyses. A recent study has reported higher levels of negative symptoms in ethnic minorities who also meet ARMS criteria (Velthorst et al., 2012). However, ethnicity remained a predictor of outcome even when controlling for negative symptoms. Premorbid adjustment was also controlled for, reducing the likelihood of poor premorbid adjustment in ethnic minority groups as an explanation for poor social recovery. Thus other factors are arguably more likely to play a role.

Recent evidence suggests a higher level of social disadvantage across the life course, including early parental separation (Morgan et al., 2007), poor education, and social isolation in adulthood in ethnic minority groups with psychosis, particularly in the Black Caribbean population in the UK (Morgan & Hutchinson, 2009; Morgan et al., 2008). These factors could certainly contribute to poor social outcome as individuals would have less social resources to draw upon both before and after the onset of psychosis. There is also a hypothesis within the literature that individuals from ethnic minorities have more negative experiences of services and therefore may be less likely to engage with interventions, further reducing their likelihood of recovery (Morgan et al., 2006). Moreover, levels of stigma and discrimination may be greater in this group (Karlsen & Nazroo, 2002), creating a further barrier for recovery. However, further

research is needed to substantiate these claims. Indeed, thus far the majority of research investigating relationships between ethnicity and psychosis has focused on incidence (Morgan, Charalambides, Hutchinson, & Murray, 2010). As outlined by Singh (2001), the social consequences of psychosis deserve equal if not greater attention than aetiological research, since social outcomes may be more amenable to effective intervention. The findings of the current study suggest that social outcomes may be particularly harsh for individuals from Black and Asian ethnic minorities and it is likely that these groups may require targeted intervention.

4.3.3.4 Age of onset.

Individuals with an older age of onset of psychosis were more likely to achieve a social recovery, even when controlling for premorbid adjustment. This mirrors previous findings of poorer outcomes in adolescent onset compared to adult onset psychosis (Ballageer et al., 2005; Hollis, 2000). There are several hypotheses about the processes underlying this relationship. First, adolescence is a key stage in identity development and individuation, and experiencing an episode of psychosis during this time is likely to intrude upon and influence identity formation (Harrop & Trower, 2001). As a result, the experience of psychosis may be internalised, resulting in feelings of hopelessness or demoralisation, or indeed, a belief that one is different or damaged in some way. The latter stages of identity development in adolescence involve a preoccupation with evaluation from peers. Rejection or bullying from peers as a consequence of mental health problems is therefore likely to have a significant impact on self-acceptance and self-esteem, as well as beliefs about others. Indeed, previous research discusses the impact of mental illness on social rank and the shame associated with this (Birchwood et al., 2006; Gilbert, 2000).

Second, on a practical level, psychosis may interrupt education or early career options meaning that individuals have fewer options in the workplace following remission of psychotic symptoms. The negative impact of psychosis on employment has previously been noted in the literature, as has the success of supported employment interventions (Rinaldi et al., 2010). Finally, adolescent onset psychosis has been linked to abnormalities in neurodevelopment, attributed to the neuronal pruning which occurs at this age (Keshavan, Anderson, & Pettegrew, 1994). Such a route into psychosis has been hypothesised to result in a particularly malignant course and outcome when compared to psychosis with a later age of onset (Hollis, 2000). A neurodevelopmental route into psychosis may result in cognitive deficits potentially impeding functional outcome, due to their impact on activities of daily living (Green, 1996). The current study did not examine neurological or cognitive deficits and thus cannot add to existing literature on this. However, it is likely that the existence of any neurocognitive impairment will interact with the social and environmental factors outlined above.

4.3.3.5 DUP.

DUP was not predictive of baseline social disability. However, individuals with a short DUP (< 4 months) were more likely to experience an increase in their TUS scores over the 12 month study period than individuals with a long DUP (> 4 months). Having a short DUP was also predictive of achieving a social recovery defined using cut-off scores on the TUS, but not when defining groups using LCGA. DUP has previously been linked with symptomatic outcome (Marshall et al., 2005), with studies suggesting that untreated psychotic symptoms are toxic (Sheitman & Lieberman, 1998). DUP has also been linked with functional outcome (Norman et al., 2007), although there has been some debate over whether this is confounded by premorbid adjustment. In line with other studies, the current study suggests that premorbid adjustment and

DUP both predict functional outcome in FEP independently of one another (MacBeth & Gumley, 2008; Marshall et al., 2005).

The results of the current study mirror findings from previous literature that DUP influences outcome over time, rather than at first presentation to services (Marshall et al., 2005). Reasons underlying the relationship between DUP and outcome are unclear and require further research. It could be that longer DUP reflects difficulties engaging with services and thus interventions, reducing the likelihood of change (Marshall et al., 2005). DUP may also reflect reduced social networks and increased isolation, such that psychotic symptoms remain unnoticed (Drake, Haley, Akhtar, & Lewis, 2000). If this is the case then it is likely that individuals with longer DUP will also have fewer social resources to draw upon throughout the recovery stage, potentially resulting in poorer outcomes. Indeed, social networks are hypothesised to be important in FEP, potentially providing a buffer against long-term disability (MacDonald et al., 2000). Thus, rather than a direct causal association, the relationship between DUP and functional outcome may be explained by a third variable which is correlated with both DUP and time use (e.g. social networks). However, exactly what this third variable is is yet to be determined.

4.3.3.6 Premorbid adjustment.

Poorer premorbid adjustment in late adolescence (16-18 years) predicted a fluctuating profile of change versus an increase in TUS scores over the 12 month study period. Although ANOVAs revealed significant differences in PAS scores between different recovery subgroups, premorbid adjustment did not predict social recovery defined using cut-off scores on the TUS when controlling for baseline social disability. However, as outlined above, poor premorbid adjustment in adolescence predicted social disability at baseline, and baseline social disability predicted later recovery. Moreover,

premorbid adjustment in adolescence did predict social recovery when groups were defined using LCGA. Thus, premorbid adjustment in adolescence does appear to play a role in functional outcome from FEP. As with baseline social disabilities, adolescent and not childhood premorbid adjustment was indicated as important in relation to social recovery.

Poor premorbid adjustment may influence social recovery for a number of reasons, as outlined in section 4.3.2.2, including potential neurodevelopmental correlates (Häfner et al., 1995) and the impact of early life experiences on social competence and resilience (MacBeth & Gumley, 2008; Romm et al., 2011). If premorbid adjustment does reflect difficulties with social competence and resilience, it would not be unreasonable to suggest that this would play a role in adaptation to the psychotic episode and thus social recovery. Moreover, individuals with poor premorbid adjustment may have had less experience of mastery and success and thus not have a level of functioning to which they aspire to return to. However, further research is necessary to further understand the role of premorbid adjustment on social recovery.

4.3.3.7 Baseline negative symptoms.

Higher baseline levels of negative symptoms predicted stable TUS scores (i.e. no change) over the 12 month study period. Baseline negative symptoms also predicted social recovery, with fewer baseline negative symptoms predicting a better outcome. This is in line with other studies conducted with individuals with FEP (Malla, Takhar, et al., 2002). Negative symptoms have long been linked with functional deficits (Gourevitch, Abbadi, & Guelfi, 2004; Heinrichs et al., 1984) and thus it is perhaps unsurprising that negative symptoms scores on the PANSS predicted social recovery.

Previous studies have suggested that negative symptoms represent a separate dimension of psychosis which may be related to cognitive deficits (e.g. poor memory

and attention) and thus reflect a neurodevelopmental route into illness (Kirkpatrick et al., 2006). Evidence for this includes the finding that negative symptoms often precede the onset of hallucinations and delusions (Tandon et al., 2000). In terms of their impact on functional recovery, it may be the case that cognitive deficits underlying negative symptoms have a detrimental impact on the skills required for activities of daily living or social interactions (Green, 1996). However, the correlation between negative symptoms and cognitive deficits has been found to be modest at most (Harvey, Koren, Reichenberg, & Bowie, 2006). Others suggest that motivational rather than computational difficulties may underlie reduced performance on neuropsychological tests (Schmand et al., 1994). Thus functional deficits may be due to poor motivation. As the current study did not assess neuropsychological performance, it cannot comment on the relationship between negative symptoms and cognitive deficits in this sample, or the impact of cognitive deficits on time spent engaged in structured activity. Moreover, negative symptoms were assessed at baseline and thus the extent to which they were present in the prodromal phase is unknown.

