DOCTOR OF PHILOSOPHY

The self-reported needs of people with a long-term mental illness

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By

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Summary.

Introduction.
This thesis examines self-reported need in people who have a long-term mental illness. The context is recent mental health policy in The United Kingdom which emphasises that the assessment of an individual's expressed need be undertaken in addition to a normative assessment of need. The main issue addressed concerns testing the proposition that people with a long-term mental illness can reliably and validly report their own needs.

Methodology.
The thesis is split into three stages. Stage 1 represents the piloting of client and key-worker assessment of need schedules. Stage 2 concerns refinement of the schedules based on the results of Stage 1. Stage 3 represents an examination of the reliability and validity of client's self-reported need. The basic methodology used includes the use of key-worker needs data to help verify the reliability and validity of client needs data and the use of client mental state data to help examine factors related to self-report need measures.

Results.
Results provide a) evidence that under-reporting of need by people with a long-term mental illness is more probable than over-reporting of need compared to key-workers; and b) evidence to reflect a complex interaction between client and key-worker perspectives.

Conclusions.
Overall it appears that the ability of people with a long-term mental illness to self-report need in a needs assessment situation is multi-factorial. Factors include psychiatric symptomatology, insight, cognitive deficits, motivational processes and a social desirability bias. The implication for the policy and practice of self-reported need is that people with a long-term mental illness require a thorough assessment of their mental state and verification of their needs with key-workers.

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Appendices

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Dedication.

I would like to dedicate my thesis to the clients and staff in the study without whom the research would not have been possible. Furthermore, I would like to dedicate the thesis to my father, mother, wife, daughter and son.

Chapter 1. Long-term mental illness

Chapter overview

This chapter discusses the meaning of long-term mental illness. Consideration is given to:

i) identifying long-term mental illness;

ii) highlighting several theoretical orientations to the understanding of long-term mental illness; and

iii) issues related to diagnosis and disability.

Three conclusions are made. Firstly, it is concluded that there is considerable behavioural and symptomatic heterogeneity within long-term mental illness. Secondly, there is a danger of oversimplifying a heterogeneous assortment of characteristics into an appearance of homogeneity where long-term mental illness is concerned. Thirdly, a self-report assessment of need by people with a long-term mental illness is questionable and possibly not wholly appropriate.

Introduction

This thesis examines the self-report assessment of need in long-term mental illness. The main objective is to provide an investigation of recent national and local mental health policy reform which places an increased emphasis on mental health service user participation as an important variable in the assessment of need (Welsh Office, 1989; HMSO, 1990; Welsh Office, 1991).

The notion of need is basic to human behaviour and has received widespread attention within the social sciences. However, the assessment of need, particularly a self-report assessment of need in long-term mental illness, has received little consideration. In this sense, it remains, by-and-large, an untested assumption that people with a mental illness can reliably and validly report their own needs in response to a structured assessment. Therefore, the aim of this thesis is to explore the ability of people with a long-term mental illness to self-report their own needs. This will be done by devising an assessment of need schedule specific for this purpose and then comparing the self-reported needs of people with a long-term mental illness with those of their key workers i.e., people involved in the professional delivery of mental health services. Clearly, the assessment of self-reported need and the documentation of such information have both theoretical and practical utility. As a first step in exploring such utility this chapter addresses the issue of identifying people with a long-term mental illness.

Identifying the long-term mentally ill

One of the first questions that must be confronted for the purpose of this thesis is 'What is long-term mental illness?' At a superficial level, the phrase 'long-term mental illness' is a general term, useful as a shorthand for referring to a large group of psychiatric patients whose common characteristic is that they have been ill for 'a long time'. Typically, the long-term mentally ill have been the subject of a broad spectrum of research topics (Parry and Watts, 1989); who have had special institutions created for them (Watts and Bennett, 1991) and consume considerable economic resources (Knapp, Netten and Beecham, 1993). Furthermore, the majority of people who have a long-term mental illness have a diagnosis of schizophrenia (Ciompi, 1980). Because the term is intended for general use I will

attempt to describe the types of patient who might be called the long-term mentally ill in order that I might bring some clarity to the term as it is used in this thesis. The following are considered:

- 'length of time';
- the treatment setting;
- de-institutionalisation;
- diagnosis;
- functional ability;
- the disabilities experienced; and
- theories of long-term mental illness.

There is an extensive literature available in relation to each of these areas; each will be reviewed in terms of their major findings in the hope of providing a context for an understanding and examination of an assessment of self-reported need in long-term mental illness.

Length of time.

The adjective 'long-term' is variously taken to mean lasting a long time; persistent; continuous; constant; severe; intense; and bad (Collins Modern English Dictionary, 1988). The phrase 'long-term mental illness' has been used interchangeably with concepts of 'chronic mental illness', 'serious mental illness', and 'continuing care'. A common thread amongst these terms is, as several authors (Angellini, 1982; Goldman, 1983; Shepherd, 1984; Hall, 1987; Brewin, et al., 1988; Ford et al., 1992) have identified, that the long-term mentally ill are a group of individuals, who after having first been in contact with the psychiatric services, continue that contact for all or much of their lives. If this is accepted, then it introduces a time dimension into research. Consequently, two logical questions are 'At what point does long-term mental illness start?' and 'Can it be measured?'

'Length-of-time' has been variously used, for example: by durations of admission of more than one year (Bachrach, 1983; Jones, 1985; Pryce and Preston, 1988; O'Driscoll, 1993);

continuous contact with the psychiatric services (in-patient, day-care or out-patient care) for at least the previous twelve months without a break exceeding 13 weeks (Brewin et al., 1988); minimum attendance of one visit to a hospital ward or day hospital facility in every three months (Compton and Brugha 1988); more than five years (Dellario et al., 1983, McCreadie, 1991); at least one psychiatric admission (Lynch and Kruzich, 1986); in contact with psychiatric services for and least one year and currently of day care per week (MacCarthy et al., 1986); more than six years (Van Haaster et al., 1994); hospitalised at least twice (Nelson and Earls, 1986); intensive day care and outreach facilities (Thapa and Rowland, 1989); contact with some psychiatric service (including out-patient clinics - providing there were no gaps of 90 days or more); and an aggregate one-year stay in hospital in the past five years, or three or more admissions in past five years, or any admissions in past five years (Patmore and Weaver, 1991). In a review of 225 studies on long-stay psychiatric patients Hall (1979) cites age and length-of-time in hospital as the most frequently used criteria either to select subjects or to describe them. The maximum age of 60 years being chosen as the most frequent age criterion, and a minimum of two years being the most common length-of-time criterion. Hall (op. cit.) suggests a number of basic requirements in the study of the long-term mentally ill. These include better knowledge of sex differences; better knowledge of chronicity effects; better knowledge of effects of specific psychiatric diagnosis; and the use of a wider range of proven measurement procedures. Because there is no consensus on 'length-of-time' as a criterion for long-term mental illness Strauss (1975) suggests that length-of-time should be thought of in terms of a continuous variable in research.

The treatment setting.

The effects of 'length-of-time' known to the psychiatric services starts with Stanton and Schwarz's (1954) early research which suggested that institutional care creates maladaptive behaviour. Furthermore, Goffman's (1961) concept of the total institution described how prolonged institionalisation may produce deviant behaviours. He felt that there were attempts to adapt to the total institution environment were not of themselves symptomatic of mental illness. The total institution was defined by Goffman (op. cit.) as "...a place of residence and work where a large number of like situated individuals, cut off from the

wider society for an appreciable period of time, together lead an enclosed and formally administered round of life". Goffman's thesis was that the central feature of institutional life is a breakdown of barriers between three spheres of life. Namely, sleep, work, and play. The characteristics of the total institution are that it is one organisational system embracing all aspects of resident life in the form of an homogeneous population of residents. In this sense, the total institution is hypothesised to be at one end of a continuum, the other end of which is 'normal' self-determined life in domestic surroundings, with work and leisure carried out in different places. Goffman's premise is that institutional care, in the form of asylum, is defined by a pattern of life as much as by other features of the institution.

The institutional syndrome has generated testable hypotheses. For example, Wing (1966) suggests that length-of-time hospitalised and intensity of post-admission symptoms is important. Wing and Brown (1970) attempted to separate out those symptoms hypothesised to be caused by the illness itself from those hypothesised to be caused by the experience of being a long-term psychiatric in-patient. These authors studied the relationship between institutionalisation and schizophrenia. They were able to show that there are common characteristics, which define the long-term mentally ill, independently of diagnosis, severity of illness or symptomatology. These include: social withdrawal, flattened affect, poverty of speech, slowness, and motor retardation. Wing and Brown (1970), and Gottesman (1991), conclude that 'the under-stimulating environment' is an important variable in the genesis of long-term schizophrenia and that environmental poverty is highly correlated with negative symptomatology. Although concerns can be identified in terms of using length-of-time as a variable in relation to the effects of institutionalisation there is evidence that has examined the predictive value of length-of-stay in long-term schizophrenics (Wing and Brown, 1970; Test and Stein, 1975; Owens and Johnstone, 1980; Giel, Wiersma, Jong and Sloof, 1984). By way of an example, Wing and Brown (1970) found that social withdrawal was highly correlated with length-of-stay in a positive direction and that length-of-stay and contact with outside bodies was negatively correlated. Interestingly, the correlations were higher for patients aged over 45 years. Although it is possible to delineate some of the effects of institutionalisation in

terms of long-term mental illness a further understanding of the characteristics observed in this population is necessary.

Wing and Brown (1970) propose a typology of institutionalised schizophrenics consisting of pre-morbid, primary, and secondary disabilities. In this model pre-morbid disabilities are hypothesised to be present before the onset of the illness and consist of low IQ, poor educational achievement, and low social class. Primary disabilities are hypothesised to be part of the illness itself and are characterised by such symptoms as formal thought disorder, hallucinations, and apathy. Finally, secondary disabilities are those influences, which have impacted on the patient because the patient has been ill for a 'long-time', for example, length-of-time institutionalised. Clearly, and for the purpose of research, the idea of being able to differentiate groups of people with a long-term mental illness is important. However, as Caton et al., (1985) have observed, the main difficulty in establishing any causal relationship between the effects of length-of-stay and characteristics of long-term mental illness is confounded because it is not possible to isolate the variable 'length-of-stay/length of time' sufficiently well from other extraneous variables e.g., post-discharge treatment, psycho-pharmacological treatment, and/or social factors including care regimes. What this brings to light is the issue of de-institutionalisation and long-term mental illness and current thinking.

De-institutionalisation.

The history and process of psychiatric de-institutionalisation has been described elsewhere (e.g., Borus, 1981; Bachrach, 1983; Bennett and Morris, 1983; Leff, 1991; Crosby, Barry, Carter and Lowe, 1993). Suffice to say that three points are worth mentioning. Firstly, one of the basic tenets of de-institutionalisation has been the avoidance of long-term psychiatric hospitalisation and the attendant problems of institutionalisation. Secondly, de-institutionalisation has resulted in a shift from over-riding institutional service provision to care in the community. Thirdly, policy and practice has changed markedly in the post de-institutionalisation period in terms of the assessment of need and the allocation of mental health resources for the long-term mentally ill (Brewin, et al., 1987; Bouras et al., 1992; Ford et al., 1992; Carter et al., 1995). Because there has been a change in the locus of care

this has made it more difficult to identify and count the long-term mentally ill (Goldman, 1983). This is because once defined as 'long-term' residents of psychiatric hospitals, these individuals now live in many different institutional and community settings, consisting of a wide range of living facilities and services which include in-patient treatment (Bennett and Morris, 1983; Brown, 1985; Thornicroft and Bebbington, 1989). The context is now one where the long-term mentally ill have histories of hospitalisation and aftercare whereas others have never been in psychiatric institutions (Bachrach, 1982). This situation is important in terms of identifying the long-term mentally ill. This is because changes in the treatment setting that have occurred since Goffman's work in the early 1960's and Wing and Brown's findings in the 1970's will now undoubtedly be influenced by selection factors in the long-term mentally ill population. The upshot is that 'long-term' in an era of de-institutionalisation probably measures something different things today.

In summary, the fore-going discussion has described characteristics of long-term mental illness from the perspective of 'length-of-time' and the treatment setting. Clearly, length-of-time in a psychiatric hospital is an important variable in research which attempts to describe characteristics of long-term mental illness. In essence, the notion of 'long-term' should be seen as a continuum. The rationale for this is that a measure of time can test for significant relationships with other continuous variables thought to be important in relation to long-term mentally ill people. In order to explore the issue of long-term mental illness further this discussion will proceed by examining diagnosis as a variable.

Diagnosis.

Before the idea of diagnosis is discussed the notion of 'mental illness' itself requires brief consideration. Arguments over the exact limits of mental illness per se are legion. On the one hand, as Simms (1988) and Davison and Neale (1990) consider that mental illness covers a wide range of disorders with varying degrees of seriousness; for example, depression, anxiety, schizophrenia and dementia. Each type of disorder requires different specialist medical and psychological treatments lasting from weeks to many years. On the other hand other authors have regarded mental illness as a myth (for example, Szasz, 1971). Shepherd (1990) suggests, diagnosis incorporates an individual "... whose symptoms,

behaviour, distress or discomfort leads to a medical consultation at which a psychiatric diagnosis is made by a medically qualified person". In this sense, diagnosis is a key clinical procedure. It is both a process and a label that implies a cause, treatment strategy; and prognosis. The difficulty is that currently diagnosis in mental illness is a controversial topic (e.g., Dumont, 1987; Freedman, Brotman, Silverman and Hutson, 1986). Its meaning and utility are being challenged both in research and in clinical schools of thought (Dworkin, 1992). For example, Mirowsky and Ross (1989) have argued that diagnosis has utility neither for the researcher nor for the clinician; contending that diagnosis is a weak and unreliable measurement, which groups symptoms into categories that do not correspond to statistically valid factors. Nevertheless, a review of the term long-term mental illness must take account of issues related to diagnosis.

In terms of diagnostic nosologies DSM-III-R (American Psychiatric Association, 1987) and International Classification of Diseases (WHO, 1992) provide diagnostic manuals of mental disorders. When making a diagnosis there can be considerable heterogeneity within any one diagnostic category. As Kendall (1986) and Dworkin (1992) have pointed out there is no conceptual definition of mental illness that has the consensus of the psychiatric disciplines or the social sciences. Naturally, this raises an issue for the diagnostic reliability of the particular classification system used. Diagnostic disagreement can be found in the literature. For example, Winokur, Zimmerman and Cadonet (1988) note that given the same data, clinicians may disagree on the diagnosis because of differences in the interpretation of criteria. Furthermore, Dworkin (1992) provides an example of a study where diagnosis shifted between functional psychosis and a non-psychotic illness over a three-year period. Moreover, almost one-third of the participants was given a different diagnosis each time they were hospitalised. Diagnostic uncertainty involved switches among schizophrenia, schizoaffective and affective disorder. Clearly, such diagnostic disagreement can impact even the simplest research designs. So, can long-term mental illness be described diagnostically? This review suggests that, in addition to issues surrounding 'length-of-time' there is disagreement over which psychiatric diagnoses might qualify an individual as being 'long-term mentally ill'. Under these conditions, how does the researcher deal with the issue of diagnosis? Fundamentally, the reality is that the

researcher has little choice as to whether diagnosis is to be a variable. In this sense, because medics use diagnosis, the non-medical researcher will need to do so as well.

Functional ability

With the advent of care in the community the notion of functional ability has become an important criterion and source of information, particularly in relation to an individual's ability to meet their own needs (HMSO, 1990; Thornicroft, Brewin, and Wing, 1992). Naturally, such a shift in the emphasis of mental health care has necessitated a shift in the understanding of how people with a long-term mental illness function. Several authors have tackled the issue of functional ability (Hall and Baker, 1983; Brown, 1985; Test, Knoedler, and Allness; 1985; Brewin et al., 1988; Parry and Watts, 1989; Patmore and Weaver, 1991; The World Health Organisation, 1992;Thornicroft, Margolis et al., 1992; Carter et al., 1995). What these authors highlight in relation to the concept of functional ability is the revision of concepts which relate to health and illness.

The World Health Organisation (1992) provide a classification of disease that can be used to imply the existence of a clinically recognisable set of symptoms or behaviours associated with personal functioning and ability to cope. The first level of classification involves 'impairment' i.e., loss or abnormality of function, and is thought to be appropriate for the psychological impairments that underlie the basic psychiatric symptoms in terms of interference with mental functions such as memory, attention, and emotion. The second level involves 'disability' and is intended to refer to restrictions on personal activities/abilities to perform in a way considered normal for a human being e.g., self care. This may be a direct result of impairment. The third level concerns the concept of 'handicap' and is hypothesised to derive from both impairment and disability. In this sense, an individual is prevented or limited in their performance of a role that is normal in the wider social context. In short, an individual finds it very difficult to interact with their environment. Clearly, by operationalising the concept of 'disability' in this way there is an attempt to distinguish between 'symptoms of disease' and any psychosocial consequences. However, a difficulty arises because there is presently no consensus on the specific character or relative importance of disability, duration and disability criteria. Chief

amongst these difficulties is the observation that disability may endure long after the primary symptoms of an illness have remitted (Gruenberg, 1982; Wing, 1989, 1990). Ways of overcoming such difficulties are provided by Shern et al., (1986) and Wing, (1989, 1990).