An alternative hypothesis for the relationship between negative symptoms and social recovery is that negative symptoms are more of a psychological construct, reflecting an individual's response to, and way of coping with, the experience of psychosis. Premorbid negative symptoms have also been suggested to be akin to cluster A personality traits, reflecting difficulties interacting with others, e.g. shyness, aloofness, introspection (Cuesta, Peralta, Gil, & Artamendi, 2007), arguably similar to premorbid social adjustment difficulties. The hypothesis that negative symptoms may have a psychological component has received more attention in recent years, particularly as no medical intervention has been found to be effective in reducing negative symptoms (Tarrier, 2006). Grant and Beck (2009) have formulated a cognitive

model of negative symptoms based on defeatist beliefs and fear of failure. Within this model, negative symptoms are hypothesised to be a form of avoidance or withdrawal in order to cope with these beliefs and fears, potentially explaining the relationship between increased negative symptoms and poor functioning. Recent studies suggest that psychological interventions may be promising in reducing negative symptoms and improving functioning (Gaynor, Dooley, Lawlor, Lawoyin, & O'Callaghan, 2011; Grant, Huh, Perivoliotis, Stolar, & Beck, 2012). Further research is necessary to examine the role of different types of negative symptoms on outcome. Indeed, it may be that certain types of negative symptoms overlap with cognitive deficits (e.g. poor concentration and memory), whereas others have more of a psychological basis (e.g. flattened affect, reduced social drive).

4.3.4. Social recovery vs. symptomatic recovery.

Baseline levels of positive psychotic symptoms assessed by the PANSS did not differ between social disability subgroups. Moreover, baseline hallucinations and delusions did not predict functional outcome. This supports literature suggesting that functional disability and recovery are independent from symptomatic fluctuations, with deficits in functioning occurring prior to the onset of positive symptoms and remaining after they have remitted (Agerbo, Byrne, Eaton, & Mortensen, 2004). The current findings are also in line with service user literature outlining the process of recovery as "living a meaningful life even within the constraints of mental illness" (Anthony, 1993, p. 14). Indeed, some individuals manage to return to a good level of functioning even if they still experience psychotic symptoms.

However, methodological issues should be considered when interpreting these findings. Levels of positive psychotic symptoms were relatively low across the sample. This could be because the baseline assessment for the National EDEN study occurred

within the first 3 months of being accepted into an EIP service in order to give participants enough time to be stabilised on antipsychotic medication. Thus, the acute psychotic episode is likely to have remitted by the time participants completed the baseline assessment. It could be the case that psychotic symptoms occurring in the acute phase of psychosis – which were not measured in this study – are related to social disability. However, this is not suggested by existing research. Moreover, even if positive symptoms had remitted in the current study sample, levels of social disability were still high in the sample, suggesting that social recovery may take longer to achieve than symptomatic recovery.

In addition to positive psychotic symptoms, baseline levels of depression did not differ between social disability subgroups, nor did depression predict later outcome. This finding contradicts previous studies highlighting increased levels of depression and low self-esteem in individuals with social recovery difficulties (Gureje et al., 2004). However, within the current study depression levels were comparably high in all social disability subgroups, with all groups scoring above the cut-off for clinical levels of depression. Such ceiling effects would make differences between the groups difficult to observe. Although 3 months may be long enough for psychotic symptoms to subside, depression at this point may be a common response to adjusting to having had a psychotic episode. It may be the case that it is persistent depression which predicts long-term social disability, rather than low mood observed in the early stages of psychosis. Indeed, previous studies highlighting a link between depression and functional outcome focus on post-psychotic depression (PPD), which would not usually be diagnosed until several months after the remission of psychotic symptoms (Siris, 1995). Further research is necessary to investigate this in more detail.

4.3.5 Summary.

This section has considered the theoretical implications of the study findings, placing them in the context of existing literature. Rates of social recovery in this study are broadly comparable to studies using other definitions, highlighting the validity of the TUS as a measure of functioning. However, time spent in structured activity may be a more meaningful way to measure social recovery than more subjective measures such as quality of life as hours per week are easily understandable units of measurement. Moreover, this study has defined clinical and non-clinical cut-off scores on the TUS using normative data which will be helpful in assessing whether someone is socially disabled, and to track recovery.

Using existing theory, this section has hypothesised how the variables highlighted as predictors of outcome may impact upon social recovery. It is possible that there is a common factor underlying all of the predictor variables, conferring either vulnerability or resilience and thus influencing adaptation to psychosis and eventual social recovery. Indeed, the variables included in this study accounted for less than 30% of the variance in social recovery. Therefore, other variables and the complex interactions between them are also likely to be important in the recovery process. Exactly what the common factor underlying the predictor variables might be, or if one exists at all, is currently unknown. However, one possibility is the notion of social competence, referring to an individual's ability to impact favourably on their social world. This idea was initially put forward by Zubin and Spring (1977) and has been further researched by Mueser et al. (1990) amongst others. Social competence is also likely to be influenced by an individual's environment and when considering mental health more broadly, increased social capital – defined as social cohesion and trust at a community level – has been implicated as a protective factor (Wilkinson, 1999).

In the current context, the concept of social competence may need updating and broadening in order to include occupational and other achievements. However, increased negative symptoms, poor adolescent premorbid adjustment, and a younger age of onset of psychosis may all reflect a disruption in the development of the skills required to solve life problems and achieve instrumental and affiliative goals. Such vulnerability may also increase DUP as individuals may find it difficult to seek help and they may also have smaller social networks meaning that psychotic symptoms remain unnoticed. Moreover, social networks have been found to be reduced in males (Preston et al., 2002) and ethnic minorities (Bhugra & Bhui, 2001), two additional predictors of poor social recovery, possibly indicating reduced social capital in these groups.

The notion of a common factor needs to be researched in more detail, including potential underpinning mechanisms. When considering social competence, there may be at least two pathways: first, a neurodevelopmental route influencing the cognitive skills required for problem solving and social cognition; and second, a psychosocial route influenced both by an individual's experience of interpersonal relationships, and the experience of achievement or having a sense or mastery over one's life. Social context is also likely to be important (Wilkinson, 1999). Combined, these processes may influence the onset of psychosis but also an individual's resilience and the amount of interpersonal resources they have available in terms of coping with the consequences of a psychotic episode. Although utilising existing research, this model is hypothetical and requires further testing. Indeed, the results of this study show which baseline factors are important in predicting engagement in structured activity in the first 12 months after EI, but they cannot give an indication of why or how they predict social recovery. These questions will be considered in the final sections of this chapter. The next section will consider clinical implications of the study findings.

4.4 Clinical Implications

This section will consider the clinical implications of the findings of this study including the use of the TUS as a measure for defining social disability and social recovery; the identification of individuals who may be at-risk of long-term social disability; and potential intervention strategies targeting social disability both before and after the onset of psychosis.

4.4.1 Time Use Survey as a measure for use in defining social disability and social recovery.

This study adds to existing literature on defining and assessing functional recovery from psychosis, an area which has been the subject of much debate over the last 30 years (see Liberman & Kopelowicz, 2002 for a review). Indeed, this study has attempted to quantify different levels of social disability and recovery using comparisons with non-clinical and at-risk mental state samples to create cut-off scores on the TUS. Quantifying recovery has previously been perceived as a challenge, with service user and professional views often being at odds with one another (Frese, Knight, & Saks, 2009).

The use of different cut-offs on the TUS is in line with Harvey and Bellack's (2009) notion of functional remission and recovery, akin to symptomatic remission and recovery. Indeed, it may be over ambitious to suggest that individuals will return to non-clinical levels of activity 12 months after an episode of psychosis, particularly when their premorbid functioning may have been poor. Thus, partial recovery (i.e. scoring within the at-risk of social disability range) may be a reasonable short-term goal. Nevertheless, having a non-clinical cut-off on the scale provides a hopeful message that full recovery is possible.

A recent review highlighted the need for more meaningful measures to assess functional and social recovery from psychosis, with more of a focus on social outcome (Shrivastava, Johnston, Shah, & Bureau, 2010). Moreover, it has been argued that everyday activities should be included in outcome measures assessing recovery (Harvey & Bellack, 2009). As such, the TUS arguably provides a more meaningful and real-life assessment of social disability and recovery than other measures of functioning, which are more subjective, were developed for people with more chronic presentations, and may also be confounded by psychotic symptoms. The finding that individuals with different levels of social disability also differed on GAF scores highlights the validity of the TUS as a measure of functional outcome. In addition, the variables which predicted outcome on the TUS have also been found to predict outcome on other functional outcomes, such as quality of life (Harrigan et al., 2003), further emphasising the validity of time use as a measure of social recovery.

The TUS provides an objective measure of the number of hours per week a person is spending in everyday structured activities, including work, education, household chores and childcare, and structured leisure and sports activities. Stakeholders, policy makers, service users, and clinicians are all likely to have a good understanding of what this means and how it may impact upon mental health and quality of life. Indeed, activity levels have long been linked to mood and psychological well-being (Fletcher et al., 2003; Lewinsohn & Graf, 1973; Waddell & Burton, 2006). Using the TUS may also promote conversations about an individual's interests, hopes, and dreams, providing valuable material for developing personalised interventions and helping people to reengage with activity after a psychotic episode.

4.4.2 Identifying individuals who may be at-risk of long-term social disability.

The results of this study suggest that certain groups of people may be more at risk of long-term social disability than others, including males and individuals with Black African-Caribbean and Asian ethnicities. Moreover, high levels of baseline negative symptoms and poor premorbid adjustment, particularly in adolescence, are also indicative of social disability upon entry into EIP services and poor social recovery at 12 months, as are a younger age of onset and a DUP longer than 4 months. Conversely, baseline positive symptoms and depression did not predict functional outcome. As outlined above, it may be the case that there is a common factor underlying all of the predictor variables, which warrants further research. Nevertheless, individuals displaying the characteristics found to be linked with social disability may require monitoring and targeted intervention in relation to their activity levels and functional recovery.