Shern et al., (1986) attempt to delineate long-term mental illness in a way which involves concepts of diagnosis, duration and disability. Within their model patients must meet three separate criteria to be considered long-term mentally ill. The first criterion relates to the duration of patient's mental health problems. Those individuals whose problems have existed for a year or longer are considered candidates for long-term status. The second criterion involves the individual's treatment history i.e., either a psychiatric in-patient episode or a partial hospitalisation/day treatment experience. Thirdly, individuals meeting these two criteria must also present with serious dysfunction in basic life skills by having at least two of the following: sheltered employment, unemployment, basic needs problems in relation to food, clothing, housing and finances; social skills problems, self-care problems; inappropriate behaviour or be psychiatrically disabled. The model shares several general characteristics of that offered by Test and Stein (1975) with a relative emphasis on psychosocial functioning.

Wing (1989, 1990) attempts to relate severity of disablement to long-term mental illness with the concept of 'social disablement'. The model includes three measures as follows:- the severity and duration of impairment, adverse circumstances and disadvantages, and personal reactions. Importantly, Wing (op. cit.) makes several points:

i) social disablement is associated with an amalgam of factors that produce a pattern, level, and persistence of malfunctioning that may not be diagnosis-specific;
ii) the greater the number and the greater the severity of symptoms the more severe social disablement tends to be;
iii) however long an impairment lasts this may lead to stigma, a low standard of living, and demoralisation;

iv) in turn these can exacerbate psychiatric symptomatology; and

v) if need for mental health services is defined in terms of impairment or other factors causing social disablement then instances of long-term mental illness are multi-factorial in terms of severity that may not be diagnosis-specific in relation to the services they require.

Clearly, there is a need to review those disabilities experienced by the long-term mentally ill and how it is they relate to core components of an individual's long-term mental illness.

The disabilities experienced

The early literature concerning care in the community for those with a long-term mental illness in the UK begins with Mann and Cree's (1976) study of approximately four hundred long-stay psychiatric in-patients. The study concluded that the psychiatric disorders with the greatest chronicity - schizophrenia, major depression, and organic syndromes - were those most in need of a skills-training focus and that at least two thirds of the patients could be maintained in the community with some support from the psychiatric services. However, it must be noted firstly, that the notion of 'some support' remained unqualified by these authors and secondly, that most people with a long-term mental illness were cared for by the psychiatric hospital at this time. More recent papers have shown a high level of psychiatric morbidity in the long-term mentally ill. Typically, the group has been characterised as having a wide range of disabilities in relation to social and clinical functioning that limit their ability to survive in the community without help. For example, Wykes et al. (1982, 1985); Brugha et al., (1988) and Pryce and Preston (1988) have found that social problems are common, particularly those involving higher order management and decision functions such as personal planning and domestic affairs. Ford et al., (1992) and MacCarthy et al., (1986) found that medication monitoring, psychosocial treatment, day and vocational activities are rated as high priority needs. Other studies have found securing employment to be very difficult in long-term mental illness (Floyd et al., 1983) and that familial problems are also prevalent in long-term mental illness (Leff and Vaughan, 1985; Kuipers and Bebbington, 1988).

In summary, several characteristics of dysfunction in long-term mental illness can be identified. The main issue concerns a long-term mentally ill person's ability to live independently in a given environment. In this sense, disability is characterised in terms of functioning and any discrepancy in relation to what might be considered normal for a society. For example, MacCarthy et al., (1989) found major social and personal functional deficits in over 50% of long-term psychiatric patients in their study. However, such data needs to be balanced against the finding that it is possible for long-term mentally persons to learn skills essential for successful living in the community and furthermore, that long-term mental illness does not prevent skill learning in this population (e.g., Creer and Wing, 1974; Brown and Mumford, 1983; Cutler et al., 1983; MacCarthy et al., 1986). Clearly, alternative ways of examining functional disability in long-term mental illness require consideration.

Theories of long-term mental illness: a similarity of symptoms.

As was stated earlier that the majority of people in hospital who have a long-term mental illness have a diagnosis of schizophrenia (Ciompi, 1980). There are several features, which are central to the concept of schizophrenia in addition to delusional ideas and hallucinatory experiences. Wing and Brown (1970) and Strauss et al., (1974) developed the conceptualisation of 'positive and negative' symptoms in order to provide a framework for relating schizophrenic symptoms to functioning in daily life. Positive symptoms are hypothesised to reflect an excess of behaviour whilst negative symptoms are hypothesised to entail the reduction of normal behaviour. In general, negative symptoms are considered to have a more devastating impact on long-term adjustment in schizophrenia. However, Zubin et al., (1983) argue that there is a similarity of symptoms presented by different long-term mental illnesses. Zubin et al., (op. cit.) assert that negative symptoms are clearly found in individuals classified by a different diagnosis. Bearing this in mind, some common attributes found in the long-term mentally ill include: slowness in speech and time needed to do tasks, poor concentration, distractibility, low levels of motivation, an unwillingness to initiate conversations with other people, poor eye-contact, and poor skills related to self-care e.g., personal hygiene, willingness to cook. So why is it that, having alleviated psychiatric symptomatology e.g., delusions and hallucinations, many patients

remain seriously disabled? In order to answer this question evidence from five theoretical perspectives will be examined, namely, the stress-vulnerability model, theories of patient behaviour, psycho-dynamic models, cognitive-neuro-psychology, and the bio-psychosocial model.

The stress-vulnerability model

The stress-vulnerability model focuses on the environment external to the individual. Theories of stress suggest that even in the normal individual, severe environmental stress can cause such emotional distress that normal coping mechanisms are rendered inadequate, and the individual suffers a mental disorder (Zubin and Spring, 1977). However, the link between stress and the major psychiatric illnesses is not well understood and it is unlikely that it is the single causal factor in long-term mental illness (Zubin, Magazine, and Steinhauer, 1983). Neuchterlien and Dawson (1984) attempted to develop a stress-vulnerability model of mental illness by highlighting the way difficult coping and poor outcome feedback to increase vulnerability. In this sense, the social selection hypothesis posits that mentally ill persons tend to drift down in socio-economic status. Although a stress-vulnerability model is helpful in providing an explanation of the way potentially intractable situations might lead to long-term mental illness evidence has failed to support a causal link (Gove, 1982). The present position is one where stress-vulnerability is thought to be a process where social reaction is placed over the illness and that the two interact (Bachrach, 1988).

Theories of patient behaviour

Theories of patient behaviour include: the sick role; the health belief model; the application of locus of control models to health belief behaviours, and behavioural intention theories. Fuller descriptions of each can be found in reviews by Wallston and Wallston (1982); Kirscht (1988) and Ritter (1988). In short, these models are given as examples of difficulties that can be encountered when adopting physical theories of patient behaviour to the study of mental illness.

The sick role

The sick role (Parsons,1975) is central in many theories of patient behaviour. However, some have suggested that the model is felt to be inappropriate when applied to the mentally ill (Cockerham, 1989), or to any illness that is long-term and carries social stigma (Twaddle, 1979). Furthermore, there is evidence to support the idea that the long-term mentally ill are often reluctant to accept sick roles (Morgan, Calnan, and Manning, 1985).

The health belief

The health belief model has been used in studies which include compliance with treatment e.g., conditions under which individuals will seek and comply with mental health care regimes, including belief in one's susceptibility to illness and the severity of the disease, and belief in the efficacy of treatment (DiMatteo and DiNicola, 1982; Kelly, Mamon, and Scott, 1987). A difficulty with the approach is that the model implicitly assumes that people adopt a logical means-end schema as a basis for their action (i.e., reasoned action). It also assumes that illness is negatively evaluated and that the individual is an autonomous actor. However, as Estroff (1981) indicates, people with a long-term mental illness who exhibit symptoms of thought disorder or delusions may exhibit a weakening of means-end rationality. In addition, the mentally ill person may also evaluate symptoms differently compared to others, for example, a mental health professional. In this sense, there may be a denial of symptoms.

The locus of control model

The locus of control model (Rotter, 1966) assumes actor volition. However, people with a long-term mental illness often experience assaults on their autonomy (Birchwood et al., 1988). Such assaults may be in the form of hallucinatory voices compelling the individual to act in certain ways. Externally, autonomy may be compromised from several directions as others actively seek help for the patient's symptoms. The difficulty with the model is that patient functioning and patient interpretation of symptoms will specify conditions for the applicability of theory. What this means is that since symptomatic and symptom-free periods are interspersed over time, a locus of control model must become correspondingly complex.

Behavioural intention theories

Behavioural intention theories attempt to expand theories of patient behaviour by including variables that may make it more adaptable to questions involving long-term mental illness. For example, Mechanic (1969) suggested that patient behaviour models should include psychological processes that could distort the actor's perception of reality. A fuller model would include a measurement of those actor needs that may conflict with his or her assumption of the sick role, as well as the actor's interpretations of symptoms, and variations in the stress levels of those in contact with the symptomatic individual. The addition of such variables would help strengthen the basic health belief model because they reduce the number of assumptions that must be made about the actor's definition of reality, and their autonomy.

Psychodynamic theories

Psychodynamic models provide an approach, which assumes that mental illnesses can be explained by mind rather than brain. This approach encompasses a variety of psychoanalytic theories, which propose that events in childhood lay the foundations for mental illness. However, few today would contend that childhood events are the direct and the sole cause of long-term mental illness. This observation aside, the pattern and nature of childhood attachments are considered to be important factors contributing to vulnerability to stress (Bowlby, 1988). Such life experiences may indirectly impact on psychological functioning (Rutter, 1986). Although concepts in this tradition are especially difficult to operationalise several authors have attempted to do so. For example, Blatt et al., (1980) have hypothesised the long-term mentally ill person's lack of stable identity and secure sense of self which contributes to the sense of "dread and panic" that many long-term mentally ill experience. In addition, Will (1980) has suggested that such experiences have serious implications for this group's treatment, management and rehabilitation. Furthermore, Pepper et al., (1984) have related the lack of identity variable to the long-term mentally ill person's subjective experience of being scattered, disorganised and easily distracted. These authors hypothesise that regardless of whether or not this experience is the result of underlying cognitive deficits, intra-psychic defences, or organic damage the experience of the long-term mentally ill person is one of "confusion and befuddlement".

As a result of such deficits the long-term mentally ill person often finds themselves easily overwhelmed by changes in external events or contingencies (Neligh and Kinzie, 1983). In summary, although the psychodynamic perspective helps characterise the concept of long-term mental illness, the problem with such an approach is twofold. Firstly, it is difficult to test, and secondly the ways in which some long-term mentally ill people may come to identify with aspects of the therapeutic process will be confounded by biological factors intrinsic to the illness.

Cognitive-Neuropsychological theory

The cognitive-neuropsychological approach utilises various models, which conceptualise mental illness as a disease of the brain that can be treated biologically, given the development of the proper medical technology. In essence, biological aetiologies assume that psychiatric symptoms are caused by physical insult to the brain or gross congenital abnormalities, which can be observed. David and Cutting (1994) define cognitive-neuropsychology as "... any study of behaviour in relation to the hardware of the brain". The approach utilises the application of psychometric tests to psychiatric patients. Such tests are aimed at detecting deficits in psychological function (e.g., visual-spatial or linguistic skills) and their correlates with brain areas. David and Cutting (op. cit.) say that the approach is "argument by analogy" and assert that the analogy may hold at a number of levels. For example, at the behavioural level, the apathy and amotivation of the frontal-lobe-patient may resemble that of the long-term schizophrenic, as well as at the neurological level when there may be frequent persevarative errors. What the approach is producing is several lines of evidence in support of biological abnormality in the brains of patients with various diagnoses of mental illness. Examples included an imbalance of dopamine in the development and maintenance of schizophrenia (Lyon and Robbins, 1975; Robbins and Sahakian, 1983); abnormalities in norepinefrine and/or seratonin in depression (Winokur, 1986); correlates of cerebral blood flow that relate to psychomotor poverty, disorganisation and reality distortion in schizophrenia (Liddle, 1994); and a disturbance of information processing which can be linked to biological and social aspects of long-term mental illness (Hemsley, 1977; Cutting, 1985; Hemsley, 1987; Cutting and Murphy, 1988;

McKenna et al., 1990; Frith and Frith, 1992; Wykes et al., 1992; Neuchterlein, et al., 1994; and Dunkley and Rogers, 1994; Mckenna et al., 1994).

In summary, these studies demonstrate impairments in cognitive functioning in relation to the long-term mentally ill. However, as Pantelis and Neslon (1994) indicate, there is no unanimous agreement as to the extent or neurological implications of these cognitive deficits.

The Biopsychosocial theory

The bio-psycho-social model is an effort to integrate the biological, psychological, behavioural, and social approaches. The model asserts a multiple-causation theory of mental illness (Engel, 1977). Noticeable among such theories is the inherent assumption that the biological is fundamental. The theories postulate that first activated is a biological vulnerability: a genetic predisposition, a birth trauma, or an imbalance of neurotransmitters. To this is added some psychological or developmental inadequacy. Then symptoms are tripped by environmental stress. For example, Liberman et al., (1984) provide the 'diathesis-stress interactive model' which posits that schizophrenic symptoms develop from social stressors and the inability of the individual to cope with them. However, this order should be considered an empirical question because it assumes a causal direction. Mirowsky and Ross (1989) show that such an hypothesis can be challenged as being ambiguous in that causal order may not be fixed and may vary across types of mental illness.

Conclusion.

The question that was asked at the beginning of this chapter was 'What is long-term mental illness?' It was stated that at a superficial level, the phrase long-term mental illness is a general term, useful as a short-hand for referring to a large group of patients whose common characteristic is that they have been ill for 'a long time'. What this introductory chapter has been able to highlighted is number of elements associated with characterising the long-term mentally ill. What is indicated, both from a research and practice perspective, is that there is a danger of oversimplifying a heterogeneous assortment of

characteristics into an appearance of homogeneity where long-term mental illness is concerned. Therefore, it is important to understand that not all long-term mentally ill persons exhibit all the characteristics described, and that considerable behavioural and symptomatic heterogeneity exists within the category. However, there is no consensus on the specific character or the relative importance of the elements that make up long-term mental illness, and furthermore, there is no consensus on the inter-relationships among the composite elements. The important point for the purpose of this thesis is that long-term mental illness should be measurable in terms of a self-report assessment of need. On the one hand single variables (e.g., duration) are attractive because of their parsimony, and on the other hand more discriminating characterisations (e.g., disability) of long-term mental illness have the potential for greater descriptive and explanatory power. Clearly, this suggests that research into long-term mental illness should allow for functional disability, the type and intensity of symptoms, the length-of-time known to services and or hospitalised, and diagnosis. This is because evidence suggests that long-term mental illness is a multidimensional disorder in which various disturbances can occur influenced by both internal and external factors. In view of this point, and in order for this thesis to proceed, such variables will have to be taken into account in researching an assessment of self-reported need in a sample of long-term mentally ill people. The intriguing question for this thesis in view of the literature reviewed above is 'Can people with a long-term mental illness self-report need reliably and validly?' The answer to this question would seem doubtful when set against the background just outlined. Chapter 2 introduces the concept of need and approaches to the assessment of need.

Chapter 2. Need and the Assessment of Need.

Chapter overview

This chapter provides a brief introduction to an assessment of need in relation to mental health policy in the United Kingdom. A review of the mental health literature shows that a normative approach to needs-assessment is the usual method used. Further evidence suggests that a self-report assessment of need might not be an appropriate undertaking for people with a long-term mental illness. This is seen to be at least partially related to a) the difficulty in conceptualising needs and therefore needs-assessment and b) the cognitive and social difficulties of the long-term mentally ill outlined in Chapter 1. Consideration is given to concepts of need and needs-assessment; methods of needs-assessment; the role of values in assessing need; and approaches to self-reported needs-assessment. The case is put forward for increased evidence of a self-report assessment of need in the long-term mentally ill.

Introduction.

This chapter introduces firstly, mental health policy in The United Kingdom and the ideology contained within it which emphasises that assessment of an individual's self-reported need be undertaken in addition to a normative assessment of need. Secondly, the concept of and methodological approaches to need and needs-assessment is introduced with special reference to the long-term mentally ill.

Mental health policy.

In recent times, formal assessment of need has become an important and integral part of health service planning. Considerable time is devoted to the assessment and analysis of need for people who require mental health services. In the UK developments have their underpinning in a number of national and local policy reforms (HMSO, 1988; HMSO, 1990).

The main principles of the policy reforms include continuity of care; accessibility, effectiveness, efficiency and accountability of services; patient advocacy for services; the development of services to enable people to live in their own homes wherever feasible; the provision of practical support for carers; to make needs-assessment and good case management the cornerstone of high quality care; clarification of agency responsibilities; and making agencies account for their performance.

In practice, the NHS and Community Care Act (HMSO, 1990) requires that the principles be realised by Local Authority Social Services and District Health Authorities agreeing, co-ordinating, publishing and implementing Joint Community Care Plans and making individual assessments of need for community care services. The term 'assessment of need' is a key factor and is intended to constitute a process via which refinements of service provision and user uptake can be made accessible, appropriate, efficient and effective. The idea is that mental health services become much more user driven, rather than fitting clients into existing services (HMSO, 1990). The thrust of a needs-assessment is that it will lead to action facilitated via the appointment of a care manager who is to be the lynch-pin of an individual client needs-led assessment (HMSO, 1989). As Thornicroft (1991) points out,

the concepts of care management and the assessment of need are to provide a mechanism for structuring, maintaining and continuing care in the community via a model that emphasises the provider-user relationship as the key component through which effective care is channelled. Policy principles which underlie the management of care and the guidelines for a needs-assessment include: building on the strengths and weaknesses of the service user; reflecting an ongoing reviewable process; respect for the rights, privacy and independence of the individual; individual user participation; separate needs-assessments for user and carer; clear statements of action, quantitative and qualitative goals for care management; a named responsible individual; simple and easily understood access to services; and information related to the service user about the assessment process, the range of services available and the objectives (Welsh Office, 1991). In short, the intention of policy reform is to put the person with a mental illness at the centre of the needs-assessment process to the extent that client participation becomes a critical variable in the assessment of mental health need. The basic idea is to arrive at a greater understanding of what the user has to say concerning their own needs. However, the following three concerns arise for research with respect to such a policy notion:

a) although policies emphasise the complexity and variety of need they fail to provide any precise conceptual and operational definition of need, let alone a method by which self-reported need by people with a long-term mental illness might be measured;

b) there are few clear evaluations in the psychological literature of needs-assessment research, development and implementation in mental health which take as their focus what the user has to say concerning their own needs; and

c) perhaps more importantly, and in view of the findings reviewed in Chapter 1, it would seem questionable that people with a long-term mental illness can reliably and validly self-report their own needs.

Concepts of and methodological approaches to need and needs-assessment

This section identifies and discusses concepts of need; approaches to needs-assessment in general, and approaches to needs-assessment specific to long-term mental illness. This is followed by discussion of conceptual and methodological controversies in needs-assessment.

Concepts of need

Various theories have identified a number of human needs; these include for example, needs for motivation and achievement (McClelland et al., 1953; McClelland, 1961); needs for positive social regard (Rogers, 1961); needs for self actualisation (Maslow, 1970); needs for effects of one's actions (Seligman, 1975) and needs for respect from others (Harré, 1979). Each, has historical significance, however, such theories have not helped in defining, measuring or assessing need directly. One of the difficulties inherent in defining objectively and consequently assessing need is its subjective nature and the assumption that people 'know' when they are in need and what they are in need of (Bebbington, 1992). Clearly, there are a number of complex issues in relation to the assessment of need in long-term mental illness. Part of the explanation for this complexity is that policy reform alone can never be enough to tackle both the conceptual and methodological puzzle of assessing mental health need (Liss, 1993). If the principle concern of policy reform and implementation is to look for new ways of improving peoples' Quality of Life, then research has a key role to play in clarifying conceptual and methodological questions surrounding 'need' and a self-report assessment of need in long-term mental illness. The key point is that a clear concept of what a 'need' is has to be established. This is important because there are a number of philosophical issues, which have implications for how need might be assessed. For example, is there such a thing as a 'need' and if there is can it be measured? What this highlights is that without a clear conceptual and methodological base the assessment of self-reported need in long-term mental illness is destined to be problematic. This is because the priority attached to different need raises conceptual, methodological and analytical problems. For example, should the principle criterion be that greater priority be given to 'health' as opposed to 'social' needs? In answering this question we need to consider 'need' in terms of mental health services that can be supplied

when this is in opposition to patients who may have a different view of what would make them healthier or indeed improve their Quality of Life - for example, a job, or decent accommodation as opposed to an increase in medication. As the WHO (World Health Organisation, 1992) note, "Health is a state of complete physical, psychological, and social well-being and not simply the absence of disease or infirmity". In this sense, health needs incorporate the wider social and environmental determinants of health, such as deprivation, housing, diet, education and employment. The advantage of conceptualising 'need' in this way is that it allows one to look beyond the confines of a medical model to the wider influences on health. The disadvantage of conceptualising need in this way is that an assessment is not simply a process of listening to patients or relying on personal experience; it is a systematic method of identifying unmet needs in individuals and making changes to meet those needs. This sort of issue leads on to asking whether an assessment of need in long-term mental illness ought or should be based on expert knowledge or participatory methods? The potential difficulty here is for example, that experts and people with a long-term mental illness might have different views about what 'needs' are and how to assess them. In order that such issues might be addressed the databases PSYCHLIT and MEDLINE were used to detect articles in relation to concepts of 'need' and an assessment of need in long-term mental illness. The keywords 'needs-assessment-mental-illness-psychiatric' were used as search descriptors.

Several writers have focused on the broad conceptual challenges confronting need and needs-assessment. For example, approaches include sociological, Bradshaw (1972); medical (Matthew, 1971; Stewart, 1979; Doyal and Gough, 1984) and philosophical Liss (1993). Bradshaw (1972) provides a 'Taxonomy of Need' in an attempt to firstly, allay confusion with the term 'need' and secondly, to offer a conceptually clear distinction for the operational use of the word. Four types of need are classified in the following ways. Firstly, *'normative need'* is an expert or social scientist in any situation defines where need and services are measured by an agreed standard. The approach works well where there is a discrepancy between a situation and the agreed standard - need is said to exist whether the person in need is aware or not. Limitations of the definition are that the nature of normative standards is subject to change over time as a result of advances in knowledge

and changes in societal values. This may not be a bad thing. In addition, there is no one definition of normative need, different agencies may have different norms. Secondly, *'comparative need'* characterises individuals in terms of groups who utilise services. The measure of need is derived by studying the salient features of those in receipt of a service to the extent that if people can be identified as having similar features and are not seen as being in receipt of services then they are said to be in need. The approach attempts to standardise services in terms of service provision with a potential net effect of provision possibly not relating to need. Thirdly, *'felt need'* is defined as a need, which is experienced by the individual and is possibly equivalent to a feeling of 'want'. Bradshaw asserts that 'felt need' is an inadequate measure of real need, which is subject to one or a combination of the following i.e., a limited perception by the individual, a lack of informed choice, a reluctance to admit need and an overestimation of personal need. Fourthly, *'expressed need'* has features of felt need but more specifically defines a person who not only wants or experiences need but converts that felt need into action by communication e.g., as a demand for services.

In summary, Bradshaw's taxonomy of need has the advantage of defining both a service-led or client-led perspective of need. Furthermore, the taxonomy provides a measure, which can lead to a concept of total need i.e., a sub-definition, which helps characterise those people who demand a service or support. Although the definitions provide an important conceptual base for measuring need they are potentially subject to limitations which might typically relate to an under or over expression of need from either a service-led or a client-led perspective.

Matthew (1971) looks at the measurement of need for medical care in the community and the creation of a scientific base for planning and providing health services. He offers the following definition:

> "The need for medical care must be distinguished from the demand for care and from the use of service or utilisation. A need for medical care exists when an individual has an illness or disability for which there is effective and

> acceptable treatment or care. It can be defined either in terms of the type of illness or disability causing the need or of the treatment or facilities for treatment required to meet it. A demand for care exists when an individual considers that he has a need and wishes to receive care. Utilisation occurs when an individual actually receives care. Need is not necessarily expressed as demand and demand is not necessarily followed by utilisation, while, on the other hand, there can be demand and utilisation without real underlying need for the particular service used".

As Balaki (1988) points out, Matthews' model suggests illness or injury can be recognised as a result of organic, biological or psychological problems and that attitude and behaviour changes can occur where there are secondary difficulties related to primary ones, and that difficulties can be independent of an illness e.g., social. In terms of Matthew's definition and the scientific planning of needs, if any of these components are present there would be a need for services and support. However, one limitation of defining needs in terms of the availability of services raises more conceptual and methodological issues and seems to endorse a service-led approach to needs-assessment. This situation leads on to asking how a definition of 'need' and a needs-assessment can be related to the level of either professional or non-professional support required. Bennet and Morris (1983), argue that social support is central to human development and well-being in terms of standing at the interface between the individual and the social system of which they are part. Moreso, support is a key process in rehabilitation. Orford (1992) asserts that well-chosen questions can help establish an individual's perception of their social world in relation to social skills and competencies. He focuses on a distinction between functional and structural approaches to social support and concludes that any distinction between formal and informal support are blurred and often unhelpful in understanding people's needs and how they are best met.

Stewart (1979) describes and evaluates three methods of needs-assessment from social statistics and looks at the complexity of operationally defining 'need' when assessment is added. His analysis suggests that needs-assessment have three essential components: the

identification of a problem, a statement about priorities, and the determination of a solution. Stewart speaks of 'problem' rather than 'need', arguing that the word need refers to 'a lack that is not directly measurable'. Although Stewart does not elaborate on the needs-assessment, he does refer to a range of different techniques by which conditions, needs, or resources may be identified. In conclusion, Stewart suggests that "needs-assessment is not a unitary concept ... but one that encompasses a variety of techniques which can be used for a variety of purposes". He asserts that the researcher "does not assess need" but "undertakes to look at problems" - this is taken to mean problems in relation to resources, individual and group desires, and priorities. Stewart recommends that needs-assessment is most useful when it is the first step in planning for new or altered services and that the researcher develops a plan that evolves into new or improved services.

Doyal and Gough (1984) discuss how human needs should be conceptualised and argue that individuals have a right to their optimal and not just minimal satisfaction. Doyal and Gough (1984) go on to talk about the absence of a clear and detailed theory of human need on which an accurate needs-assessment can be based and the issue of which needs must be satisfied in order to enable optimum social participation. In asking 'What are the basic human needs?' Doyal and Gough (1984) allude to the importance played by social participation and suggest that if an individual lacks the capacity for such participation, then they are seriously and objectively harmed as a result i.e., disabled with respect to continuing to express themselves through performing skills and learning new skills. They go on to say that identifying significant personal harm with seriously impaired social participation provides the key with which to identify universal objective human needs. The necessary conditions, and basic needs that everyone must meet in order that they might avoid harm include: physical survival; individual autonomy; and social opportunities. Doyal and Gough (1984) define individual autonomy as "... the capacity to formulate aims about what to try to achieve and beliefs about how to do this - the ability to reason and to act on the basis of reasons i.e., to plans one's life". Clearly, the degree of autonomy will depend on the absence of mental illness. As Chapter 1 describes mental illness entails both cognitive and social constraints. In this sense, access to support and services are necessary for the satisfaction of the basic human needs. However, you are left with asking the

question of who decides what the needs are and what constitutes need satisfaction? In answer to this question Liss (1993) notes that there seems to be an 'evaluative element' at every stage of an assessment of need which means that the process is bound to generate controversy in practice. The key point made by this author concerns the issue of being clear about what sort of 'thing' is being assessed in the first place and perhaps equally who does the assessing.

Approaches to Needs-assessment

The origins of needs-assessment are epidemiological. Epidemiology attempts to establish both the distribution and determinants of states of health and disorder in the population. The assumption being that the incidence and prevalence of a particular disability or pathology can be used to determine services needed. The approach is predominantly a service-led or normative perspective. Early epidemiology and studies of mental illness in particular, were important in three respects. Firstly, they showed that psychological distress was widespread and severe, even among people who were not receiving treatment. Secondly, studies found a relationship between social factors such as income and education and rates of mental disorder. Thirdly, epidemiologic studies found that people with the fewest social resources were most likely to be ill and least likely to find help for the difficulties they were experiencing. Cooke (1989) states that epidemiological research is important because not only can it describe the overall level of need but it can also identify those in greatest need and that statistical probability statements can be made about the findings. However, as Goldberg and Huxley (1980) and Lord, Schnarr and Hutchison (1987) suggest, epidemiologists have encountered difficulties in analysis, interpretation and utilisation of needs-assessment data. The problem is caused by difficulties in measuring the extent of actual mental illness because of a lack of agreement on operational definitions of 'mental illness' and the non-standardisation of needs-assessment approaches.

Warheit et al., (1983) review the development of needs-assessment as a research and service evaluation approach. They discuss the five most used methods of needs-assessment in relation to mental health needs. A brief characterisation of the approaches is as follows. Firstly, the *community forum methodology* consists of gathering information on needs from

community members via public meetings. The advantage of such an approach is that it has the potential for everyone to express a view and interest. The remit of the forum is to identify the perceived current needs of the community and use this information at the planning stage. The main disadvantages are that both quantifiable and qualifiable impressions of need by the community will be incomplete and may not be representative of the general population, and furthermore, will not reflect user involvement in terms of an individual assessment of need. In this sense, and for the methodology to be effective, it has to make the assumption that those in need will attend a forum and express their view. The benefits of a small as opposed to a large forum offers a partial solution but at best is impressionistic and lacks a precise quantification of needs. Overall, the methodology may be useful but serious doubts exist as to the value of the community forum as a needs-assessment methodology.

Secondly, the *key-informant approach* assesses need by interviewing professionals who are assumed to have knowledge of a community's mental health needs. On a pragmatic level the value of this methodology is firstly, the conceptual simplicity of its design and secondly, it's relative inexpensiveness. Planners are therefore in a position to receive an overall indication of the needs of the community from various agency perspectives, e.g., public and private sectors. The approach brings both planners and providers together in the discussion of needs-assessment. A benefit of the key-informant approach is that data has the potential to suggest high levels of unmet need but a drawback is met in discriminating problems and establishing service. Warheit, Buhi and Bell (1978) caution against making general assessments of need and from those making decisions about the needs of individuals. They suggest a more fine-grained individual analysis be undertaken in relation to a persons' needs status.

Rates-under treatment provides a third approach to assessing need within a mentally ill population. The methodology is epidemiological and makes use of case registers to identify the service user in the form of descriptive statistics. Variables looked at include age, sex, socio-economic status, diagnosis, type of treatment, and whether or not people are receiving treatment. The assumption underlying this approach is that once service users

are identified the needs of the community can be estimated from the data. However, as Bachrach (1988) suggest this method of needs-assessment has not been geared toward the precursors or antecedents of need in terms of psychological problems but more with: 'who' had 'what' problems and 'where' did they live. In this sense, this method has the potential to under-estimate service need and its use is therefore questionable in determining a community's actual mental health needs. However, the importance of establishing need as an expression by demand is useful for planners and policy makers in terms of prioritising need and co-ordinating resources and services. Unfortunately, the method leaves the clear idea that demand for services may not be a true reflection of the real level of need.

The social indicators approach provides a fourth method and utilises data sources that contain items presumed to be associated with mental health problems and their treatment. Essentially, descriptive statistics are employed to infer the mental health needs of a population. Stewart and Poaster (1975) describe and evaluate three methods for assessing need using social statistics. The first method is the visual identification of areas with the greatest concentration of need. The second method identifies and locates relative amounts of need by assuming that the indicators used have a reliable and valid relation to the prediction of need. On this basis resources can be allocated to need accordingly by planners. The third and final component is the identification of need in absolute numbers. A disadvantage of the approach is that it again can only provide general estimates that predict overall levels of need. Individual needs are not assessed and the targeting of precise service provision is not accurately determined.

The *survey approach* offers a further needs-assessment methodology. Essentially, data is collected from a sample or entire population, this leads to information which can be grouped into three different categories: a) incidence and prevalence of mental health problems; b) service demand and availability within a defined system of care; and c) the views of service users regarding mental health issues. Advantages of the approach include the ability to find both groups and individuals that are in need and to relate unmet need to service resource and provision. Disadvantages are that the approach is costly, time

consuming and requires that planners have increased skill in the realms of data collection, analysis and presentation.

In summary, Warheit et al., (1978, 1983) conclude that each of the methods has value where the objective of the research is a general indication of numbers requiring mental health services. This gives rise to a situation in the literature where a limitation of approaches to needs-assessment is that the predominant methodology has been a normative, service-led, top-down assessment of need for people with a long-term mental illness. As Liss (1993) states, service provision and utilisation has been to all intent and purpose estimated. The danger is that service-led or 'top down' approaches may not in themselves provide sufficient information about need, particularly when the needs of the individual may vary significantly in any one need domain. Warheit et al., (op. cit.) and Balacki (1988) suggest that different concepts, methodologies and meanings of need produce different sorts of information about what is needed, how much is needed and who needs it. In terms of outcome it can be speculated that bottom-up and top-down methodologies are different in that a self-report assessment of need i.e., bottom-up, may result in a more localised, more flexible and responsive means to establishing and evaluating the needs of people with a long-term mental illness. As Baldwin (1986) points out, the use of a client-led needs-assessment is dissimilar to traditional usage in that the focus and definition of need is made with respect to the clients' own expressed need as opposed to an overall organisation strategy.