In line with previous research, it seems that at least for some people, functional disability may occur prior to the onset of FEP. Thus, further research focusing on the prodromal phase is needed. Such research should not necessarily focus on positive psychotic symptoms per se, but rather functioning and activity levels, as well as potential underlying mechanisms of social disability, including social competence (Mueser et al., 1990), early negative symptoms (Cuesta et al., 2007), and cluster A personality traits (Couture, Lecomte, & Leclerc, 2007; Cuesta, Peralta, & Caro, 1999). This is not the first study to make this suggestion, with previous research suggesting that GAF scores of less than 50 may predict transition to psychosis in individuals with at-risk mental state (Yung et al., 2006). This poses the question of whether EIP should focus more on the emergence of social disability and adjustment difficulties in the

premorbid phase – sometimes referred to as duration of untreated illness – as opposed to the emergence of positive psychotic symptoms (Fowler et al., 2010).

4.4.3 Interventions.

When considering potential interventions for social disability, the results of this study suggest that all approaches may need to consider gender and ethnicity. Indeed, both males and individuals from ethnic minorities may particularly benefit from interventions which focus on developing and rebuilding social skills and networks and engaging with vocational and educational services. Previous research suggests that these groups may also find it difficult to engage with interventions (Cotton et al., 2009; Morgan et al., 2010). This is also likely to be the case for individuals with high levels of negative symptoms and premorbid adjustment difficulties. Thus, engagement is likely to be a key focus for any and all interventions. Interventions targeted to specific stages of psychosis will now be discussed.

4.4.3.1 Before the onset of psychosis.

Considering the finding that baseline levels of social disability were high and predicted later social recovery profiles, there is an argument for early intervention at the first stages of social disability, rather than waiting for the onset of positive psychotic symptoms. Indeed, just as the research on DUP suggests that untreated psychotic symptoms may be toxic in terms of symptomatic recovery (Marshall et al., 2005), the finding that poor premorbid adjustment predicts later social disability suggests that untreated social functioning problems may be toxic for social recovery.

Interventions prior to the onset of psychosis will involve detection and monitoring of individuals displaying early signs of social disability, as well as management of individuals' presenting problems. These may be diverse and include: emotional difficulties, relationship difficulties, problems with schooling or work,

loneliness, social withdrawal, and substance misuse (Fowler et al., 2010). Engagement will also be key with this client group who may find it difficult to access services due to a high level of social exclusion (Mental Health Foundation, 2001). Early intervention at this stage may be useful in reducing social disability and improving long-term outcome. However, debate exists over the most appropriate time to intervene and further research is necessary (Warner, 2005). Moreover, any intervention must be careful to avoid stigma in individuals who may or may not go on to develop mental health problems, and to promote a hopeful and optimistic outlook (Young Minds, 2006a).

Recent research has suggested the use of peer interventions to promote acceptance of mental health problems in cohorts of young people with the aim of reducing loss of social networks (Brand, Harrop, & Ellett, 2011). Peer mentoring schemes have been proposed to provide non-stigmatising support and a safe environment to discuss difficulties in their early stages, and to reduce the frequency and impact of adverse events such as bullying (Houlston, Smith, & Jessel, 2009). At a public health level, suggested interventions include the promotion of a nurturing educational ethos in schools, as well as teaching children and young people effective coping skills and strategies to enhance their self-esteem (Davies & Burdett, 2004). In addition, particular subgroups of young people may be more at-risk of severe mental health difficulties than others and thus require particular support, including looked after children, minority groups, and young offenders (Young Minds, 2006a, 2006b).

4.4.3.2 After the onset of psychosis.

The results of this study are in line with previous research suggesting high levels of social disability following an episode of psychosis (Crumlish et al., 2009). This suggests that as well as potential premorbid social disability, the impact of psychosis may trigger or exacerbate functional deficits. Indeed, as outlined in section 1.2.4.2

psychosis can be viewed as a traumatic life event and have extensive emotional and psychological consequences (McGorry et al., 1991). Although, social recovery is a central feature of EIP policy (Birchwood et al., 2002), the findings of this study suggest that it may be difficult to achieve. Thus, specially designed and targeted interventions are likely to be necessary in formulating social recovery difficulties and improving functional outcomes. Existing interventions include supported employment (Rinaldi et al., 2004), cognitive remediation (Wykes et al., 2007; Wykes & van der Gaag, 2001), and social recovery oriented CBT (Fowler, Hodgekins, Painter, et al., 2009; Penn et al., 2011), all of which have produced promising results. CBT for negative symptoms is a further recent development (Grant et al., 2012). Moreover, peer support groups have been found to be useful following the onset of psychosis in order to improve social networks (Castelein et al., 2008). However, as well as improving skills and providing opportunities for reengaging in activity, interventions should also consider barriers to social recovery in the formulation and intervention stages, thus increasing preparedness for returning to work, education and social interaction. Helping individuals to understand and overcome barriers is likely to be important in maintaining long-term gains in activity, and in reducing the likelihood of stress-induced exacerbations of psychotic symptoms. Furthermore, interventions should aim to promote hope and build a positive sense of self (Hodgekins & Fowler, 2010).

4.5 Strengths and Weaknesses of the Study

The results of the current study need to be considered in the context of the strengths and weaknesses of the methodology and design. These will now be discussed in more detail.

4.5.1 Strengths.

Two considerable strengths of the study are the large sample size and longitudinal design. Indeed, the National EDEN study is the largest longitudinal study of a FEP cohort in the UK. Recruitment and follow-up rates were also good, thus increasing the transferability of the findings to wider FEP populations. Moreover, the current study controlled for a large number of variables when examining predictors of outcome, whereas previous studies have only examined the contribution of a few (e.g. Norman et al., 2007). A further strength is the explicit focus of the current study on the heterogeneity of the sample and the examination of smaller more homogeneous subgroups within the larger cohort. The notion of recovery from psychosis as multidimensional and heterogeneous has long been accepted (Carpenter & Kirkpatrick, 1988) but this is not well considered in research (Peer, Kupper, Long, Brekke, & Spaulding, 2007). Cross-sectional studies using group means neglect within- and between-person variance, resulting in the loss of valuable information about individual differences (Hoffmann, 2007). Moreover, studies using linear regression to examine predictors of outcome are based on the assumption that estimated variance across participants and predictors is constant, an assumption which is counter to the well-acknowledged heterogeneity existing within recovery from psychosis (Liu, Choi, Reddy, & Spaulding, 2011). The current study embraces this heterogeneity with the results providing information about different types of baseline and longitudinal social disability, which will be useful in developing and targeting interventions. Although studies examining heterogeneity in outcomes are increasing, this study is one of the first in a FEP cohort.

4.5.2 Weaknesses.

In contrast to the strengths outlined above, there are a number of methodological weaknesses within the current study which need to be considered. First, there were some missing data on the TUS and on baseline predictor variables and this may have biased the results. Indeed, only 65% of the sample had complete data on all variables. However, missing data analyses did not highlight any differences in time use between participants with and without missing data on predictor variables (see Appendix D) and thus the data were assumed to be missing at random (Tabachnick & Fidell, 2001). Moreover, as the sample size was large, missing data did not affect the power of study. Nevertheless, individuals completing the TUS were from a more disabled group (higher PANSS and lower GAF scores) than National EDEN participants who did not complete the TUS and were therefore not included in the study (see section 3.2.1). As a result, findings may not be generalisable to all individuals with FEP. However, considering the focus of this thesis is social disability, the inclusion of participants who are more disabled is arguably less problematic than recruiting a sample with low levels of social disability.

An additional weakness is the retrospective nature of the PAS in assessing functioning prior to the onset of psychosis. However, this weakness is true of all studies using the PAS and has not previously been highlighted as a problem. Furthermore, participants were assessed up to 3 months after being accepted into the EIP services, by which time the acute psychotic episode had usually been stabilised and is unlikely to have influenced responding. There is some variation in how previous studies have scored the PAS, some separating it into social and academic functioning, and others examining developmental profiles of adjustment over time. The current study examined

combined social and academic adjustment at each developmental stage, but future research could tease these apart in more detail.

It is also possible that the follow-up period of the current study was not long enough to fully assess social recovery from FEP. Indeed, previous studies have examined recovery over a 2 to 7 year period (e.g. Keshavan et al., 2003; Milev et al., 2005). It may be the case that the first year of EIP is mostly about primary recovery, i.e. remission of symptoms and adjusting to the impact of the episode (McGorry, 1992), rather than secondary recovery, i.e. getting one's life back on track, which may take longer to achieve (Crumlish et al., 2009). Moreover, in terms of the latent class growth modelling approach used in this study, a longer follow-up period would have provided more time points, so that fluctuations in functioning could have been more appropriately modelled. The three time points included in the current study only allowed linear functions, rather than quadratic curves to be fitted to the data (Jung & Wickrama, 2008). As highlighted by previous research and views of service users, recovery is not always a linear process (Frese et al., 2009).