Approaches to Need and an Assessment of Need in Long-term Mental Illness.

Conceptual and methodological approaches more specific to assessments of need in long-term mental illness have been studied in relation to: identifying the importance of needs from differing perspectives (Shapek, 1975; Siegel et al., 1978); defining unmet need (Carr and Wolfe, 1979); matching need to services (Mann and Cree, 1976); functional skills (Dellario, Anthony and Rogers, 1983); services needed to succeed in the community (Solomon and Davies, 1985); rehabilitation needs (Crocker and George, 1985); client perceptions of their own skills and motivation (MacCarthy et al., 1986); mental health services required (Lynch and Kruzich, 1986); after care needs (Perez et al., 1987); clinical

and social functioning (Brewin et al., 1987, 1988; 1993; Hogg and Marshall, 1992; Marshall, 1994; Phelan et al., 1995; Slade et al., 1996; Carter et al., 1996) and community support and residential needs (Ford et al., 1992). A review of these conceptual and methodological approaches, including their main findings and conclusions will now be undertaken. This will be done in two parts. Part 1 will review each of the afore-mentioned papers, apart from the paper by Brewin et al., (1987) who developed the Medical Research Council Need For Care Assessment Schedule (MRC NFCAS). This paper will be reviewed in Part 2. This is because Brewin et al., (1987) it might be argued, provide the most researched conceptual and methodological approach to and assessment of need in long-term mental illness. This is evidenced by criticisms surrounding the approach and the number of papers appearing in the literature that have attempted to utilise and refine Brewin et al's., concept and methodology (Brewin and Wing, 1989; Wing, 1989; Mangen and Brewin,1991; Pryce et al., 1991; Lesage et al., 1991; Hogg and Marshall, 1992; Brewin and Wing, 1993; Van Haaster et al., 1994; Marshall, 1994; Marshall et al., 1995; Stansfield et al., 1998).

Part 1.

Shapek (1975) and Siegel et al., (1978) discuss identifying the importance of individual needs and ranking needs from differing perspectives and suggest that any problems with needs rankings in terms of inconstancy and lack of meaning will seriously limit their utility. Shapek (1975) suggests that one way of looking at the formulation of a needs ranking is the relative value attached to each item via the perspectives of for example, the expressed need of the person with a long-term mental illness and a professional concerned and asking the question 'How important is one need compared to another?' Siegel et al., (1978) define needs-assessment as a process aimed at estimating the relative importance of needs within a given population via two distinct steps: a) the application of a measuring tools; and b) the application of judgement to assess the significance of the information gathered. The proposition is that in any assessment of need a measure of relative value could be derived from the frequency indicted by a given need from different perspectives. This suggests that not only is there a requirement for research which looks at the assessment of need from both client and key-informant perspectives in relation to the importance of need and how

need is ranked but also what happens when there is unmet need. Carr and Wolfe (1979) define unmet need as being contingent upon the recognition of a problem i.e., a dysfunctional somatic or psychological state. In this sense, unmet need is seen as the difference between those services and levels of support judged necessary to deal appropriately with defined health problems and those services and levels of support actually received. An unmet need is the absence of any, or of sufficient, or of appropriate care services and support.

Early work by Mann and Cree (1976) produced interesting implications for community care and the development of needs-assessment as an approach to matching need to services. Mann and Cree (1976) demonstrated in their survey of new-long-stay populations that at least two thirds of the mentally ill could be maintained in the community with some support from the psychiatric services. Medical, nursing and social work staff was asked to make judgements of the potential placement of patients. All categories of staff made the judgement that one third of the patients needed further in-patient care and that the majority of the remainder could be discharged. Care staff also judged that not all of an individual's needs were being met and that patients in community care were rarely reviewed at regular intervals by all the professionals who were responsible for particular aspects of service care and support.

Dellario et al., (1983) looked at the relationship between practitioner's ratings of long-term mentally ill patients' functional skills and the client's own ratings of their functional skills. The sample consisted of n=383 people, mean age 46.2 years, hospitalised for more than 6 years and having a main diagnosis of undifferentiated schizophrenia. This study was set against a background where a) very little literature existed that examined whether clients and practitioners agree on the status of clients' level of skill functioning; and b) no reported research had addressed the agreement between client and practitioner in the assessment of need. The basic rationale for the paper is the argument that the process of psychiatric rehabilitation should be done 'with' rather than done 'to' clients. In this sense, it is very important that a client and a practitioner share the same perspective with regard to the client's functional strengths and deficits, particularly as people with a long-term mental illness have shown an increasing interest in basing their treatment plans on the assessment

of skills, rather than on diagnostic labels and symptom patterns (Dellario et al., 1983). The study used the Multifunction Needs-assessment Form (MFNA) in order to report selected practitioner-rated global assessment items and their corresponding client self-report items (self-care, mobility, household, personal appearance, community living, psychological functioning, work/school, family, social functioning, and leisure). The study had two main implications. Firstly, psychiatric rehabilitation workers should consider client's self-reports about their own skills, and secondly, researchers should not assume that information about client's functional skills obtained from practitioners is an indication of the clients' functional skills from the client's perspective. These authors conclude that firstly, client and practitioner information may represent two different sources of information; and secondly, that treatment processes must develop strategies to check for and maximise practitioner-client agreement prior to treatment planning.

Soloman, Gordon and Davies (1984) assessed a cohort of five-hundred and fifty,16 - 65 year old long-term mentally ill individuals, who were being discharged from two psychiatric hospitals, in terms of their post-discharge mental illness service needs. Need was defined as support necessary for the patient to function adequately in the community, i.e., to be self-sufficient or to be working towards self-sufficiency. Functioning was assessed in relation to difficulty with basic activities of daily living and included needs for food, clothing, finances and household tasks; lack of motivation; employment, physical needs, social roles, use of leisure time, and use of aftercare programs. The authors found that patients were assessed as having an average of 11 needs out of a total possible number of 37 and that the need for the 'daily living category' was consistent with the functional assessment ratings. Chief amongst the needs was pharmacotherapy and counselling as well as social rehabilitative services and family support. Higher levels of need were identified among younger subjects and those people with longer hospital stays and lower levels of functioning.

In a further paper, Solomon and Davies (1985) compared the perspectives of patients, families, and mental health practitioners in regard to what patients needed to succeed in the community. Patients focused on the needs for help finding a job, aftercare services, and

finding a place to live. Family members thought clients would need assistance in those areas as well as in managing money, taking medications, and performing household chores. Family members and service practitioners were more likely than patients to identify a need for supervised housing and needing assistance engaging in leisure activities. In a similar vein, Crocker and George (1985) assessed the need for formal rehabilitation training programmes for the chronically mentally ill in terms of skills necessary for independent living and community resettlement. Client and key-informant interviews were used to get a variety of perspectives on client needs. Broadly, the study examined the extent to which clients thought other clients could benefit from skills training in a given area, as well as the extent to which they personally would benefit. Client involvement was seen as important because the use of a list of skills-needs based on client interviews could be used to ensure the relevance of future skills offered to clients. Twenty topics were rated on a five-point scale. Key-informants i.e., those people in close contact with the target population, were asked to indicate the five most important components of a skills training programme designed for this population. Results show that: client's ratings of the potential benefit of the 20 suggested skills topics to themselves and to other clients were found to be highly correlated; clients saw e.g., learning to cope with depression and anxiety management as their top rating and assertiveness training as their bottom ranked skill. In contrast, key-informants rated more functional needs e.g., housing, job location, friends, nutrition and cooking and community awareness as the five most important skills for clients. In addition, key-informants ranked all needs highly. Crocker and George (1985) conclude by saying that that increased client involvement yields benefits in terms of improved social and vocational skills and increased capacity for independent living.

Lynch and Kruzich (1986) focused on the service needs of the long-term mentally ill to function independently in the community from both mental health practitioner and client perspectives. Structured interviews were conducted in relation to obtaining information about housing, employment, using transport, managing finances and developing social relations. Ratings were made with the use of a five-point scale developed to measure an individual's ability to maintain independent living in relation to self-care, threatening behaviour, decision making, interaction with others, employability, and financial

management. Results showed that client and practitioner perspectives were different. For example, practitioners identified medication checks, individual therapy, and episodic case management as the most needed services. Whereas clients saw a need for more active programmes, increased daily living skills, increased activities in hospital, services at weekends and evenings, more information on what is available in the community - with financial problems being a major barrier to obtaining services.

MacCarthy, Benson and Brewin (1986) describe a study which questioned long-term mentally ill patients being cared for in the community about their own perceptions of their own skills, motivation to perform a range of everyday tasks, current problems and coping strategies. They also examined whether or not their appraisal would agree with that of the care staff. MacCarthy et al., asked patients to rate the importance to themselves of various basic tasks of daily living, and to estimate the difficulty of each task which they had not performed for a period of at least 12 months. Judgements of importance were obtained using simple 4 point forced choice scales presented on a card and also read out by the research worker. Two further questions asked about the construct of expectancy i.e., patients were asked to rate how difficult it would be to perform a task ('Not at all difficult for me', 'Not very difficult for me', 'Fairly difficult for me', 'Very difficult for me') and to rate how successful their efforts to perform the task were likely to be ('My efforts would be very successful', 'My efforts would be fairly successful', 'My efforts would not be very successful', and 'My efforts would not be successful at all'). In terms of 'Problem appraisal and coping' patients were asked to describe their main current problems to a maximum of three. MacCarthy et al., (1986) suggest that with this approach, patients with long histories of serious psychiatric disorder could respond to a structured interview with questionnaire type measures in an internally consistent way. Interestingly, the paper reports that, on occasions, patients had more accurate and up-to-date information than staff, suggesting that it is likely that staff's rather than patients' responses will have had lower reliability. This is particularly likely to be true in community settings where staff have less opportunity to observe patients' behaviour. These authors conclude that there seems little reason to give less weight to patients' own accounts of their difficulties compared with the views of the staff.

Schnarr and Hutchison (1987) suggest that people who need mental health services and support tend to emphasise their own capabilities and capacities in contrast to some professionals who see client needs in terms of deficiencies without considering people's capacities. These authors recommend that a needs-assessment methodology should include a balance between qualitative and quantitative methods, as well as a recognition of the consumer perspective as being vital to understanding expressed needs and support requirements. Lord et al., suggest that listening to concerns and dilemmas faced by service users helps researchers focus on the kinds of formal and informal support individuals need, rather than assuming that formal services alone can address the needs people might have. Perez, Mortimer and Russell (1987) carried out a survey to find out the expressed aftercare needs of the long-term mentally ill. The sample had previous long-term psychiatric hospital admissions and was now living in the community. The survey method used a semi-structured questionnaire which consisted of closed and open ended questions addressing each of the following areas of interest: sociodemographic and clinical characteristics, information on medical services, housing, financial situation, employment, educational-vocational, and social-recreational services. Respondents were asked to describe services they had used, what they had liked and disliked about them, and their level of satisfaction. The study found that locating affordable housing was the most common difficulty faced by respondents. The financial situation of respondents was rated highly and a large proportion of the respondents wanted jobs. Perez et al., conclude that effective discharge planning successfully connected patients to community treatment services and that they remained in clinical remission longer.

Ford et al., (1992) present the results of a survey which asked 90 community mental health agency case managers and their clients with long-term mental illness to assess community support and residential needs. Needs included personal hygiene, housekeeping, budgeting, socialisation, daily activities, household maintenance, and mental/physical health care. Respondents were asked to estimate the frequency, intensity and duration of assistance needed in each identified area in relation to usual functioning. Medication monitoring and therapy were rated high priority needs by key-informants as were day and vocational activities and counselling to help clients learn to set limits on behaviours.

Results also indicated some differences between key-informant and client assessments in regard to optimal housing options. For example, 31% of key-informants said that clients needed their own home compared to 52% of clients. Also a higher percentage of clients said day services were needed as was socialisation compared to key-informant perceptions. Phelan et al., (1995) present a method of assessing need using the Camberwell Assessment of Need (CAN). Two versions of the CAN exist: the clinical version to be used by staff to plan patient's care; and the research version used as a mental health service evaluation tool. The CAN has been developed in order to provide a comprehensive assessment of 'complex clinical and social needs' in people with serious mental illness; assist in the routine care and treatment of people with a SMI by encouraging systematic and regular needs-assessments to shape care plans; and provide a powerful tool for evaluative research (Phelan et al., 1995). Four principles underpin the CAN: firstly, is the acknowledgement that everyone has needs – although people with a mental illness have some specific needs; secondly, people with a mental illness may have multiple needs unrecognised by mental health services; thirdly, any needs-assessment instrument should be easily learned; and fourthly, needs should not be defined by staff alone but should include the client perspective. In order to address these issues Phelan et al., (op. cit.) base the CAN on a model of need as a subjective concept, accepting that frequently there will be differing, but equally valid perceptions about the presence or absence of specific need. In essence, the CAN includes 22 items (e.g., accommodation, self-care, daytime activities, physical health, psychotic symptoms, money etc.) similarly structured and measured in the following way. The first section establishes whether there is a need, by asking about difficulties in that area. Responses are rated on a three point scale: 0 = No serious problem; 1 = No serious problem or moderate problem because of continuing intervention (met need); 2 = current serious problem (unmet need). The strength of the approach is that it does provide an approach to the assessment of need which includes both client and key-informant perspectives. The approach is shown to be both reliable and valid and has been used in four studies Phelan et al., (1995), Hansson et al., (1995); Slade et al., (1996) and Slade et al., (1998). One aspect of what Slade et al., (1998) have been able to show is that patients and staff differ in their assessments of need. For example, 25% of patient needs were unmet according to staff whereas 37% of needs were unmet according to patients.

Part 2. The MRC NFCAS: Concept of need in long-term mental illness

The Medical Research Council Need For Care Assessment Schedule (MRC NFCAS) is a procedure developed specifically for measuring the needs and service provision of people with a long-term mental illness living in the community and in touch with psychiatric services (Brewin et al., 1987). The conceptual model has three key elements described by the authors as representing an explicit model of clinical practice. These include: firstly, *'social disablement'* i.e., lowered physical, psychological and social functioning compared with what would ordinarily be expected in society; secondly, *'methods of treatment, care and support'* which includes lists of potentially effective interventions and support specified in advance; and thirdly, *'services and support needed'* which includes guidelines laid down concerning when to try new interventions, or when to make further attempts with previously ineffective interventions in accord with the patients' own priorities and shared goals with professionals.

Essentially, the principles that underpin the MRC approach to needs-assessment are designed to equip the long-term mentally ill for independent life in the community as far as possible. Importantly, with regard to the approach, a distinction is made between what a 'need' is as distinct from a 'want'. This is done by implicating the idea of the harm that a person might suffer through not being given what, from a normative or comparative perspective, he or she might need (Miller, 1976). In this sense, if an individual's needs remain unmet i.e., no action is taken, the individual is caused harm. As Wing (1989) suggests, such a definition can be used for the equivalent problems met when assessing psychiatric services. This is because the concept of need adopted by the MRC NFCAS provides an indication of the 'need for action' (if any), a distinction between 'needs for items of care and 'needs for services', and allowance for a variety of 'potential interventions' thought to be effective in reducing or containing social disablement in long-term mental illness (e.g., medications, treatment programmes and various kinds of support and shelter). In essence, the approach attempts to provide a link between a problem, an action and subsequent evaluation. What this means is that an individual's need status is defined by their level of functioning and appropriate interventions are agreed by

experienced interviewers using standardised scales to rate the actual or potential effectiveness of the intervention, its appropriateness and acceptability to the patient.

The MRC NFCAS measurement of need in long-term mental illness

Brewin et al's., (1987) model identifies twenty-one areas of social and clinical functioning (minor alterations resulted in a 20 item version by Brewin and Wing, in 1989) each area being related to an appropriate intervention specification. In essence, there are three steps in the MRC NFCAS measurement of need. Step 1 concerns the twenty areas of functioning – aspects of life in which the long-term mentally ill commonly have problems. These are split into two areas a) symptoms and behavioural problems; and b) skills and abilities. Step 2 determines whether or not the patient has a problem in a given area of functioning. In order to do this, standardised behavioural and psychiatric rating scales are used to find out if a problem in an area of functioning is present. Instruments include: The Present State Examination (Wing et al.,1974); the Social and Behavioural Schedule (Wykes and Sturt, 1986); the Mini-Mental State Examination (Folstein et al., 1975); a test of educational attainment; and a test of movement disorders e.g., the Abnormal Involuntary Movements Scales (NIMH, 1976). 'Problem' functioning is present when a subject's score in an area exceeds a threshold agreed by the investigators. Once an unacceptable level of functioning has been identified this leads to Step 3, which relates to the 'need status' of a given individual and a list of items of care (such as remedial training or medication) that experts in psychiatric rehabilitation believe are suitable interventions for a problem area identified i.e., interventions agreed to be useful for difficulties in that particular area. In this sense, the MRC NFCAS procedure indicates 'decision rules' in order to establish a given individual's 'need status', the definitions of which are as follows:

1. Need is present when a) a patient's functioning falls below or threatens to fall below some minimum specified level, and b) this is due to some remediable, or potentially remediable cause.
2. A need (as defined above) is met where a level of functioning is currently satisfactory or has recently been found to be unsatisfactory and the patient is

receiving a potentially effective or at least partly effective intervention, and when no other interventions of greater effectiveness exist.

3. A need (as defined above) is unmet whenever it has attracted only partly effective intervention or no intervention and when other interventions of greater effectiveness exist form the agreed set of care items. If this is the case then the patient is rated as having a 'primary unmet need' in that particular area of functioning.
4. No need exists when there is no effective treatment intervention available and/or when all suitable interventions have been given a reasonable trial but have not been effective. In addition no need exists in areas of functioning in which the level of functioning is acceptable. (It must be noted that Brewin and Wing (1989) make a minor change to this category with the use of 'no meetable need'. The new category being intended to identify areas where patients have problems but no action is currently feasible).

In essence, the MRC NFCAS provides a framework for recording what action should be taken when a problem is present. What this means for the measurement of need is that it follows on from the initial identification of a significant problem in clinical or social functioning using a variety of standardised instruments. A 'need' is defined as a problem for which there is a suitable intervention that has not been given an adequate, recent trial. In this sense, any symptom, behaviour problem, or lack of competence at a skill of daily living likely to harm or 'disadvantage' someone with a long-term mental illness is a potential target for intervention. Following this principle, the assessment targets skill deficits such as inability to cook and shop even though the patient's immediate requirement are being met, and will continue to be met, by relatives or care staff. In essence, the concept of need put forward by Brewin et al., (1987) stresses that users of the term 'need' should be clear about the extent to which they are simply identifying a problem, recommending a likely course of action, or making an imperative claim about the avoidance of harm to a given person with a long-term mental illness In line with this, Brewin et al., (1987) hypothesise that an outcome of this model would be that a service response would be to prioritise client difficulties in functioning and to start by controlling psychiatric symptomatology, encouraging appropriate levels of activity and compliance

with treatment regimes, and then focusing on self-help and communication needs. Furthermore, Brewin et al., (1987) say that the MRC Needs for Care Assessment is not suitable for investigators who have not had clinical experience of the long-term mentally ill.

In summary, it would seem fair to say that there is uncertainty about how 'best' need should be defined and how best an assessment of need should be done. On the one hand official guidelines are complex, and on the other a number of studies that have tried to measure need have given rise to both conceptual and methodological issues. In the main, controversy is centred on the MRC NFCAS. Although the MRC NFCAS has been shown to be reliable (Brewin et al., 1987; Pryce et al., 1991; Lesage et al., 1991; Hogg and Marshall, 1992; Van Haaster et al., 1994; Marshall et al., 1995; Stansfield et al., 1998) difficulties have included the observations that data collection is time consuming (Pryce et al., 1991; Holloway, 1991); the approach is essentially normative (Clifford et al., 1991; that interpretation of the MRC NFCAS method of rating and interpretation of results is complex and problematical (Lesage et al., 1991; Hogg and Marshall, 1992; Pryce et al., 1993; Marshall et al., 1995); and that the schedule does not make an explicit attempt to elicit the opinion of clients (Lesage et al., 1991; Hogg and Marshall, 1992; Pryce et al., 1993; Marshall et al., 1995). In order to address these issues more fully, the next section identifies and describes the controversies concerning concepts of need and approaches to an assessment of need in long-term mental illness in more detail. Description centres on knowledge that has been gained with the MRC Needs for Care Schedule in the main.

Need and the Assessment of Need: The criticism and the controversies.

Hogg and Marshall (1992) attempted to use the MRC NFCAS to assess the needs of long-stay hostel residents. They did this because the schedule appeared to be designed to measure need in a systematic and standardised way in populations of long-term mentally ill. The aim of the study was: a) to determine whether the schedule could be used to assess the needs of these disabled and relatively inaccessible clients; b) to determine if the pattern of need identified appeared to reflect conditions in hospitals; and c) to determine if the additional information provided by the schedule would be of use in planning future interventions. Hogg and Marshall (1992) and Marshall (1994), as do other authors (Lesage

et al., 1991; Pryce et al., 1993; Hogg and Marshall, 1992; Marshall et al., 1995), conclude that although it is possible to use the schedule, it gives rise to a number of conceptual and methodological difficulties. The two main difficulties identified include a) the MRC NFCAS's concept of 'clinical decision making'; and b) the experience that the MRC NFCAS takes insufficient account of the views of staff, relatives and patients. The net result is that the need status categories generated by the MRC NFCAS can create 'unfortunate consequences' for the user of the schedule in terms of interpreting the output of the schedule (Marshall et al., 1995).

In more detail, the first difficulty relates to Brewin et al's., (1987) idea that the MRC NFCAS 'replicates clinical decision making in a systematic and standardised way'. The controversy, as Hogg and Marshall (1992) and Marshall (1994) comment, is that experience with the use of the schedule and the identification of needs differed in some circumstances from needs identified clinically, thereby giving rise to some distortions. In essence, Marshall (1994) argues that the "The clinical team ... would probably take a different approach altogether". An example given by Marshall relates to his own experience of using one item from the schedule's 'Skills and Abilities' section. What the item does is suggest that the assessor should begin by a) asking hostel residents if they wish to move to more independent accommodation in which they would have to get and cook their own meals and b) them saying that they were willing to learn the skill. In Marshall's view the need thus defined would be close to what most clinicians would consider a need i.e., a patient's lack of a basic life skill that the patient wanted to acquire, and that would probably improve his or her Quality of Life. The essential difficulty identified by Marshall (1994) is that the MRC NFCAS departs from everyday clinical practice in terms of clinical judgement without having any idea of the patient's expressed need. This gives rise to a second difficulty. The second difficulty relates to Hogg and Marshall's observation that the MRC NFCAS does not give sufficient account of the views of staff, relatives and patients. Typical problems identified and experienced by Hogg and Marshall (1992) and Marshall (1994) relate to areas for example, of 'employment skills' or 'household management' where it is unrealistic to expect severely disabled patients to exercise these skills themselves. The controversy centres on whether or not it is worthwhile for psychiatric

patients who are fairly severely handicapped and need sheltered accommodation to engage in skills training.

Both of the difficulties just outlined, according to Marshall (1994) are shown to have arisen ultimately from a misconception about the nature and measurement of need ("the personification error"), according to which it is assumed that need must be assessed exclusively from one point of view. In the case of the MRC NFCAS, Marshall argues that the relevant point of view is in effect taken to be that of the clinician or clinical team. Because of this the consequence is that information produced cannot be of sufficient quality to assist in planning services. This is due a) to an underlying deficiency of the schedule in taking the views of staff and patients into the assessment; b) the assumption that all needs, even needs in different areas of functioning, are roughly equivalent; and c) the MRC approach to measuring need having no explicit criteria for deciding when it is appropriate to act on a problem (Stage 3). The difficulty here is that the schedule implies that at this stage the clinician must 'use his or her judgement', but in everyday clinical practice such judgements are normally based on the views of the patients and their care-givers.

In order to overcome the conceptual and methodological difficulties encountered with the use of the MRC NFCAS Marshall et al., (1995) introduce the Cardinal Needs Schedule (CNS), a modified version of the MRC NFCAS. In essence, the approach is an alternative model of 'need decision making', which incorporates the perspectives of patients and relevant care-givers. The model has four stages corresponding to criteria for identifying need: a) determining relevant levels of functioning; b) identifying problems in these areas; c) deciding when it is appropriate to act on a problem identified; and d) choosing an appropriate intervention. Further modifications include the requirement to provide a simplification and a shortening of the MRC NFCAS procedure; and that needs should be defined and identified in a way that is concise and easy to interpret. The model put forward by Marshall (1994) looks at the extent the criteria applied to the MRC approach agree with those that would probably be applied in everyday clinical practice. He argues that clinicians decide when to act on an identified problem when faced with one of three situations: a) a patient has a problem for which he or she wants help; b) a patient has a

problem likely to be a danger to his or her health or safety or the safety of others; and c) those who are caring for the patient are suffering as a result of the patient's problem. The key point made by Marshall (1994) in relation to situations b) and c) is that the views of patients and their carers constitute criteria for action but are omitted from the MRC NFCAS. This, according to Marshall (1994) is wrong because in everyday practice most clinicians will decide a course of action having sought the views of patients and their caregivers.

In line with this point a chief modification introduced by Marshal et al., (1995) relates to Step 3 of the MRC NFCAS i.e., the decision-point to act or not to act on an identified problem. The modification relates to the following criteria for action: a) the 'co-operation criterion' i.e., is the patient willing to accept help for the problem? b) the 'care-giver stress criterion' i.e., is people caring for the patient experiencing anxiety, stress etc. as a function of the problem? and c) the 'severity criterion' i.e., is the nature and severity of the problem such that the patient's health and safety or safety of others is at risk? By using the modified version of the MRC NFCAS in the form of structured interviews with patients and care-givers Marshall et al., (1995) argue a) that this reflects better what is done in every-day clinical practice; b) the assessment procedure remains standardised with explicit guidance on how the views of patients and their carers are to be elicited and how these views should be taken into account when rating need; and c) that it has been found that some patients regard some 'problems' identified by clinicians as unimportant, particularly in relation to 'life skills' (McCarthy et al., 1986). This Marshall et al., (1995) argue is important for skills training needs because of a given patient's willingness and motivation to co-operate.

In essence, the CNS continues to identify problems on the basis of scores on standardised measures of behaviour and mental state. However, before problems identified can become needs they must pass a second test to determine whether they are problems that require action i.e., cardinal problems. In order to achieve this Marshall et al., (1995) apply the 'co-operation', 'care-giver stress' and 'severity criteria'. The process remains standardised because the information required to judge co-operation and care-giver stress is provided by

the structured interviews with patient and care-giver, whereas that required to judge severity comes from the standardised clinical assessment. In essence, Marshall's approach produces two main types of output: a) 'needs'; and b) 'placement failures'.

'Need' is defined as a cardinal problem for, which there is a least one suitable intervention that has not been given a recent trial. 'Placement failure' is defined as a cardinal problem for which all suitable interventions have been offered. In this sense, each subject can have one cardinal problem for each area of functioning, giving a maximum of 15 cardinal problems. The number of needs, placement failures and 'suspended status cardinal problems' will always be equal to the number of cardinal problems. Needs are always stated in relation to particular interventions, for example, 'a need for anti-psychotic medication'. The basic idea is that ratings of need are a measure of intervention delivery; that is, they show how far a service has not been delivering suitable interventions. On the other hand, ratings of 'placement failure' are a measure of 'intervention failure'; that is, they show how far the interventions have proven ineffective.

In summary, a number of issues arise in relation to the concept of need, the assessment of need and recent attempts to overcome such problems in long-term mental illness. The main controversies centre on the use of the MRC NFCAS (Brewin et al., 1987) and the modifications of Marshall (1994) and Marshall et al., (1995) using the views of patients and their care-givers as criteria for action. As Marshall argues it is not the nature of the rater but rather the criteria applied during the decision-making process that determines the character of need. In this sense, what Marshall does in order to address some of the problems with the original MRC schedule is provide a basis for clinical decision making which is closer both to everyday clinical practice and to the actual needs of patients and their caregivers. However, this does not go unqualified by Marshall (1994), who says that there are many unresolved conceptual as well as empirical difficulties in the assessment of need requiring both continued conceptual and practical work. The problem is that an assessment of need cannot be straight-forward. This statement centres on two issues: one concerns the meaning of 'need' and the meaning of 'need' when 'assessment' is added; and

the other relates to who is assessing the need. Each of these raises complex conceptual and methodological issues. As Marshall points out, need comes in different varieties depending on the type of person who is making the judgement and the nature of the criteria applied when making the judgement. This, as Brewin et al., (1987; 1988) say, is centred on the fact that needs cannot be objectively determined but are always based on a system of values that involve value judgements. The reason for this is because statements of need imply both factual and value elements. In this sense, not only do statements of need describe an actual state of affairs, they also depend on an implicit or explicit value system, which determines which states of affairs are accepted and which actions are thought appropriate. As Royce and Drude (1982) point out, needs and needs-assessment is a term without conceptual boundaries, which require an operational definition in each usage.

Three points seem to emerge from the discussion so far. Firstly need can never be defined objectively. This is because 'need' must be understood in terms of those making the judgement and their frame of reference in relation to culturally defined norms and value systems. Secondly, the limitation of concepts and methodologies seems to be that the individual scientist-practitioner has been left with the responsibility for defining, operationalising and standardising conceptual and methodological approaches to need and needs-assessment. Thirdly, what seems to unify the approaches described above is, as McKillip (1987) points out, needs are invariably conceptualised as value judgements that a person has a 'problem' which can be solved. However, one difficulty with this conceptualisation is that if the identification and assessment of need involve value judgements then people with different values will recognise different needs.

Value judgements and the assessment of need

Defining and conceptualising need as a judgement points out how important values are in needs-assessment in that observers, experts or 'people who know others well' might have perceptions different from those of the target population. In terms of value judgements a central issue is whose interests might a given definition of 'need' and approach to needs-assessment represent? McClelland (1953) and Maslow (1970) hypothesise that people have

a personal stake in the assessment of their needs in terms of importance, motivation and fulfilment. This leads to a difficulty in the assessment of need both in general and in relation to long-term mental illness in that for example, one person may exaggerate need in order to gain support at one point in time, while at another may minimise need to forego any loss of self-esteem. By the same token a person may judge themselves not to be in need and an outsider may judge them to have a need, or vice-versa. In view of this point, two issues become important from both a research and application perspective. Firstly, as Marshall (1994) argues, in terms of a 'personification of need', decisions should include the views of patients and their carers. This is because criteria for action depend on knowledge of the views of patients and care-givers. Secondly, and in relation to the last point, it is crucial to both validate and establish the reliability of an assessment of need because self-reports and or observations by others may distort the true picture i.e., introduce error into the assessment of need. Consequently, if the assessment of need cannot be value free, and value judgements are considered central to the perception of needs-assessment, then the value judgements involved should be made explicit. This would suggest the necessity for a) comparing the expressed needs of a person with a mental illness with the assessments of those needs by professionals i.e., people who know them well; and b) exploring the stability of a needs-assessment from each of these perspectives over time.

If one accepts the proposition that the assessment of need is to incorporate the self-reported need of a person with a long-term mental illness then this leads to some apparent conceptual difficulties. This is particularly so in view of the multiplicity of factors which can be hypothesised to be involved in the assessment of self-reported need in long-term mental illness, e.g., individual expectations and mental illness history. Against this background one basic question is whether an assessment can simply and reliably identify the presence or absence of self-reported need? This point hinges on the many alternative definitions and value judgements of need which might encompass everyday mental and social well-being, as well as the physical ability to perform social roles and successful coping with the demands of daily living. Any differences in the definition and perception of 'need' resulting from the issue of different value judgements between for example, mental health professionals and the long-term mentally ill, may lead to confusion or

conflict in terms of mental health service demand and utility. As Hunt and McEwan (1980) point out, the perceived needs of people, their demands for health services in general and the provision of health care by professionals frequently show poor correspondence. Indeed a review of what studies there are in the area of needs-assessment in long-term mental illness that have examined client-practitioner convergence provide a mixed picture (e.g., Dellario et al., 1983; Phelan et al., 1995; Slade et al., 1996; Carter et al., 1996). What this seems to imply is that staff and patient information may be different or similar for a variety of different reasons e.g., definition of need, measuring tools, and client group. The implication of these findings is that one cannot assume agreement in an assessment of need. In this sense, clients' self-ratings of their needs and practitioner' ratings of the client's needs may represent two different sources of information about clients. Therefore, it may be very misguided to try to develop value-free operational definitions of need. As Brewin (1992) suggests needs cannot be rational, or have their basis in objective reality and cannot be defined along a uni-dimensional scale.