Finally, the predictors included in the regression models only accounted for 30% of the variance in TUS scores. This is fairly low when compared to other studies, which have accounted for up to 50% of the variance in outcome (Malla, Takhar, et al., 2002) and suggests that there are other factors contributing to recovery which were not included in the current study. Moreover, just because particular variables (e.g. negative symptoms, gender, etc) were found to predict outcome, does not necessarily highlight a causal relationship. There may be other unmeasured variables associated with both predictors and outcome which explain this relationship. For example, previous studies have included cognitive function as a predictor of functional outcome (e.g. González-Blanch et al., 2010) and this was not included in the current study. In particular, social

cognition is an increasingly researched concept, with a recent review suggesting that future studies should examine the relationship between social cognition and functional outcome (Allott, Liu, Proffitt, & Killackey, 2011). Attachment style and social competence may be additional explanatory variables (Gumley & Schwannauer, 2006; Mueser et al., 1990). Thus, further research is needed to unpick the findings of this study in more detail.

4.6 Future Research

As outlined in the previous section, although the current study has highlighted several factors as predictors of outcome, it does not explain why or how these variables impact upon outcome, and at present this can only be hypothesised in the context of existing literature. Future studies should focus on examining mediators of relationships between predictors and outcome, for example between premorbid adjustment in adolescence and social disability in FEP. This will be important in identifying mechanisms of change and thus in developing effective interventions (Malla & Payne, 2005).

In addition, the current study focused on baseline predictors of outcome but did not consider factors which may contribute to recovery occurring after the onset of psychosis, such as engagement with services, treatment adherence, and the way in which individuals understood and coped with their psychotic episode. Future research should therefore investigate post-onset factors and the influence of these variables on recovery. In addition, depression was the only measure of mood in the current study, whereas anxiety is also prevalent in FEP and needs to be considered. Moreover, examining protective factors such as hope, optimism, and personal meaning would also be interesting and fits well with both positive psychology and service user views on recovery (Frese et al., 2009; Seligman & Csikszentmihalyi, 2000).

Due to the retrospective nature of assessments of premorbid adjustment, a prospective study examining profiles of functioning using the TUS with individuals in the prodromal phases of illness would be useful in unpicking whether the baseline functional deficits highlighted in the current study were a consequence of the onset of psychosis or whether they existed premorbidly. Indeed, as has been highlighted previously, the baseline assessments in the National EDEN study were conducted up to 3 months after being accepted into the EIP service. Thus, it is unknown whether those who were functioning at the non-clinical level had been unaffected by the onset of their psychosis or if they had made a rapid social recovery. Moreover, it was difficult to assess the impact of symptoms on functioning as the acute psychotic episode had usually been stabilised by the time of the baseline assessment.

Finally, as outlined above, a longer term follow-up would enable the process of recovery from psychosis to be examined in more detail. In addition, although the focus of this study was social recovery, recovery is multidimensional and clinical or symptomatic outcomes should not be neglected (Shrivastava et al., 2010). It would be interesting to repeat the analyses conducted in this study on longitudinal symptom data to examine whether similar profiles and trajectories exist, and whether symptomatic and functional recovery are truly independent of one another in FEP. Moreover, as the TUS is a novel measure in FEP, repeating the analyses with other measures of social functioning would provide further validity to the findings.

4.7 Conclusion

It has long been known that social functioning is affected in psychosis and that functional deficits may occur even prior to the onset of frank psychotic symptoms. However, whether this is the case for everyone and which factors predict social disability are still open to debate, as is the best way to define and measure recovery in

this domain. This is particularly important considering the emphasis on social recovery within EIP policy. The work conducted in this thesis contributes to this debate. The heterogeneous nature of social disability and recovery in FEP has been examined using weekly hours spent in structured activity as an index of social functioning. The findings suggest that social disability is common in the early stages of FEP, and that a large proportion of individuals remain socially disabled at 12 months. However, a significant minority do not experience any social disability, scoring within the non-clinical range on the TUS. Predictors of baseline social disability and social recovery after 12 months of EIP service provision were identified, suggesting that males and individuals with Asian or Black African-Caribbean ethnicity may be at risk of social disability following FEP. In addition, individuals with a young age of onset of psychosis, high baseline levels of negative symptoms, DUP longer than 4 months, and poor adolescent premorbid adjustment may also be at risk. Thus, individuals with one or more of these indicators may require close monitoring and targeted intervention in relation to improving their social outcome following FEP.

Potential interventions for improving social functioning both before and after the onset of psychosis have been discussed. These focus on strategies to improve social and occupational skills but also consider the therapeutic relationship and overcoming difficulties with engagement. Future research should focus on developing a further understanding as to how and why the predictors identified in this study may impact upon outcome, thus identifying potential mechanisms of change to inform intervention development. Moreover, a longer period of follow-up is required to examine social recovery over the full duration of EIP and beyond. This will be possible using data from the follow-up study to National EDEN, SuPER (Sustaining Positive Engagement and Recovery) EDEN funded by the National Institute of Health Research. Examining

changes in functioning during the premorbid and prodromal phases will also be important in understanding when social disability becomes a problem and how just how early EIP needs to be.

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APPENDICES

Appendix A:

Copy of the Time Use Survey

TIME USE INTERVIEW

EMPLOYMENT

1. Did you do any paid work in the last month, either as an employee or self-employed?

YES → ASK DETAILS
NO → GO TO QU 3

Details

2. How many hours a week do you usually work in your main job? Include any overtime. How many hours have you worked in the last month?

Details

3. Over the last month have you been away from your main job?

YES → ASK DETAILS
NO → GO TO QU 4

Details

4. Have you ever had a paid job?

YES → ASK DETAILS
NO → GO TO 'EDUCATION AND TRAINING' SECTION

Details (What was the job? When left job, etc)

EDUCATION AND TRAINING

1. Are you studying for any formal qualifications at the moment?

YES → ASK DETAILS
NO → GO TO QU 2

Details (e.g. what, where, full/part time, hours in the last month)

2. In the last month, have you been on any taught courses or undertaken learning of any of the following sorts:

Taught courses meant to lead to qualifications (even if you did not obtain them)	
Taught courses designed to help you develop skills that you might use in a job	
Courses or instruction or tuition in driving, in playing a musical instrument, in an art or craft, in a sport or in any practical skill	
Evening classes (e.g. art/craft, languages, cookery)	
Learning which involved working on your own from a package of materials provided	

IF YES TO ANY OF THE ABOVE → ASK DETAILS
IF NONE OF THE ABOVE → GO TO 'VOLUNTARY WORK' SECTION

Details (e.g. what, where, full/part time, hours in the last month)

3. On how many occasions in the last month did you spend time studying at home outside of teaching sessions? How many hours?

Details (e.g. what, where, full/part time, hours in the last month)

VOLUNTARY WORK

Have you done any voluntary work through a group or on behalf of an organisation at any time during the last month? Have you done any unpaid work for anybody else e.g. running errands for elderly relatives?

YES → ASK DETAILS
NO → GO TO 'LEISURE ACTIVITIES'

Details of voluntary work
How many times in the past month?
How long do you normally spend doing this?

LEISURE AND SPORT ACTIVITIES

1. I am now going to ask some questions about things that some people do in their spare time. For each activity that I mention could you please tell me whether of not you have done this in the last month, AND how often?

ACTIVITY	NUMBER OF TIMES	AMOUNT OF TIME
Been to cinema		
Been to an event as a spectator (e.g. sports event, theatre, live music performance)		
Been to a museum, art gallery or heritage site		
Been to a library		
Been out to eat or drink at a café, restaurant, pub or wine bar		
Been to a shopping centre, or mall, apart from regular shopping for food and household items		
Been to some other place of entertainment (e.g. dance, club, bingo, casino)		
Been on any other outdoor trips (including going to places of natural beauty, picnics, going for a drive or going to the beach)		
Been involved in any community based activities (e.g. Scouts, going to church)		

2. I am now going to ask about sports activities. Could you please tell me whether or not you took part in any of these sports in the last month AND how often?

ACTIVITY	NUMBER OF TIMES	AMOUNT OF TIME
Swimming		
Cycling		
Gym/weight training		
Exercise classes (e.g. aerobics, martial arts)		
Team sports (e.g. rugby, football, cricket, hockey, netball)		
Racquet sports (e.g. tennis, badminton, squash)		
Jogging, cross country, road running		
Walking or hiking for 2 miles or more (recreationally)		
Climbing/mountaineering		
Fishing		
Golf		
Horse riding		
Pub games (e.g. snooker, pool, darts)		

3. How much time do you spend socialising? How many occasions in the last month have you seen friends, either visiting them or receiving visitors? How much time did you tend to spend socialising on each occasion on average?

Details

CHILD CARE

1. Are you responsible for the care of any children?

YES → ASK 2
NO → GO TO 'HOUSEWORK AND CHORES'

2. How many children do you have? How old are they? Are you their primary carer?

Details

3. How much time do you spend doing things with your children?

Physical care (e.g. feeding, dressing, washing)	
Supervision (inside and outside)	
Teaching children (e.g. helping with homework)	
Reading, playing and talking with children	
Accompanying child (e.g. to school, doctor, friend's house, etc)	

HOUSEWORK AND CHORES

1. How many people do you live with? Who is mainly responsible for the housework?

Details

2. How much time do you spend doing housework and chores per week?

Food management and preparation	
Cleaning, dusting, vacuuming, washing dishes	
Food shopping	
Washing	
Gardening	
DIY and repairs	

TIME USE INTERVIEW SCORE SHEET

EMPLOYMENT

- Is paid work in the last month present or absent?

  ☐ Present = 'YES' response to Question 1

  ☐ Absent = 'NO' response to Question 1

- Type of work/job title (Question 1)

  ☐

- Hours per week in paid employment over the last month

  ☐ NB. This should be calculated by adding all hours spent in employment (from Questions 1 and 2) and multiplying by 12 then dividing by 52 to get a weekly average.

- Have they been away from main job?

  ☐ Present = 'YES' response to Question 3

  ☐ Absent = 'NO' response to Question 3

- Reason for being away from job, e.g. Maternity leave.

  ☐

- Has paid work ever been present?

  ☐ Present = 'YES' response to Question 4

  ☐ Absent = 'NO' response to Question 4

  If yes:

  ☐ Number of weeks since last worked (Response to Question 4)

  What was the last paid job? (Question 4)

  ☐

EDUCATION

- Current education present or absent?

☐ Present = any 'YES' response to Questions 1 and 2

☐ Absent = 'NO' responses to Questions 1 and 2

Hours per week in education over the last month

☐ NB. This should be calculated by adding all hours spent in employment (from Questions 1 and 2) and multiplying by 12 then dividing by 52 to get a weekly average.

VOLUNTARY WORK

- Is voluntary work present or absent?

☐ Present = 'YES' response to Question 1

☐ Absent = 'NO' response to Question 1

- Hours per week spent in voluntary work over the last month

☐ NB. This should be calculated by adding all hours spent in employment (from Questions 1 and 2) and multiplying by 12 then dividing by 52 to get a weekly average.

LEISURE AND SPORT ACTIVITIES

- Are leisure activities present or absent?

☐ Present

☐ Absent

- Hours per week spent in leisure activities over the last month

☐ NB. This should be calculated by adding all hours spent in employment (from Questions 1 and 2) and multiplying by 12 then dividing by 52 to get a weekly average.

- Are sport/physical activities present or absent (taken from Question 2)

☐ Present

☐ Absent

- Hours per week spent in sport/physical activities over the last month

☐ NB. This should be calculated by adding all hours spent in employment (from Questions 1 and 2) and multiplying by 12 then dividing by 52 to get a weekly average.

- Hours per week over last month spent socialising:

☐

CHILDCARE

- Childcare

☐ Applicable

☐ Non-applicable

- How many children? ☐ Age of youngest child? ☐

- Primary carer?

☐ Yes

☐ No

- Hours per week spent on childcare

☐ NB. Taken from estimate of average time including items from checklist in estimate

HOUSEWORK AND CHORES

- Hours per week spent on housework and chores

☐ NB. Taken from estimate of average time including items from checklist in estimate

Appendix B:

Approval to Use Data

I confirm that Joanne Hodgekins was involved in the collection of National EDEN data in Norfolk and has approval from the study team to use the full National EDEN data set for her Doctorate in Clinical Psychology thesis research.

Signed: …….

Professor David Fowler

(Research Supervisor and National EDEN Principal Investigator/grant holder)

Appendix C:

Ethical Approval for National EDEN study

C1 Letter of ethical approval

C2 Participant Information Sheet

C3 Participant Consent Form

Suffolk Local Research Ethics Committee
NO28
The Ipswich Hospital NHS Trust
Heath Road
Ipswich
Suffolk
IP4 5PD

Tel: 01473 278068
Fax: 01473 278133
Email: SLREC@ipswichhospital.nhs.uk

06 May 2005

Dr Helen Lester
Reader in Primary Care
The Medical School
University of Birmingham
Edgbaston
Birmingham B15 2TT

Dear Professor Birchwood and Dr Lester

Full title of study: ***A National Evaluation of Early Intervention for Psychosis Services: DUP, Service Engagement and Outcome. (The National Eden Project)***

REC reference number: ***05/Q0102/44***

The Research Ethics Committee reviewed the above application at the meeting held on 29 April 2005.

Documents reviewed

The documents reviewed at the meeting were:

Document Type:	Version:	Dated:	Date Received:
Application	2	04/04/2005	13/04/2005
Prof. Birchwood's CV		not dated	08/04/2005
Dr Helen Lester's CV		not dated	13/04/2005
Protocol	6	07/04/2005	08/04/2005
Covering Letter		12/04/2005	13/04/2005
Letter from Dr Laverty		04/04/2005	08/04/2005
Letter from Prof. Chilvers		08/04/2005	13/04/2005
Letter from Mrs Hammersley		06/04/2005	08/04/2005
Supplementary Information List		not dated	08/04/2005
Instructions for Completing Consent Forms for Service Users 16+	1	April 2005	08/04/2005
Patient Information Sheet -16+	1	April 2005	08/04/2005
Consent Form-16+	1	April 2005	08/04/2005
Patient Information Sheet -<16	1	April 2005	08/04/2005
Consent Form-<16	1	April 2005	08/04/2005
Patient Assent Form-<16	1	April 2005	08/04/2005

Health Professionals Information Sheet	1	April 2005	08/04/2005
Consent Form- Health Professionals	1	April 2005	08/04/2005
Instructions for Completing Consent Forms for Carers	1	April 2005	08/04/2005
Carer Information Sheet	1	April 2005	08/04/2005
Consent Form- Carer	1	April 2005	08/04/2005
Timetable for data collection	1	April 2005	08/04/2005
Measures collected by table	1	April 2005	08/04/2005
Employment Questionnaire	1	April 2005	08/04/2005
The National Survey of Time Use		not dated	08/04/2005
Personal Details Form	1	April 2005	08/04/2005
Family History Form	1	April 2005	08/04/2005
Duration of Untreated Psychosis	1	April 2005	08/04/2005
Pathways to Care Collated Form	1	April 2005	08/04/2005
Premorbid Adjustment Scale	1	April 2005	08/04/2005
Positive and Negative Syndrome Scale	1	April 2005	08/04/2005
Insight Scale (IS)	1	April 2005	08/04/2005
EQ-5D (Health Questionnaire)		not dated	08/04/2005
Calgary Depression Scale		not dated	08/04/2005
Drug Check		not dated	08/04/2005
The Young Mania Scale		not dated	08/04/2005
Adverse Outcomes Screening Questionnaire	1	April 2005	08/04/2005
Adverse Outcomes Detailed Questionnaire	1	April 2005	08/04/2005
Adverse Outcomes Screening Questionnaire- Carer	1	April 2005	08/04/2005
Global Assessment Of Functioning Scale (GAF), Disability, Symptoms		not dated	
Treatment Documentation Sheet	1	April 2005	
CUtLASS- 7-point Compliance Scale Record		not dated	
Service Engagement Scale		not dated	
Operational Procedure and Criteria for Rating Relapse and Recovery		not dated	
OPCRIT for Windows (v4)		not dated	
Early Intervention Service Fidelity Scale	3	not dated	
Peer Review		not dated	
Semi- Structured Interview Schedule- Users	1	February 2005	08/04/2005
Semi- Structured Interview Schedule- Carers	1	February 2005	08/04/2005
Semi- Structured Interview Schedule- Team Leads and Team Members	1	25/01/2005	08/04/2005

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further clarification set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving further clarification of the role of the Participant Information Sheet for the under 16s. We would like the heading/title of this to reflect its role for informing relatives/ legal guardians as well as patients about the project in order to obtain both assent as well as consent. We would be grateful if you could submit a Information Sheet with a revised title..

When submitting a response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 02 September 2005.