What this seems to suggest is that if need is conceptualised as a value judgement, and as was pointed out above, one of the objects of mental health reform is to arrive at a greater understanding of what the user has to say concerning their own needs then this highlights how important values are in the assessment of need. What this points to is the following issue: if different perceptions of need are to constitute any part of the assessment of need in psychiatric services then a standard concept and operational definition of assessing the expressed need or self-reported need of people with a long-term mental illness and the perceived needs of those patients by staff requires development. However, in view of the evidence presented in Chapter 1 in relation to various cognitive and social disturbances in long-term mental illness, and the difficulty in conceptualising and assessing need, one has to ask whether or not assessing the expressed need of someone with a long-term mental illness is necessarily appropriate. As indicated, a main criticism of most approaches to needs-assessment is that they do not take the individual with a long-term mental illness into the assessment. However, this criticism can only be valid if it can be shown that a self-reported needs-assessment is firstly, appropriate and can lead to measurable improvements in client outcome (Carter et al., 1995); secondly, is useful to the extent in which it allows

assessors to improve the precision with which need might be identified (Hogg and Marshall, 1992); and thirdly, brings attention to areas of unmet need where an intervention or potential intervention is available. If this argument is followed through i.e., that needs are necessarily subjective, then using a method which does not reflect the expressed need of the people with a mental long-term mental illness leads one to speculate that the outcome can only be a partial indication of need. If one accepts the argument that the main focus of a needs-assessment is normative, what emerges is a picture where professionals identify mental health care needs and determine plans to meet those needs and in so doing assume the mantle of lead agents who both identify, prioritise and meet need. This gives rise to three key questions. Firstly, 'Do people with a long-term mental illness and their key-workers agree on the presence of need?' If they disagree, 'Where do the disagreements lie?' and 'Why do disagreements exist?'

Conclusions

In conclusion, few studies have developed or adapted a client-centred approach to needs-assessment, which takes the self-reported view of the client themselves as its basis. The main approaches to an assessment of need have been predominantly normative. Reasons for this can at least be seen to be partially related to a) the difficulty in conceptualising need and need assessment; and b) the cognitive and social difficulties of the long-term mentally ill as outlined in Chapter 1, suggesting that giving weight to clients' own accounts of their needs is questionable. The difficulty is that a normative approach may not in itself provide sufficient information about need, particularly a) when the expressed needs of the individual with a long- term mentally illness have not been taken into account; and b) there is some evidence to suggest client-professional concordance. However, the upshot is that to date the systematic identification of basic self-reported needs in the long- term mentally ill presents little data in the mental health literature.

What the review in this chapter has shown is that some important issues should be considered prior to undertaking an assessment of self-reported need in long-term mental illness. These include: firstly, the view that assessment information is essentially a value-based process potentially representing disparate values; secondly, social and mental health

needs are both potentially diffuse and interrelated and as a result it may be difficult to establish priorities amongst needs; and thirdly, needs will be influenced by factors such as the capabilities and motivation of respondents - in the case of this thesis people with a long-term mental illness. In view of these points, both conceptual and methodological issues remain with respect to how an assessment of self-reported need in a sample of long-term mentally ill people might be translated into a need rating. Clearly, the fundamental question concerning this thesis is whether or not a self-report assessment of need in long-term mental illness is reliable and valid and furthermore, that such an undertaking is appropriate. In order to contribute to the debate on how to measure needs this thesis proceeds by providing another method to measuring need. However, before such a method is introduced, potential difficulties relating to the measurement of a self-report assessment of need in long-term mental illness are discussed in Chapter 3.

Chapter 3. Assessing people with a long-term mental illness.

Chapter overview

This chapter provides a description of assessment procedures used in research with subjects who have a long-term mental illness. This includes reviews of which main variables have been used; a review of the way instruments should be designed for data collection, and the importance of defining key variables. Potential problems with getting accurate accounts of self-reports from people who have long-term mental illness are discussed.

Introduction.

The aim of this chapter is to address design and methodological issues related to conducting research in people who have a long-term mental illness. For example, can a person with a long-term mental illness complete a self-report interview schedule? What reliability can be expected in their responses? What validity can be expected in their responses? The justification for addressing such issues is to highlight primarily special problems identified in the literature such as recognition of mental pathology; and then to discuss incorporating such findings into a research design. Clearly some of these difficulties could potentially have a methodological impact on this thesis. For present purposes, this thesis takes the form of a prospective, non-experimental design with repeated measures. The rationale and details of the research design adopted will be discussed in Chapter 4.

Assessment: an overview.

With the advent of de-institutionalisation and community care, the mental health literature has broadened in nature to include not only psychiatric screening instruments but also subjective indices of patient well-being. An example of this would indicate constructs such as Quality of Life and service user satisfaction in mental health have appeared in the more recent literature (e.g., Lehman, 1983 and 1986; Oliver et al., 1995). The increase in assessment methodologies has its routes in several sources including:

- changes in patterns of mental health service provision (HMSO 1990);
- the multi-disciplinary nature of care in the community (e.g., Welsh Office, 1989);
- the increased emphasis on comprehensive and integrated individualised mental health care (e.g., Welsh Office, 1991);
- the necessity for the development of more appropriate assessment methodologies compared to those used in psychiatric hospitals (Mitchell et al., 1995);
- using the patient as a source of information (MacCarthy, Benson and Brewin 1986; Lesage et al., 1989; Brewin, 1992; Hogg and Marshall, 1992; Marshall at al., 1995); and

- the necessity to develop instruments which are sensitive to detecting change in a population who are frequently severely disabled socially and cognitively (Wykes and Sturt, 1986; McKenna et al., 1994; Neuchterlein et al., 1994).

In order to place this thesis in its general context, what will now be presented is a summary of various measurement issues in relation to the assessment of people with a long-term mental illness. Five main area will be examined. These include:

1. 'gold standards';
2. devising and evaluating measures;
3. measures that assess symptoms;
4. potential problems in design; and
5. the long-term mentally ill as respondents.

1. Gold standards

The purpose of psychiatric assessment is to identify some characteristic that is always associated with the illness and is never seen in someone without the illness (Simms, 1988; Peck and Shapiro, 1990; WHO, 1992). This begs the question of how to measure a trait or characteristic that is necessary to diagnose a specific condition especially if it needs to be of a sufficient magnitude. Dworkin (1992) maintains that for both clinicians and non-clinical researchers, the clinical interview is the gold standard for collection of diagnostic data against which the validity of all other methods must be compared. However, the way people with a long-term mental illness have been assessed in terms of the instruments and methodologies used are not without its difficulties. Several authors (e.g., Hall, 1979; Braun et al.,1981; Wykes, Sturt and Creer, 1985; O'Driscoll, 1993; Mitchell, Crosby and Barry, 1995) review studies of the long-term mentally ill - with particular reference to de-institutionalisation - and highlight a number of methodological inadequacies which hamper reliable and valid conclusions. Chief among these is: biased selection; uninformative sociodemographic and clinical descriptions; a lack of a comparison group; and the use of inappropriate assessment procedures of unknown or questionable validity and reliability. Clearly, such inadequacies may seriously compromise various aspects of the reliability and

validity of research into people with a long-term mental illness. Therefore, methods of devising and evaluating measures, which constitute 'gold standards', need to be reviewed.

2. Devising and Evaluating Measures

In relation to this section, and the task of devising and evaluating measures, an immediate question is how can a particular empirical indicator (or set of empirical indicators) represent a theoretical concept? More specifically, how can a researcher devise and evaluate the extent to which items used to measure need accurately represent that concept? In order to answer to these questions we need to look at the underlying concepts and definitions of measurement. These include: reliability and validity. However, before each of these is discussed we need to consider some of the issues concerning measurement.

Measurement: A definition.

Stevens (1951) defines measurement as the "... assignment of numbers to objects or events according to rules". In this sense, measurement involves the ordering of observations along a dimension for the purpose of analysis and manipulation. However, one problem we meet in the social sciences is that many of the phenomena to be measured are neither clearly objects nor events. Typically, they are too abstract to be adequately characterised as either objects or events. The reason for this is because much of human behaviour is not amenable to direct observation. In this sense, measurement is a process involving both theoretical as well as empirical considerations. The theoretical considerations involve the unobservable concept (the directly Un-measurable) i.e., that which is represented by the response, and the empirical entails the observable response (the measurable) e.g., the answer given to an interviewer in response to a given question. In the case of this thesis the response signifies the presence or absence of need from both normative and subjective sources. However, as Peck and Shapiro (1990) point out, using different types of measures produces different types of error in measurement. In order therefore to demonstrate that a scale or set of items are measuring what was intended we need to introduce the concept of reliability.

Reliability

The researcher needs to show that an instrument is measuring a hypothetical construct in a reproducible and consistent way. Nunnally (1978) refers to reliability as "...measurements are reliable to the extent that they are repeatable and that any random influence which tends to make measurements different from occasion to occasion or circumstance to circumstance is a source of measurement error" (p.225). In this sense, the reliability of a measure refers to its consistency, that is, the extent to which any measuring procedure yields the same result on repeated trials (Bryman and Cramer, 1992). Because this thesis is concerned with devising a method for measuring need, two points have to be taken into account a) investigations of reliability should be made when new measures are developed (Kline, 1993); and b) the measurement of any phenomena always contains a certain amount of chance error. In relation to this latter point, Stanley (1971) has said that the goal of error-free measurement is never attained and is always universally present. In this sense, two sets of measurements of the same individual will never exactly duplicate each other. This leads us to consider what kinds of reliability there are and how are they expressed? Several texts (e.g., Nunnally, 1978; Peck and Shapiro, 1990; Pedhazur and Schmelkin, 1991) discuss approaches to the many kinds of reliability and make some recommendations in relation to how research investigations should be undertaken in the development of an assessment instrument. For the purpose of this thesis three broad forms of reliability will now be presented: test-retest reliability, inter-rater reliability and internal consistency reliability. However, before this is done some general issues concerning measurement error will be considered.

Measurement error

Nunnally (1978) suggests that in practice there are many factors which prevent measurements from being exactly repeatable - the number and kind of factors depending on the nature of the assessment and how the assessment is used. Broadly speaking, differences among individuals in observed scores may be due to 'true' differences among them on the attribute being measured or as a result of 'errors' (e.g., guessing, in-attentiveness, and carelessness). As Kline (1993) points out, no measurement is error free and therefore most psychological tests and assessments are confounded by measurement

error. Therefore, the aim becomes one of partitioning the observed-score variance into true and error components.

Pedhazur and Schmelkin (1991) note that it is imperative that reports of reliability include sufficient information about the procedure used in its estimation so that readers can ascertain the sources of error that have been addressed. Classical test theory (The true-score model) forms the statistical basis of both reliability and validity, in that an observed score is conceived of as consisting of two components - a 'true' component and an 'error' component (O = T + E). The rationale is that because perfect conditions do not exist, the observed score always contains a certain amount of error. Two principal sources being: random and non-random measurement error.

Random error i.e., chance factors, are at the heart of classical test theory and are the more serious of the two sources of error in their effects on the accuracy of measurement. Random error is inversely related to the degree of reliability of the measuring instrument. Thus, a highly reliable indicator of a theoretical concept is one that leads to consistent results on repeated measurements because it does not fluctuate greatly due to random error. However, as Pedhazur and Schmelkin (1991) argue: a) indicators always contain random measurement error to a greater or lesser degree; b) effects on random measurement error are totally unsystematic in character; and c) sources of random measurement error are endemic in the social sciences and include potential errors due to coding, ambiguous instruction, differential use of wording during the interview, interviewer fatigue, and interviewee fatigue.

Non-random error or systematic error effects empirical measurement and has a systematic biasing effect on measuring instruments. It is usually considered during the construction of an assessment instrument. Notably, non-random error is crucial to validity in that such error prevents indicators from representing what they are intended to i.e., the theoretical concept. What this suggests is, the less the error in an assessment or test the more reliable it is, i.e., repeatable. Since replicability is the essence of science it is regarded as axiomatic that assessments or tests should be as reliable as is possible (Kline, 1991).

However, as Guilford (1954) and Nunnally (1978) point out, reliability is necessary but not sufficient for validity. In this sense, reliability is an empirical issue, focusing on the performance of empirical measures. Validity, in contrast, is usually more of a theoretically oriented issue because it inevitably raises the question 'Valid for what purpose?' To conclude, for an assessment to be useful in social science research, it must lead to consistent results on repeated measurements and reflect its intended theoretical concept. In relation to this latter point, the reliability of assessments and tests has three meanings: test-retest reliability, inter-rater reliability, and internal consistency reliability.

'Test retest reliability' is the one corresponding most closely to a view of reliability as consistency or repeatability of measurement i.e., external reliability (Pedhazur and Schmelkin, 1991). In this approach to reliability the same measure is applied to the same group of subjects, under similar conditions, at two different points in time. If the measure is assessing the characteristic consistently, those who score high (or low) on the first occasion should score high (or low) on the second. From this we can establish the correlation coefficient as an estimate of the reliability measure or coefficient of stability. Streiner and Norman (1991) suggest that there is no standard interval between the administrations of the measurement, but a three week interval is commonly used. This is considered long enough to reduce the risk of inflating consistency due to recall of previous responses, but short enough so that reliability is not reduced by major fluctuations in the characteristic being measured. Test-retest reliability however has to be measuring a characteristic, which has an appropriate measure of consistency. Measurement errors are thought to be occur include the following three reasons: a) changes in subjects due to recall of their previous responses, too short a time interval between test and retest, and transient variables such as mental state; b) the sampling of subjects which may lead to distortion of the correlation coefficient; and c) characteristics of the assessment which can lead to poor test-retest reliability and might include poor test instructions or guessing. 'Inter-rater reliability' concerns the situation where two or more observers examine, for example, the presence or absence of events, and the degree of agreement between them is assessed.

Finally, the concept of 'internal consistency reliability' links in with the concept of validity in the sense that if a test is to be valid, in that it measures what it claims it measures, then internal consistency must be high. The rationale is that if an assessment or test is measuring one variable, then the other parts, if internal consistency is low, cannot be measuring that variable. Internal consistency is a prerequisite of high validity. Its use is for retaining items in an assessment or test (Guilford, 1954; Nunnally, 1978).

In summary, several authors (e.g., Carmines and Zeller, 1979; Peck and Shapiro, 1990) emphasise the use of reliability in the psychological assessment of individuals. Therefore, in relation to this thesis, and in order to produce useful data and have confidence in results it is essential the instruments employed consistently measure the concepts of interest reliably. This is especially so when measures involve ratings done by human observers e.g., inter-observer ratings. In this sense, it seems clear that in devising a new measure, indices of temporal consistency (test-retest reliability), inter-rater reliability and internal reliability should be reported. However, three points are worth noting: a) the samples from which the reliability coefficients are derived must be representative of the populations for whom the test or assessment is designed; b) samples must be sufficiently large to be statistically reliable; and c) high reliability can be achieved at the expense of validity. This naturally brings us onto the issue of validity.

Validity

The validity of a measure addresses the question of whether or not a measure is measuring what the measurer claims it is measuring (Kidder and Judd, 1986). Unlike reliability, where there is general agreement about its utility and how to assess it, there is considerable confusion about the concept of validity (Peck and Shapiro, 1990; Kreiner, 1993). In the realm of human assessment, and measures of variables like 'mental state', and 'human need', the importance of validity testing is twofold. Firstly, taking Quality of Life as an example, since Quality of Life is not something which can be observed and measured directly, various questionnaires and assessment schedules have been developed to assess it (Lehman, 1983; Bowling, 1991; Barry, Crosby and Bogg, 1993). Needless to say, each instrument yields somewhat different results, raising two questions: which, if any, gives the

'correct answer' and moreover, what is the 'true' nature of what is being measured? The second reason why validity is important has to do with the relationship of that variable to its hypothesised cause. In this sense, the question asked is how validly does an actual measure predict an actual outcome? It seems that there are different approaches to assessing the validity of psychological measures and that there is no one validity coefficient. For example, whereas some forms of validity are reported in the form of a correlation, others are purely descriptive, and are not reported statistically. In addition, some authors have applied different names to the same kind of validity, adding confusion. Such issues have led to a growing disenchantment with the concept of validity. Nevertheless, most authors of existing psychological measures report on validity. Therefore, it is important for the development of this thesis to outline some of the main kinds of validity in order that a decision about what might be most appropriate for establishing the validity of a new needs-assessment schedule can be made. Clearly, there are a number of potential major threats to validity in non-experimental research from a number of confounding variables. In order to address these issues four types of validity will now be discussed in turn: face validity, content validity, concurrent validity and construct validity. This will be followed by a discussion of the relationship between reliability and validity in relation to a self-report assessment of need.

The main kinds of validity

'Face validity' - the advantage of face validity is that it can increase motivation in that respondents answer accurately - a quality essential for valid testing or assessment. A disadvantage of face validity is, that by definition respondents may fake or distort responses for whatever reason. For example, in the case of this thesis an assessment of self-reported need may result in an underestimate of need in order to preserve self-esteem. Naturally, to what degree such distortion affects scores depends to a large extent upon what is being measured and whether or not items are validly written in the first place, that is, have 'content validity'.