"No local investigator" status

The Committee agreed with your declaration that this is a "no local investigator" study. Site-specific assessment is not required for sites involved in the research and no information about the study needs to be submitted to Local Research Ethics Committees. However, you should arrange for the R&D Departments of all relevant NHS care organisations to be notified that the research will be taking place before the research commences.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Communication with sponsor and care organisation(s)

This communication is confidential but you may wish to forward copies to your sponsor and/or relevant NHS care organisation(s) for their information.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q0102/44	**Please quote this number on all correspondence**

Yours sincerely,

Dr D M Bailey
Chair

Enclosures *List of names and professions of members who were present at the meeting and those who submitted written comments*

SUFFOLK LOCAL RESEARCH ETHICS COMMITTEE

Protocol submitted: 05/Q0102/44
A National Evaluation of Early Intervention for Psychosis Services: DUP, Service Engagement and Outcome- The National EDEN Project

Chief Investigators: Professor Max Birchwood
Dr Helen Lester

Date viewed: 29 April 2005

Member	Title/Name	Occupation	Male/Female	Present at Committee Meeting
Chairman:	Dr D M Bailey	Consultant in Pain Management & Anaesthetics	m	Yes
Deputy:	Mrs B Patterson	Retired School Teacher	f	Yes
Administrator:	Miss W Arnolds	Administrator	f	Yes
Members:	Ms V Arkell	Community Nursing Sister	f	Yes
	Ms F Bevan	Herbalist	f	No
	Mr D Burgess	Retired Wool Broker/Company Director	m	No
	Rev S Carlsson	Hospital Chaplain	f	No
	Ms J Coates	Psychiatric Nurse	f	No
	Dr P Hayward	Retired General Practitioner	m	Yes
	Dr B Keeble	Director of Public Health	m	No
	Dr K P O'Neill	Consultant Paediatrician	m	Yes
	Mr K Purser	Manager of Hospital Pharmacy Services	m	Yes
	Ms P Strang	Statistician	f	Yes
	Dr F O Wells	Chairman Wales Cancer Bank	m	Yes

(Committee members who could not be present when this protocol was discussed were required to submit their comments in writing)

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK

Signed W Arnolds Administrator Telephone: 01473 278068

THE UNIVERSITY
OF BIRMINGHAM

May 2005, Version 2.

INSTRUCTIONS FOR COMPLETING CONSENT FORMS FOR SERVICE USERS

- **All Service users who have been incepted with your service after 1st July 2005 are eligible to take part in the National EDEN Project.**

- For service users over 16 years, there are two consent forms: the service user and the individual taking their consent should sign and date both.

- The service user retains the information sheet and one signed consent form and the remaining copy, along with the completed demographic sheet, is to be returned to the Project Team at Birmingham University. You may if you wish, keep a copy of the signed consent form on the service user's notes so you are aware of who has taken part and what research projects that individual is taking part in.

- For service users under 16 years, there are two consent forms, as well as two assent forms which the carer (relative/legal guardian) needs to sign.

- For participants under 16 years, the service user retains the information sheet and one signed consent form, and the carer retains a copy of the information sheet and the assent form. The remaining copies along with the completed demographic sheet, is to be returned to the Project Team at Birmingham University. You may if you wish, keep a copy of the signed consent and assent forms in the service user's notes so you are aware of who has taken part and what research projects that individual is taking part in.

- The clinical judgement of the care co-ordinator will be respected, and it is a matter for your discretion whether you feel a service user is well enough to consent to take part. The success of the Project however, depends upon as many service users as possible taking part.

- A small number of service users, who have consented to take part in National EDEN, from each EIS taking part in the Project, will be interviewed. No service user will be approached to take part in an interview without the relevant care co-ordinator first being consulted.

THANK YOU FOR YOUR HELP!

THE UNIVERSITY
OF BIRMINGHAM

PATIENT INFORMATION SHEET
(Over 16 years)

May 2005: Version 2.

Study Title: A National Evaluation of Early Intervention in Psychosis Services: DUP, Service Engagement and Outcome (The National EDEN Project).

You are being invited to take part in a research study. Before you decide whether or not you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

The purpose of the study:
The aim of the project is to evaluate the implementation and impact of Early Intervention Services (EIS) for people aged between 14-35 years of age in different areas of the country.

Why have I been chosen?
We are inviting everyone aged between 14-35 years of age who has been referred to the Early Intervention Service to take part in this study. This will involve approximately 800 young people across the country.

Do I have to take part?
No - involvement in this study is entirely voluntary. However if you decide to take part, you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of health care you receive now or in the future.

What will happen to me if I take part?
If you agree to take part in the study, we will use the data from assessments that have been completed with you by the clinical team. The data will be put into a database and analysed together with data from other clients of the Early Intervention Service (EIS). All data will be anonymised. We would also like to ask you some questions about when you first became unwell, including any incidences of self-harm or violence. This is to determine how you came into contact with the EIS, and also how long you were unwell before contact was made with services.

At this stage we will ask a small number of people (20 in each service, over 2 years) to also take part in a face-to-face interview with a trained researcher who is part of the research team, about their experiences of the Early Intervention Service. The researcher will ask you questions about how easy services are to access, the types of treatments you have been offered, and your general observations on the treatment you have received. The interview will be in a place where you feel comfortable, for example in a quiet room in the Early Intervention Service or in your own home. If you like, you can invite a relative or carer to be present during the interview.

You may also be asked whether you feel that it is appropriate for the research team to contact a friend or relative to ask similar questions. However, this contact will only be made with your permission and the purpose of this contact is to provide them with an opportunity to share their perceptions of how the Early Intervention Service has responded to your needs.

What are the possible side effects of taking part?
Some of the questionnaires **may** cover issues that are sensitive and/or distressing for you – you can stop if you feel uncomfortable at any stage of the interview, and refuse to answer questionnaires that you feel are too distressing.

What are the possible benefits of taking part?
At a national level, since up to 3% of people in the UK develop a serious mental illness, access to good quality mental health services at an early stage of developing an illness may improve an individual's chances of recovery and the quality of life for individuals and their families. On a personal level, involvement in the project may help you think about and reflect more on your treatment and the treatment you would like to receive in future.

What will happen when the research study stops?
This research study lasts for 2 years from July 2005. There will be no change to your care or to services when the study stops, but we hope that the final results of the study will help the health professionals involved in running Early Intervention Services to make changes in the medium to longer term to further improve services. The results of the study will be written up in 2008, you will be able to obtain findings from this project on www.iris-initiative.org.uk and the Rethink website www.rethink.org

Will my taking part in this study be kept confidential?
All information collected as part of this research, including questionnaires, typed up notes of interviews and tape recordings of interviews will be kept in a locked filing cabinet in the Department of Primary Care and General Practice at the University of Birmingham. Any information from or about you will have your name, address and any other identifying features removed, so that you cannot be recognised from it. This means that your anonymity will be preserved at all times during and after the study time period. The tapes will be destroyed 5 years after the study has been completed in line with University of Birmingham research policy.

What will happen to the results of the research study?
The results of the study will be written up for publication in health professional journals and will be presented at conferences in the UK and abroad. However your anonymity will be preserved at all times.

Who is organising and funding the research?
The research is organised by The University of Birmingham, Department of Primary Care and General Practice and funded by a grant from the Department and Health and NIMHE (National Institute for Mental Health in England). Indemnity is provided by the University of Birmingham. The protocol has been reviewed by the Suffolk Local Research Ethics Committee.

Contact for Further Information
Dr Helen Lester, Senior Lecturer in Primary Care, on 0121 414 2684, or Dr Natasha Posner, (National EDEN Project Evaluation Coordinator), on 0121 414 8581, Department of Primary Care and General Practice, University of Birmingham, Edgbaston, Birmingham B15 2TT. If you agree to participate, you will be given a copy of this Patient Information Sheet and a copy the signed consent form to keep.

If you have any concerns about the study and wish to contact someone independent, please telephone Ella Wright, the local ethics committee co-ordinator on 0121 507 5712 between 9am and 5pm.

Thank you for reading this.

THE UNIVERSITY
OF BIRMINGHAM

PATIENT INFORMATION SHEET
(Under 16 years)

May 2005: Version 2.

Study Title: A National Evaluation of Early Intervention in Psychosis Services: DUP, Service Engagement and Outcome (The National EDEN Project).

You are being invited to take part in a research study. Before you decide whether or not you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

The purpose of the study:
The aim of the project is to evaluate the implementation and impact of Early Intervention Services (EIS) for people aged between 14-35 years of age in different areas of the country.

Why have I been chosen?
We are inviting everyone aged between 14-35 years of age who has been referred to the Early Intervention Service to take part in this study. This will involve approximately 800 young people across the country.

Do I have to take part?
No – involvement in this study is entirely voluntary. However if you decide to take part, you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of health care you receive now or in the future.

What will happen to me if I take part?
If you agree to take part in the study, we will use the data from assessments that have been completed with you by the clinical team. The data will be put into a database and analysed together with data from other clients of the Early Intervention Service (EIS). All data will be annonymised. We would also like to ask you some questions about when you first became unwell, including any incidences of self-harm or violence. This is to determine how you came into contact with the EIS and also how long you were unwell before contact was made with services.

At this stage we will ask a small number of people (20 in each service, over 2 years) to also take part in a face-to-face interview with a trained researcher who is of the research team, about their experiences of the Early Intervention Service. The researcher will ask you questions about how easy services are to access, the types of treatments you have been offered and your general observations on the treatment you have received. The interview will be in a place where you feel comfortable, for example in a quiet room in the Early Intervention Service or in your own home. If you like, you can invite a relative or carer to be present during the interview.

You may also be asked whether you feel that it is appropriate for the research team to contact a friend or relative to ask similar questions. However, this contact will only be made with your permission and the purpose of this contact is to provide them with an opportunity to share their perceptions of how the Early Intervention Service has responded to your needs.

What are the possible side effects of taking part?
Some of the questionnaires **may** cover issues that are sensitive and/or distressing for you – you can stop if you feel uncomfortable at any stage of the interview, and refuse to answer questionnaires that you feel are too distressing.

What are the possible benefits of taking part?
At a national level, since up to 3% of people in the UK develop a serious mental illness, access to good quality mental health services at an early stage of developing an illness may improve an individual's chances of recovery and the quality of life for individuals and their families. On a personal level, involvement in the project may help you think about and reflect more on your treatment and the treatment you would like to receive in future.

What will happen when the research study stops?
This research study lasts for 2 years from July 2005. There will be no change to your care or to services when the study stops, but we hope that the final results of the study will help the health professionals involved in running Early Intervention Services to make changes in the medium to longer term to further improve services. The results of the study will be written up in 2008, you will be able to obtain findings from this project on www.iris-initiative.org.uk and the Rethink website www.rethink.org

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All information collected as part of this research including questionnaires, typed up notes of interviews and tape recording of interviews will be kept in a locked filing cabinet in the Department of Primary Care and General Practice at the University of Birmingham. Any information from or about you will have your name, address and any other identifying features removed so that you cannot be recognised from it. This means that your anonymity will be preserved at all times during and after the study time period. The tapes will be destroyed 5 years after the study has been completed in line with University of Birmingham research policy.

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Contact for Further Information
Dr Helen Lester, Senior Lecturer in Primary Care, on 0121 414 2684, or Dr Natasha Posner, (National EDEN Project Evaluation Coordinator), on 0121 414 8581, Department of Primary Care and General Practice, University of Birmingham, Edgbaston, Birmingham B15 2TT. If you agree to participate, you will be given a copy of the Patient Information Sheet and a copy the signed consent form to keep. If you have any concerns about the study and wish to contact someone independent, please telephone Ella Wright, the local ethics committee co-ordinator on 0121 507 5712 between 9am and 5pm.

Thank you for reading this.

THE UNIVERSITY
OF BIRMINGHAM

Centre No:
Patient Identification No for this study:

PATIENT CONSENT FORM

May 2005- Version 2.

Study Title:
A National Evaluation of Early Intervention in Psychosis Services: Dup, Service Engagement and Outcome (The National EDEN Project).

Name of Researcher:

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2005 (version 2) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that sections of any of my medical notes may be looked at by responsible individual from the Early Intervention service, and/or research staff from the University of Birmingham or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐
4. I agree to take part in the above study. ☐

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

THE UNIVERSITY
OF BIRMINGHAM

Centre No:
Patient Identification No for this study:

PATIENT ASSENT FORM

May 2005 - Version 2.

Study Title:
A National Evaluation of Early Intervention in Psychosis Services: Dup, Service Engagement and Outcome (The National EDEN Project).

Name of Researcher:

The relative/legal guardian should complete the whole of this sheet himself/herself

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2005 (version 2) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my relative's participation is voluntary and that s/he is free to withdrawal any time, without giving any reason, and without her/his medical care or legal rights being affected. ☐

3. I understand that sections of any of my relative's medical notes may be looked at by responsible individuals from the Early Intervention Service, and/or research staff from the University of Birmingham or from regulatory authorities, where it is relevant to my taking part in research. I give permission for these individuals to have access to my relative's records. ☐

4. I agree to my relative taking part in the above study. ☐

_____	_____	_____
Name of Carer	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

THE UNIVERSITY
OF BIRMINGHAM

Centre No:
Patient Identification No for this study:

PATIENT CONSENT FORM (Under 16 years)

May 2005- Version 2.

Study Title:
A National Evaluation of Early Intervention in Psychosis Services: Dup, Service Engagement and Outcome (The National EDEN Project).

Name of Researcher:

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2005 (version 2) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. ☐
3. I understand that sections of any of my medical notes may be looked at by responsible individuals from the Early Intervention Service, and/or research staff from the University of Birmingham or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐
4. I agree to take part in the above study. ☐

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix D:

Missing Data Analyses

Table D1

Descriptive Statistics and Frequency of Missing Data for TUS Item-level Data at Baseline (N = 878)

	N	Mean (*SD*)	Median	*n* Missing *(%)*
Work Hours	876	4.42 (12.00)	0.00	2 (0.2%)
Education Hours	850	3.20 (8.76)	0.00	28 (3.2%)
Voluntary Work Hours	876	0.43 (3.14)	0.00	2 (0.2%)
Leisure Hours	863	5.13 (8.53)	2.40	15 (1.7%)
Sport Hours	872	3.25 (9.02)	1.00	6 (0.7%)
Childcare Hours	873	3.53 (15.16)	0.00	5 (0.6%)
Chores Hours	778	5.15 (8.92)	2.50	100 (11.4%)

Table D2

Descriptive Statistics and Frequency of Missing Data for TUS Item-level Data at 6-month Follow-up (N = 673)

	N	Mean (*SD*)	Median	*n* Missing *(%)*
Work Hours	668	6.44 (13.45)	0.00	5 (0.7%)
Education Hours	645	4.47 (10.35)	0.00	28 (4.2%)
Voluntary Work Hours	671	0.97 (3.82)	0.00	2 (0.3%)
Leisure Hours	671	6.44 (8.77)	4.00	2 (0.3%)
Sport Hours	670	3.43 (5.37)	1.50	3 (0.4%)
Childcare Hours	669	3.40 (13.48)	0.00	4 (0.6%)
Chores Hours	618	5.32 (9.70)	3.00	55 (8.2%)

Table D3

Descriptive Statistics and Frequency of Missing Data for TUS Item-level Data at 12-month Follow-up (N = 623)

	N	Mean (*SD*)	Median	*n* Missing *(%)*
Work Hours	616	7.16 (14.53)	0.00	7 (1.1%)
Education Hours	601	4.43 (10.02)	0.00	22 (3.5%)
Voluntary Work Hours	622	1.12 (4.33)	0.00	1 (0.2%)
Leisure Hours	619	6.96 (10.37)	4.00	4 (0.6%)
Sport Hours	620	3.43 (6.22)	1.00	3 (0.5%)
Childcare Hours	618	3.35 (12.86)	0.00	5 (0.8%)
Chores Hours	585	5.34 (6.97)	3.50	38 (6.1%)

Table D4

Comparison of TUS Data (Structured Activity) with and without Prorating of Missing Data

	Non-Prorated		Prorated	
	N	Mean (*SD*)	N	Mean (*SD*)
Baseline	719	25.21 (25.98)	878	25.17 (26.22)
6 month follow-up	574	30.26 (24.85)	673	30.82 (25.28)
12 month follow-up	543	32.45 (26.82)	623	32.49 (26.97)

Table D5

Comparing TUS data between Participants with and without Missing Data on Predictor Variables

Predictor Variable	*n* Missing (%)	Mean Baseline TUS score (*SD*)		*t*	*p*
		Missing	Not missing		
Gender	0 (0%)	-	25.17 (26.22)	-	-
Ethnicity	0 (0%)	-	25.17 (26.22)	-	-
Age of Onset	37 (4.2%)	27.86 (30.10)	25.05 (26.05)	-0.64	.52
PANSS Positive	42 (4.8%)	24.28 (30.18)	25.22 (26.02)	0.23	.82
PANSS Negative	57 (6.2%)	22.25 (24.73)	25.38 (26.32)	0.87	.38
PANSS General	51 (5.8%)	25.78 (28.74)	25.13 (26.07)	-0.17	.87
Calgary Depression Scale	33 (3.8%)	20.70 (28.60)	25.35 (26.12)	1.00	.32
Global Assessment of Functioning	32 (3.6%)	25.12 (28.92)	25.17 (26.13)	0.01	.99
PAS up to 11 years	67 (7.6%)	20.90 (29.00)	25.53 (25.96)	1.39	.17
PAS 12-15 years	98 (11.2%)	22.61 (29.35)	25.49 (25.80)	1.03	.31
PAS 16-18 years	221 (25.2%)	23.10 (27.86)	25.87 (25.62)	1.36	.18
DUP	13 (1.5%)	28.64 (25.42)	25.12 (26.24)	-0.48	.63

Note. PAS = Premorbid Adjustment Scale, DUP = Duration of Untreated Psychosis

Appendix E

Tests of Normality for Untransformed and Transformed Time Use and Baseline Predictor Data

Table E1

Tests of Normality for TUS data – Untransformed

	Kolmogorov-Smirnov			Z-score for
	Statistic	*df*	*p*	Skewness
TUS Baseline	.17	878	<.001	21.25***
TUS 6 months	.11	673	<.001	13.56***
TUS 12 months	.11	623	<.001	11.90***

Table E2

Tests of Normality for TUS Data – Log Transformed

	Kolmogorov-Smirnov			Z-score for
	Statistic	*df*	*p*	Skewness
TUS Baseline	.07	878	<.001	-5.25***
TUS 6 months	.07	673	<.001	-7.44***
TUS 12 months	.09	623	<.001	-7.90***