Kline (1993) refers to *'content validity'* as a measure that includes a representative sample of the target behaviour that lends itself to accurate inferences under a wide range of

circumstances and is only applicable where the domain of items is particularly clear cut. In this sense, if there are important aspects of the outcome that are missed by the measures, then it is likely that some inferences will prove to be invalid. Thus, the higher the content validity of a measure, the broader are the inferences that can be validly drawn about an individual under a variety of different situations and conditions. What the literature (e.g., Kline, 1993) recommends in the instance of developing the content of an instrument is that it be given to a representative sample who are asked whether or not the assessment tool covers all important aspects as intended to which people could reasonably be expected to respond. The sample are asked to indicate where they think the assessment might be lacking or where items assessed are not important for its target population. By using this approach it is argued that the relevant content of an assessment can be found for its intended purpose. Clearly, it might be argued that 'content validity' is little more than face validity. In this sense, face and content validity might be thought to overlap. The difficulty for the researcher is that an attempt has to be made to demonstrate that measures used are in fact valid. This is because items can be distorted by such factors as outlined above regardless of content and so on. Of course such factors might not happen and the item (s) might be valid. The crux of the matter is that an attempt to establish content validity still has to be made. Streiner and Norman (1991) say that content validity is the validity to aim for, where it is relevant, and it should be backed up with evidence of some other form of validity, for example, 'criterion' or 'concurrent' validity.

'Criterion validity' is traditionally defined as the correlation of a scale with some other measure of the trait or disorder under study, ideally, a 'gold standard' which has been used and accepted in the field.

'Concurrent validity' forms one type of 'criterion validity' and involves correlating a new scale with a concurrent measure, which has been administered during the same interview or within a short period of time. In this sense, a test is said to have concurrent validity if it can be shown to correlate highly with the other test. Potentially there are a number of problems with concurrent validity. The first concerns the meaning of 'correlate highly' and the question of how high a correlation must be before it indicates that a test is valid. Several

authors (e.g., Kidder and Judd, 1986; McDowell and Newell, 1986; Streiner and Norman, 1991) say that the question has no simple answer, since it depends, to some extent, on the quality of the criterion test with which the new test is to be correlated. Furthermore, if a test is so good that it can be taken as a standard, one has to ask the question, what is the point of the new test? Clearly a new test must have qualities that differentiate it from the concurrent test. The issue then for this thesis is finding a concurrent test of accepted validity, which can be used as one test of validity. Several authors (e.g., Kidder and Judd, 1986; McDowell and Newell, 1986; Streiner and Norman, 1991) comment that in the vast majority of cases a test or assessment will measure a variable in which there is no concurrent test available of acceptable validity.

'Construct validity' refers to how well a particular measure accurately represents or reflects the theoretical construct of interest. There is a wide range of assessments for which none of the previous methods of trying to establish validity is appropriate. In order to overcome this difficulty Cronbach and Meehl (1955) introduced the notion of construct validity. Construct validity applies to assessing variables that are abstract and not directly observable for example, Quality of Life, anxiety, and intelligence. In this sense, such variables cannot be seen, all that can be done is a) assess self-reports and/or b) observe such behaviours which, according to some theory, are the result of it, that is, are hypothetical constructs (Kidder and Judd, 1986). Such constructs are then used to explain the relationships among various abstract thoughts, feelings and behaviours. However, the difficulty with an hypothesised construct like 'need' and the assessment of self-reported need is that it is difficult to directly study or observe 'need' because of the different value judgements people might have in relation to a given individual's need status. One solution is to carry out a number of studies and demonstrate the definition of need used is construct valid (Kline, 1993). So, in this sense it seems justified to investigate self-reported need in mental illness in order that people can be classified and that the relationship of need to other constructs like mental status and levels of dependency might be explored. What this suggests is that construct validity is established by setting up a number of hypotheses derived from the nature of the variable and putting them to the test - bearing in mind that not every type of validity can be used. However, the problem is that the approach is

inferential. In this sense, what this thesis will have to do is make the derivation of its hypotheses clear in order that it is possible to demonstrate that the method of assessment method does measure what it claims it measures. In essence, what is sought is some confirmation of construct validity whilst being aware of the caveats mentioned above and the realisation that establishing validity of a self-report assessment of need is necessary but not sufficient and may be something that can never achieve complete satisfaction.

The relation of validity and reliability.

Traditionally, concepts of reliability and validity have been and continue to be of crucial importance in the development of psychological measures. As this discussion has tried to highlight, any one researcher attempting to devise a measurement instrument needs to be aware of the strengths and limitations of the notions of reliability and validity. Reliability and validity are closely related. In one sense, for a test to be valid it must be reliable, however, it is possible to have a test that is reliable but not valid, that is a test might be a consistent measure but could, in practice be measuring something entirely different from that which was intended. Clearly, it is never sufficient to demonstrate that a test is reliable and then assume that it must be valid. Bausell (1986) recommends in the field of psychology and related disciplines, that validity should be de-emphasised and that utility should be concentrated on a gradual build up of a number of studies over time. If a measure proves useful, it's continued use would be justified. If a measure does not prove useful it's continued use would decline. Furthermore, utility is best seen as the end of a series of steps, including various forms of reliability and validity, with the final step being construct validity. That is, construct validity will be demonstrated when a measure has been shown to work with different samples.

Threats to validity.

Several texts provide comprehensive discussion with regard to the many potential confounding variables which may, in general, influence results in social sciences research (whether experimental, quasi-experimental or non-experimental) and lead to unreliable and invalid conclusions (e.g., Cook and Campbell, 1979; Kidder and Judd, 1986; McDowell and Newell, 1987; Parry and Watts, 1989; Streiner and Norman, 1991; Pedhazur

and Schmelkin; 1991; Breakwell, Hammond and Fife-Shaw, 1995). A brief outline of the more important influences for this thesis will be discussed in relation to internal validity and external validity.

Threats to internal validity

Given, as outlined at the beginning of this chapter, that this thesis entails the development of an instrument which assesses the self-reported need of people with a long-term mental illness in the form of a non-experimental repeated measures design, i.e., at least two assessments spaced over time, it is especially prone to a number of potential confounding variables. A first potential confound relates to selection and threats to group differences. In experimental or quasi-experimental studies internal validity refers to the extent to which potentially confounding variables and alternative explanations for any observed 'effect' can be considered improbable. In the broadest sense, this can be stated in the form of the question: Is what has taken place due to the variables the researcher claims to be operating or can it are attributed to other variables? In essence, the validity of the answer to this question depends on the plausibility of alternative explanations. For example, in the absence of random selection of subjects and assignment to treatment conditions, one of the major threats to the validity of an experiment is selection. A confound of selection can occur if comparisons are made between treated and non-treated groups when there are systematic differences in group composition. The possibility of a selection bias is especially probable if already formed or naturally occurring groups are used. Unless it can be demonstrated that the groups were equivalent on the measures of interest before the intervention, it cannot be known for certain if differences found after the manipulation are the result of the treatment or due to pre-existing differences. Although this thesis is non-experimental i.e., does not involve the manipulation of variables and the assignment of subjects to treatment conditions, group comparisons will be considered. Therefore, it will be important to determine whether or not subjects differ on any variables and whether or not there is a confound in relation to selection that might threaten the internal validity of the measures undertaken.

A second potential confound relates to 'maturation and history threats'. The threat of 'maturation' to the validity of measures refers to systematic changes that people undergo with the passage of time (e.g., growing older, gaining experience). The concern is that responses attributed to items or treatments may be, in part or wholly, due to such maturational processes. There can also be numerous extraneous events, which occur over the course of the study that may affect the outcome. Such 'history effects' are events that took place over the course of the study that might have affected its outcome. Such effects may be local for example, the introduction of a new medication which coincides with an assessment, or more generally, an impact on the Quality of Life of individuals in terms of an increase in benefits paid to people with a long-term mental illness. The internal validity of the study would be confounded to the extent that the research participants were aware of such effects and that this influenced their responses to assessment items. The point is that threats of maturation and history become increasingly probable with longer measurement intervals. Allied to maturation and history effects is 'mortality'. Mortality refers to the attrition of people in the course of a study and is particularly prone to happen when a study involves repeat assessments and is of relatively long duration. The reasons for people 'mortality' might include death, moving to live in another area or simply withdrawing from the study. The point is that in terms of a threat to internal validity, mortality may be characterised as a 'self-selection process', the reasons for which are difficult to discern. For example, people may choose not to respond and are not willing or able to provide an explanation, or they may conceal their real motive for withdrawing and so on.

'Testing effects' relates to a third potential confound and occur when people are measured or assessed more than once on the same variables or construct of interest. In this sense, changes in responses might be the result of the measurement process itself and may be affected by, among other things, practice, memory of earlier responses, sensitisation and/or 'guesses' regarding the purpose of the research and the expectations of the researcher. All such biases may accordingly effect subsequent responses. Similarly, if the assessment procedure involves human observers, the effects of being involved in the measurement process are not restricted only to the subjects of a study. For example, with repeated use of a measurement instrument, raters may become more proficient in administering

assessments as the study progresses. A fourth potential confound relates to instrumentation. This can compromise internal validity when differences in responses and/or outcomes may be attributed to aspects of the instrument used. For example, when 'minor' changes are made in the instruments, which actually constitute changes in what, is being measured. Further possible threats to validity (particularly construct validity) include: ambiguous or vague definitions of the relevant constructs; similarly vague or ambiguous questions which tap the relevant construct; and utilising only one measure to represent the construct of interest (Cook & Campbell, 1979; Kidder and Judd, 1986). These various threats will now be considered in more detail.

Ambiguous or vague definitions of the relevant constructs are of particular importance for survey and/or assessment studies since it is often difficult to obtain precise specification of intended outcomes over time. For example, and in relation to assessing the expressed need of a person with a long-term mental illness, policy is couched in terms of arriving at a greater understanding of what the user has to say concerning their own needs (Welsh Office, 1989; HMSO, 1990; Welsh Office, 1991). Clearly, intended assessments stated in this way are inadequately specified for objective measurement. As discussed in Chapter 1, the concept of 'need' and the assessment of need must be precisely defined so that it can be operationalised and agreement reached that the measures used are both reliable and valid indices of the construct. Schuman and Presser (1981) suggest various methods for writing specific questions, which avoid vagueness and/or ambiguity when tapping a particular construct. This is because vague and or ambiguous terminology has the potential to lead to erroneous information/data and thereby invalidate study findings. Such techniques include: eliminating those items which are ambiguous or un-interpretable e.g., words being too difficult, jargon, or are double-barrelled; and pre-testing the instrument on a group of people comparable to those who will be the ultimate targets. Furthermore, Cook and Campbell (1979) advise that it is good research practice in the development of a new test or assessment to use more than one measure to represent each of the constructs of interest. This is because any one measure may not capture all the dimensions of a construct or, may contain dimensions, which are irrelevant to the construct of interest i.e., construct under-representation and surplus construct irrelevancies, respectively. Using more than one

measure acknowledges the fact that all measures contain error or unwanted variance and can increase construct validity by a convergence of measures which operationalise the same construct.

Threats to external validity.

Cook and Campbell (1979) make the point that internal validity is a necessary although not sufficient condition for external validity. External validity, refers to the generalisability of results of a study to or across other persons, settings, and times. Although the concern of this thesis is the development of an instrument which assesses the self-reported need of people with a long-term mental illness i.e., a particular sample of individuals in a particular setting, a key issue is how generalisable might the findings be to the overall population and/or other settings? Clearly, when internal validity is in doubt it makes little sense to inquire 'to what' or 'across what', are the findings generalisable. Also, because external validation entails inductive inference, it "...is inherently more problematic than internal validity whose biases are more obviously deductive" (Cook and Campbell, 1979). Whether or not 'generalisations to' a population are valid is dependent upon how well the initial sample accurately represents the population of interest. Consequently, whatever the target population the validity of this type of generalisation is predicated on the sample-selection procedures. Issues of sampling will be discussed shortly. 'Generalising across' concerns the validity of generalising across populations. For example, results obtained with a sample from a given population (e.g., males) are generalised to other populations (e.g., females) or results obtained in one setting (e.g., hospital) are generalised to another setting (e.g., the community). The method most often employed to achieve the goal of representativeness is random sampling of the population. However, as Kidder and Judd (1986) have noted, probability sampling is uncommon in field research and that strict generalising to targets of external validity is rare; contending that even when one begins with a probability sample attrition is almost inevitable. Cook and Campbell (1979) suggest that a case can be made that external validity is enhanced more by a number of smaller studies with haphazard samples than by a single study with initially representative samples. They further caution that people or settings in haphazard samples under study should belong to the classes of people or settings to which one wishes to generalise.

In summary, this thesis will have to address the adequacies and the inadequacies of methodology associated reliability and validity. Such issues are addressed in Chapter 4. Measures that assess symptoms and functioning of people with a long-term mental illness are considered next.

3. Assessing symptoms in people with a long-term mental illness.

Wing et al., (1992) say that the concept of mental illness itself is based on concepts of the signs and symptoms of 'dysfunction'. Several authors review the nature and range of measures used to assess the behaviour of people with a long-term mental illness and express some concern about how methods of assessment in psychiatric populations have been conducted (e.g., Bachrach, 1982; Hall, 1979, 1980; Stein and Test, 1985; Wykes and Sturt, 1986; McDowell and Newell, 1987; Bowling, 1995; Mitchell et al., 1995). Hall (1979 is useful for addressing these concerns. What Hall (1979) has outlined is a number of basic requirements of patient assessment procedures in relation to people with a long-term mental illness. These include: the use of more than one scale or type of assessment method; the use of standard assessment methods and procedures which have been shown to be reliable; respondent selection criteria; and the requirement that the reliability of any assessment method should not be assumed but should be positively demonstrated during the study reported. In relation to this last point and for the present, all that needs to be said is that recent literature shows that an undertaking of an assessment in a psychiatric population has come to include not only the use of diagnostic screening tools but also on occasions the use of a self-report questionnaires or interviews. The impetus for this approach has its basis in the tenets of normalisation (Wolfensburger, 1972; Brown and Smith, 1992). Such research is reported by Leff (1993) and Crosby and Barry (1995) amongst others in the context of the resettlement of long-term mentally ill into community care. What such research shows is that the use of screening tools in terms of measuring mental state and social functioning of the long-term mentally ill are important for two reasons. Firstly, screening tools for measuring mental state can provide information in relation to the number of psychiatric symptoms present, and also their duration and intensity over time. Secondly, screening tools for mental state can be used to measure the

extent to which psychiatric symptoms relate to other measures thought to be important in the study of long-term mental illness e.g., social functioning (Braun et al., 1981; Bachrach, 1983; Leff, 1993; Crosby and Barry, 1995). Clearly, such an approach is important for the development of this thesis and the measurement of self-reported need. This is because the majority of people who have a long-term mental illness do not attain a stable clinical remission (Ciompi, 1980).

4. Problems in design: Populations and sampling frames

Pedhazur and Schmelkin (1991) say that probability sampling is a *sine qua non* for validity of non-experimental studies. Unfortunately, in various areas of socio-behavioural research, it is customary to present findings about comparisons among all sorts of groups, on an assortment of variables without the slightest concern about sampling representativeness. Dworkin (1992) states that when conducting research on persons with a mental illness, methodologists have a range of designs at their disposal for methodological guidance. This section will briefly outline some of the basic tenets of design, and go on to examine some of the problems encountered in these designs in relation to studies of people with a long-term mental illness.

Firstly, and in relation to populations and sampling frames, the strength and utility of a study start with the definition of the study population (Kidder and Judd, 1986). Unless that population and its attendant sampling frame can yield a sample that is representative of and generalisable to the population of interest, interpretation of data will be limited. The point is that the reader needs to know how sampling frames are decided in order that any limitations can be understood. Dworkin (1992) says that the most reasonable alternative to 'general' sample is to use a clinical sample. However, sampling within a population of cases has its own problems. When there are people sampled who, at a specified time have some mental illness, they will have acquired their illnesses at different points. For example, Vernon and Roberts (1982) found that reliance on a community sample led to an underestimation of the rates of severe disorders, because some of the sample were hospitalised at the time of the survey. The implication for this thesis is that when sampling from a population of long-term mentally ill one has to be aware of community care rates of

hospitalisation. This is because numbers of long-term mentally ill may vary by community care provision as well as severity of illness and its duration. What this means is that there may be some distortion between the relationship of mental illness and time hospitalised. Clearly, for the purpose of this thesis an appropriate sampling frame needs to be established in order that the selection of actual subjects may begin. Pedhazur and Schmelkin (1991) suggest that criterion-based selection may be indicated when the study is predictive and/or exploratory and when one task of the research is to define the boundaries of the population of interest. In this instance only a small number of population characteristics are considered relevant to the research and researchers specify inclusionary and exclusionary criteria to individuals who are available as potential study participants. These criteria are used in an attempt to develop a homogeneous sample. On the basis that this thesis utilises an exploratory and predictive approach, the suggestion that the most appropriate sampling frame be criterion-based will be taken. This discussion will now consider the evidence that relates to the long-term mentally ill as respondents.

5. The long-term mentally ill as respondents

This section considers the characteristics of long-term mental illness in terms of clinical symptoms, the effects of medication and chronicity, and how such factors relate to the reliability and validity of responses made by people with a long-term mental illness to questionnaires and interviews.