Table E3

Tests of Normality for TUS data – Square Root Transformed

	Kolmogorov-Smirnov			Z-score for
	Statistic	*df*	*p*	Skewness
TUS Baseline	.08	878	<.001	6.38***
TUS 6 months	.05	673	<.001	2.66**
TUS 12 months	.05	623	<.001	1.80

Table E4

Tests of Normality for Baseline Predictor Data – Untransformed

	Kolmogorov-Smirnov			Z-score for
	Statistic	*df*	*p*	Skewness
Age at Onset	.12	841	<.001	8.50***
PANSS Positive	.09	836	<.001	6.00***
PANSS Negative	.11	821	<.001	10.33***
PANSS General	.08	827	<.001	8.89***
Calgary Depression Scale	.12	845	<.001	10.25***
Premorbid Adjustment Scale				
Childhood	.12	811	<.001	8.00***
Early Adolescence	.09	780	<.001	5.67***
Late Adolescence	.08	657	<.001	6.40***
Global Assessment of Functioning	.07	846	<.001	2.50*

Table E5

Tests of Normality for Baseline Predictor Data – Log Transformed

	Kolmogorov-Smirnov			Z-score for
	Statistic	*df*	*p*	Skewness
Age at Onset	.08	841	<.001	0.88
PANSS Positive	.09	836	<.001	-0.88
PANSS Negative	.09	821	<.001	2.11*
PANSS General	.04	827	<.001	2.58*
Calgary Depression Scale	.12	845	<.001	-6.13***
Premorbid Adjustment Scale				
Childhood	.11	811	<.001	5.11***
Early Adolescence	.07	780	<.001	2.67**
Late Adolescence	.07	657	<.001	3.2**
Global Assessment of Functioning	.07	846	<.001	-9.13***

Table E6

Tests of Normality for Baseline Predictor Data – Square Root Transformed

	Kolmogorov-Smirnov			Z-score for Skewness
	Statistic	*df*	*p*	
Age at Onset	.10	841	<.001	4.88***
PANSS Positive	.09	836	<.001	4.88***
PANSS Negative	.09	821	<.001	5.67***
PANSS General	.06	827	<.001	4.22***
Calgary Depression Scale	.10	845	<.001	-2.88**
Premorbid Adjustment Scale				
Childhood	.07	811	<.001	-3.56***
Early Adolescence	.07	780	<.001	-4.78***
Late Adolescence	.07	657	<.001	-4.00***
Global Assessment of Functioning	.06	846	<.001	-2.63**

Appendix F:

Results of Kruskal-Wallis Tests

Table F1

Mean Ranks and Results of Kruskal-Wallis Tests for Differences in Predictor Variables between Baseline Social Disability Subgroups

	Severe SD (n = 436)	SD (n = 159)	At-risk SD (n = 117)	No SD (n = 166)	Kruskal-Wallis Test H (df)
Age of onset	421.65	409.36	378.70	461.20	8.13 (3), p = .04
PANSS Positive	438.76	410.74	393.05	391.58	6.29 (3), p = .10
PANSS Negative	466.49	377.65	369.29	329.56	47.26 (3), p <.001
PANSS General	454.68	378.63	393.82	355.95	25.31 (3), p <.001
Calgary Depression Scale	440.35	384.98	413.58	420.77	6.01 (3), p = .11
GAF	353.06	442.45	499.96	535.32	80.31 (3), p <.001
Premorbid Adjustment					
Childhood	410.24	390.07	375.58	431.92	4.66 (3), p = .20
Early Adolescence	416.44	370.83	388.07	344.49	12.42 (3), p = .006
Late Adolescence	376.94	308.50	273.93	271.86	41.08 (3), p <.001

Table F2

Mean Ranks and Results of Kruskal-Wallis Tests for Differences in Predictor Variables between TUS Change Profile Subgroups

	Decreasing Group (n = 138)	Stable Group (n = 182)	Fluctuating Group (n = 171)	Increasing Group (n = 273)	Kruskal-Wallis Test H (df)
Age of onset	341.16	343.80	383.54	382.17	6.44 (3), p = .09
PANSS Positive	328.85	352.96	381.49	378.05	6.50 (3), p = .09
PANSS Negative	324.17	409.20	344.90	354.05	14.54 (3), p = .002
PANSS General	316.80	366.80	366.55	377.01	7.51 (3), p = .06
Calgary Depression Scale	339.74	360.59	381.01	380.38	4.09 (3), p = .25
GAF	419.66	328.88	351.20	379.48	15.63 (3), p = .001
Premorbid Adjustment					
Childhood	361.04	363.48	363.09	349.35	.69 (3), p = .88
Early Adolescence	330.66	371.89	343.62	337.17	4.10 (3), p = .25
Late Adolescence	252.36	319.95	304.30	289.07	10.46 (3), p = .02

Table F3

Mean Ranks and Results of Kruskal-Wallis Tests for Differences in Predictor Variables between Social Recovery Subgroups

	No Social Recovery (n = 429)	Partial Social Recovery (n = 127)	Full Social Recovery (n = 208)	Kruskal-Wallis Test H (df)
Age of onset	344.61	362.28	413.84	14.38 (2), p <.001
PANSS Positive	376.99	383.69	325.32	9.43 (2), p = .01
PANSS Negative	396.49	351.34	289.63	35.35 (2), p <.001
PANSS General	379.44	362.42	324.61	9.17 (2), p = .01
Calgary Depression Scale	372.39	350.22	371.50	1.08 (2), p = .58
GAF	319.44	402.29	448.57	53.73 (2), p <.001
Premorbid Adjustment				
Childhood	371.54	327.37	349.96	4.71 (2), p = .10
Early Adolescence	375.76	327.40	298.14	20.62 (2), p <.001
Late Adolescence	326.21	274.50	240.34	29.48 (2), p <.001

Table F4

Mean Ranks and Results of Kruskal-Wallis Tests for Differences in Predictor Variables between Social Recovery Classes

	Low Stable (n = 507)	Moderate/Increasing (n = 204)	High/Decreasing (n = 53)	Kruskal-Wallis Test H (df)
Age of onset	345.62	390.27	472.14	19.82 (2), p <.001
PANSS Positive	384.28	320.57	342.18	13.55 (2), p = .001
PANSS Negative	393.24	303.20	259.01	38.87 (2), p <.001
PANSS General	381.57	320.79	330.07	13.03 (2), p = .001
Calgary Depression Scale	371.58	351.45	404.21	2.85 (2), p = .24
GAF	325.07	460.40	426.44	61.15 (2), p <.001
Premorbid Adjustment				
Childhood	366.30	330.95	386.52	5.14 (2), p = .08
Early Adolescence	371.16	298.71	298.72	20.71 (2), p <.001
Late Adolescence	325.62	236.62	222.22	39.55 (2), p <.001

Appendix G:

Definition of Social Recovery Subgroups

No Recovery
Partial Recovery
Full Recovery

Change over 12 month study period

Baseline Social Disability

	Large decrease	Moderate decrease	Small decrease	No change	Variable	Small increase	Moderate increase	Large increase
Severe (S) (0-15 hrs)	-	-	8 hr decrease within same category: S-S-S	<8 hr increase/ decrease within same category: S-S-S	S-S-S S-SD-S S-AR-S S-AR-SD S-N-S S-N-SD S-N-AR	8 hr increase within same category: S-S-S	Moved to SD group: S-S-SD S-SD-SD	Moved to AR group: S-S-AR S-SD-AR S-AR-AR Moved to N group: S-S-N S-SD-N S-AR-N S-N-N
Socially Disabled (SD) (15-30 hrs)	-	Moved to S group: SD-SD-S SD-S-S	8 hr decrease within same category: SD-SD-SD	<8 hr increase/ decrease within same category: SD-SD-SD	SD-SD-SD SD-S-SD SD-AR-SD SD-N-SD SD-N-S SD-AR-S SD-N-AR SD-S-AR SD-S-N	8 hr increase within same category: SD-SD-SD	Moved to AR group: SD-SD-AR SD-AR-AR	Moved to N group: SD-SD-N SD-AR-N SD-N-N
At-risk (AR) (30-44 hrs)	Moved to S group: AR-AR-S AR-SD-S AR-S-S	Moved to SD group: AR-AR-SD AR-SD-SD	8 hr decrease within same category: AR-AR-AR	<8 hr increase/ decrease within same category: AR-AR-AR	AR-AR-AR AR-N-AR AR-SD-AR AR-S-AR AR-N-SD AR-N-S AR-S-SD AR-SD-N AR-S-N	8 hr increase within same category: AR-AR-AR	Moved to N group: AR-AR-N AR-N-N	-
Normal (N) (45+ hrs)	Moved to SD group: N-N-SD N-AR-SD N-SD-SD Moved to S group: N-N-S N-AR-S N-SD-S N-S-S	Moved to AR group: N-N-AR N-AR-AR	8 hr decrease within same category: N-N-N	<8 hr increase/ decrease within same category: N-N-N	N-N-N N-AR-N N-SD-N N-S-N N-S-AR N-SD-AR N-S-SD	8 hr increase within same category: N-N-N	-	-