As outlined earlier, it is unrealistic to expect that interview or questionnaire data will be completely reliable, regardless of the population sampled. Even among non-psychiatric medical patients there are data errors from a variety of sources (DiMatteo and Friedman, 1982). Furthermore, Cannell et al., (1977) found discrepancies when comparing medical patient responses with their written medical records. Hospital episodes, doctor visits, and number of medical conditions were under-reported. Thus, researchers should normally expect some respondent-generated error to be present in self-report data. However, when interviewing a person with a mental illness there may be additional error due to the nature of the factors outlined in Chapter 1. For example, the effects of institutionalisation and cognitive deficits. In view of this point, the focus of this discussion will now be on how

symptoms of mental illness may impact the research process when interview data are collected directly from an individual who has a long-term mental illness.

Chapter 1 argued a) that there is a danger of oversimplifying a heterogeneous assortment of characteristics of the mentally ill into an appearance of homogeneity; b) it is important to understand that considerable behavioural and symptomatic heterogeneity exists even within a diagnostic category; and c) that different levels of functioning contribute to diversity among the mentally ill, just as within a general population. Having taken these factors into account this thesis needs to be aware of how various symptoms associated with long-term mental illness can impact on data gathering. For example, Cameron (1987) has shown that depressive symptoms are associated with schizophrenia. Therefore, the researcher needs to be aware of how depressive symptoms can influence data gathering. Common symptoms of depression include: depressed mood, but not always sadness; loss of interest; anxiety; psychomotor retardation; and lack of energy (Hamilton, 1986). There is often a change in cognitive functioning, memory loss, feelings of guilt, helplessness, and hopelessness (Williams, 1984). Thus, two considerations are important with the long-term mentally ill a) it may be difficult to motivate the person who has depressive symptoms to participate in a study; and b) more time and assistance may be required to complete an interview or questionnaire than would normally be the case.

The decision about interviewing a person with a psychotic illness for the purpose of this thesis is formidable. ICD-10 (1992) characterises the psychoses as any major mental disorder of organic or emotional origin marked by derangement of personality and loss of contact with reality, often with delusions, hallucinations, or illusions. Furthermore, schizophrenia, paranoid disorder, bipolar disorder (manic-depressive illness), and some major depressions are psychotic illnesses. A brief overview of the more typical psychotic symptoms likely to interfere with the research process will be made. Birchwood, Hallett and Preston (1988) and David and Cutting (1994) should be consulted for more complete descriptions. Difficulties include: a poor ability to establish rapport; fearfulness; super-sensitivity, particularly responsive to non-verbal cues; poor social skills; a low level of social functioning, for example, making it difficult for participants to keep appointments for

a study; the denial of the existence of any mental illness; delusions; thought disorder e.g., meaning that the respondent may difficulty interpreting abstract ideas, long sentences, or colloquialisms; dis-connectedness; neologisms; poverty of speech and/or speech content; incoherence and illogicality; effects of medication. Further difficulties include socio-demographic data and the observation that people with a major psychosis sometimes suffer time and age distortions (Crow, 1990) as well as a limited attention span along with either listlessness or restlessness (Birchwood et al., 1989). Each of these points has clear ramifications during interviews with questions that have a temporal reference. One type of ramification is the 'deviance response tendency' noted by Nunnally (1978), whereby a respondent makes an uncommon response to closed-ended questions. In this instance, uncommon responses may be indicative of particular personality traits; illness or random. The net result may be bizarre answers to questions. What is important to note is that such responses may not be a function of the assessment instrument and cannot be eliminated by revising the instrument. In this sense, if data gathering includes questions that require an open-ended or closed-ended response, it may be more difficult to judge whether a response is the result of either poor education or a different but essentially rational way of viewing the world, or whether the response is truly bizarre.

The previous discussion implies that data gathered from some mentally ill persons may have problematic reliability and/or validity, not because of weaknesses inherent in the instrument but because of characteristics of the respondents themselves. Several examples in the literature support this view. For instance, Spitzer et al., (1975) suggest that psychiatric patient variation over time accounts for some of the unreliability in psychiatric diagnosis. These authors suggest that one explanation for test-retest reliability being low, is that it indicates that subjects may be providing very inconsistent information between assessments. In relation to the validity of patient's self-report of symptoms, Chesney et al.,(1981) found that psychotic patents generally tended to under-report symptoms when compared to the physician ratings, whereas neurotic patients tended to over-report. Furthermore, McEvoy et al., (1983) assessed the accuracy of eight validity questions asked during interviews in a study of 23 chronically institutionalised subjects all of whom were taking medication with diagnoses of schizophrenia. McEvoy et al., (1983) found the

overall rate of inaccurate responses to be approximately 32%. Furthermore, Dworkin (1990) provide an example of data accuracy drawn from a study of 100 outpatients attending two community mental health centres. Sampled patients were previously diagnosed with either a subtype of schizophrenia or a major mood disorder. All had been in treatment at least two years prior to sampling. Thus all can be said to have a diagnosis of long-term mental illness. Data was collected from patients and patient's records. When asked "What is your diagnosis? That is, what does your doctor say is your problem?", only 8% of the responses matched exactly the diagnosis recorded in case-notes. Approximately 18% gave vague responses acknowledging a mental illness (e.g., nervous breakdown). Generally, patients with a diagnosis of a mood disorder more often than not named a diagnosis compatible with their case-notes than did patients with a diagnosis of schizophrenia.

Conclusions.

The intention of this chapter has been to provide a description of assessment procedures in the measurement of long-term mentally ill research. This has included reviews of which main variables have been used in mental illness research; a review of the way instruments should be designed for data collection, and the importance of defining key variables. In relation to methodological considerations reviewed it might seem reasonable to expect that the nature of long-term mental illnesses may account for the possibility of low test-retest reliabilities in the development of an instrument to assess self-reported need. Clearly, there are potential methodological problems with only having accounts from people who have long-term mental illness. What will have to be taken into account, from a methodological stance, is that it will be preferable to measure directly the behaviour of people with a long-term mental illness in terms of 'need' from two different perspectives. This should include the administration of some indicator of mental state and social and behavioural functioning. Such measures can be used to ascertain the likelihood of collecting valid data, and may also be useful as exploratory or predictive variables. In to further develop these issues Chapter 4 sets out the objectives of this thesis and how they will be pursued.

Chapter 4. Objective, conceptual approach and methodology.

Chapter overview

Conceptual approach

The conceptual approach to a self-report assessment of need in long-term mental illness is based upon Wing's (1989) concept of social disablement.

Methodology

The basic methodology includes a) the use of key-worker needs data to help verify the reliability and validity of client needs data; and b) the use of measures of client mental state to help examine factors related to the validity of self-report need measures.

Participants: include a) long-term psychiatric cases of 18 years or over (apart from people suffering from severe mental retardation, those addicted to drugs and alcohol, and those afflicted by dementia) in continued receipt of professional mental health services either in a psychiatric hospital or in the community; and b) mental health professionals who are designated as key-workers to those clients involved in the study.

Design: The design is a survey design with repeated measures. Stage 1 represents the piloting of client and key-worker assessment of need schedules. Stage 2 represents refinement of the instruments based on the results of Stage 1. Stage 3 represents an examination of the validity of client's self-reported need.

Methods of assessment: 1) a client self-report assessment of need schedule; 2) a staff perception of client need schedule; 3) the REHAB (Baker and Hall, 1983) and 4) the Brief Psychiatric Rating Scale (Overall and Gorham, 1962).

Procedure: Completion of client and staff schedules involving separate interviews.

Introduction.

The objective of this thesis is to find out whether or not people with a long-term mental illness can reliably and validly report their own needs. In essence, the basic methodology includes a) the use of key-worker needs data to help verify the reliability and validity of client needs data; and b) the use of measures of client mental state to help examine factors related to the validity of self-report need measures. This is set against a background where previous chapters have highlighted

a) the considerable importance attached to the development of a self-report needs-assessment schedule appropriate to people with a long-term mental illness;
b) limited research into a self-reported assessment of need;
c) potential conceptual and methodological challenges confronting the assessment of self-reported need; and
d) the situation where self-reported assessments of need lack an empirical base.

In order to address these substantive issues the present chapter builds on the preceding three chapters by introducing a conceptual approach to a self-report assessment of need in long-term mental illness. Details are then presented in relation to the methodology used, that is, sample selection; study design; methods of assessment, including a description of the construction of the self-report assessment of need schedule; an outline of the procedure; and a statement of the questions addressed by this thesis.

Conceptual approach.

Doyal and Gough (1984) suggest that there will probably always be a debate over how best to conceptualise needs. Liss (1993) suggests that health care need is but one type of need and that it is not necessarily established or defined by what is supplied or by expert judgement. He goes on to say that since needs-assessment is a question of evaluation, and since the ultimate purpose of work towards the achievement of the 'technical state' of health is human happiness, then it is essential to involve the subjects of health care interventions in the assessment of needs, since only they can judge what makes them happy. However, this proposition does not take into account the fact that people can be wrong in their

judgements in terms of what would make them happy or the fact that in psychiatry there is a wider social role which may mean balancing the needs of patients against those of society.

In view of these points, the conceptual model proposed in this thesis is based upon Wing's (1989) concept of 'social disablement' as a functional indicator of need and Ford, et al's (1992) efforts to assess needs on the basis of the following three factors. Firstly, the ability or competence of individuals to perform a task, that is, to go about things as ordinary people do. Secondly, the relevance of doing a skill or ability for doing the skill. Thirdly, the individual's motivation to do the task. The advantage of this conceptual approach to assessing need is that it is becomes possible to compare for example, the self-reported need of people with a long-term mental illness with need perceived by a member of mental health services staff, for example a key-worker. This approach offers the potential to distinguish an assessment of need which is measured in terms of lowered physical, psychological and social functioning compared with what would normally be expected in society. That is, how far is a given individual who has a long-term mental illness able to function normally and to carry on typical daily activities? Therefore, for the purpose of this thesis items of individual need refer to "...departures from normal functioning because, in the field of health especially, it is easier to obtain, record, and provide some measure of departure from the norm than it is to specify the norm itself" (Kaplan et al., 1976). By researching needs-assessment in this way it is possible to explore and advance the development of a standardised approach to needs-assessment both at the level of individually self-reported need and at the level of perceived need from someone who knows the person with a long-term mental illness well e.g., a mental health professional.

Such an approach has the benefit of including a definition of unmet need in the sense that:

a) the concept of need involves:
    i) a perception of what is,
    ii) a comparison level, i.e., what should be, and
    iii) an evaluation of the extent and saliency of the discrepancy between what is and what should be;
b) the recognition of different perspectives e.g., patients with a long-term mental illness and related professionals; and
c) insight into solutions viewed as capable of reducing the gap between what actually exists and what is deemed desirable or necessary from different perspectives.

This conceptual approach it is argued, embraces a means of researching the assessment of need which can be allied to the policy notion of ordinary and independent living for people with a long-term mental illness and the levels of help or support they require. In this sense, the research can be designed to focus on the assumed patterns of need associated with daily living in a population of people with a long-term mental illness. In order to provide a useful advance on the conceptual approach just outlined the next section describes the methodological approach used in this thesis in order to research a self-report assessment of need.

Choosing a methodological approach to a self-report assessment of need.

A review of the literature presented in Chapters 1, 2 and 3 suggests firstly, that giving weight to clients' own accounts of their needs is questionable; secondly, that few studies have developed or adapted a client-centred approach to needs-assessment which take the self-reports of people with a long-term mental illness as their basis; and thirdly, that if the assessment of need cannot be value free, and value judgements are considered central to the perception of needs-assessment, then the value judgements involved should be made explicit. This leads to the question for this thesis of choosing a methodology which might

help inform firstly, the development of a reliable self-report assessment of need schedule, and secondly, the development of a methodology which might help inform the validity of such a schedule. This would suggest the necessity for a) exploring the reliability or temporal stability of a needs-assessment over time and b) comparing the self-reported needs of a person with a long-term mental illness with the assessments of those needs by a mental health professional who knows them well. Such a methodology has considerable support within the literature (Cook and Campbell, 1979; McKillip 1987). However, a major drawback to using such an approach is that different types of measures have the potential to produce different types of error in measurement (Peck and Shapiro, 1990). Clearly, before it is possible to determine what those different types of error might be it is necessary to establish that the schedules developed to assess self-reported need and needs perceived by key-workers are reliable, that is, that the instruments are assessing need with an appropriate measure of consistency over time. In order to pursue these various objectives a description of study participants, study design, methods of assessment and procedure to be used is given next.

Participants.

Chapter 1 suggested that the majority of people who have a long-term mental illness have a diagnosis of schizophrenia (Ciompi, 1980). The important point for the purpose of this thesis is that characteristics of long-term mental illness should be measurable in terms of a self-report assessment of need. On the one hand single characterisations (e.g., duration) are attractive because of their parsimony, and on the other, more discriminating characteristics (e.g., the type and intensity of symptoms; the length-of-time known to services) have the potential for greater descriptive and explanatory power. Therefore, in terms of sampling, the strategy used in this thesis was to include all adults who were long-term psychiatric cases of 18 years or over (apart from people suffering from severe mental retardation, those addicted to drugs and alcohol, and those afflicted by dementia) and in continued receipt of professional mental health services either in a psychiatric hospital or in the community. Being a case was further defined as having been hospitalised for a period greater than one year; having a diagnosed serious mental illness; thought by key-workers to be likely to have great difficulty in looking after themselves if they were not in receipt of professional mental

health services support; and be capable of responding to a self-report assessment of need schedule. A disadvantage of this sampling procedure is that it emphasises people with a long-term mental illness who have 'stable' needs and it excludes those who might be in 'more need' i.e., have 'less' stable needs. These might be people who are too unwell psychiatrically, or people for whom it is difficult for the services to engage let alone researchers independent of the services. Such patients might represent a different population and therefore require a different approach to the methodology proposed here.

In summary, participants in this thesis consist of mental health professionals who were either community or hospital-based qualified staff designated as 'key-workers'. The sample of people with a long-term mental illness are or were formerly residents of psychiatric institutions. Those who were formerly residents are those individuals in a variety of residential settings e.g., supported housing schemes. The best way to describe the selection of the client sample is as a 'purposive sample' (Kidder and Judd, 1986). The assumption behind purposive sampling is that participants are judged to be typical of the population in which one is interested in, assuming that errors of judgement in the selection will tend to counterbalance each other. Details of how participants were selected and their numbers are presented in Chapters 5, 6 and 7.

Design

In order to meet the objective of the thesis the approach is split into three stages. In essence, Stage 1 represents the piloting of client and key-worker assessment of need schedules. Stage 2 represents refinement of the instruments based on the results of Stage 1. Stage 3 represents an examination of the validity of client's self-reported need.

Stage 1

The pilot study can best be described as a survey design with repeated measures (Breakwell et al., 1995). In this sense, the stage has a within-subjects design, which involves a comparison of an assessment of need between two different administrations separated by time. Naturally, the question of how many and how often assessments should be carried out to reflect need accurately had to be addressed. Taking a lead from Kidder and Judd

1986), three factors were considered in order to arrive at a decision. The first factor concerned knowing how many needs someone might have and whether or not those needs were 'stable' over time. The second factor concerned the possibility of finding that a simple empirical approach which yields results that are stable across two occasions spaced over a reasonable time period begs the question of whether or not there would be any value in continuing to repeat assessments. The third factor was simply practical in nature and concerned the fact that the number of assessments is often limited by the available number of researchers and time. As Kidder and Judd (1986) have noted, in practice, available resources are usually the limiting factor which forces a compromise between what the researcher would like to do and what is feasible. In view of these points it was decided that two assessments of need, from both client and key-worker perspectives, at approximately one month apart would be carried out.

Stage 2

Stage 2 represents refinement of the client self-report and key-worker instruments. As with Stage 1, Stage 2 consists of a within-subjects repeated measures design.

Stage 3

Stage 3 utilises a between-subjects design. The reason behind this form of design is, having once established the reliability of the need measures, it is then possible to make a comparison between self-report assessments of need and perceived need by key-workers for the purpose of establishing validity. In essence, key-worker needs data can be used to help verify the validity of client needs data. The justification for using this approach is that it is assumed that mental health professionals have the more accurate information concerning client need. Beyond this the aim has been to use measures of client mental state to help examine factors related to the validity of self-report need measures.

Procedure

In terms of recruitment all cases fulfilling the study's inclusion criteria were eligible. The initial strategy was to draw up a list of patients fulfilling the inclusion criteria by going to the local psychiatric hospital long-stay/rehabilitation wards and local CMHTs and asking ward managers and CMHT managers respectively to nominate individual key-workers and their patients for inclusion in the study within one month. This approach to recruitment was due to resource and time constraints. Although a sample was identified following professional nomination and screening to check eligibility criteria the approach did present a certain drawback i.e., the method tended to emphasise those with more serious mental illness who had 'stable' needs and, in whom psychiatric symptomatology was settled. Beyond this, the procedure was to contact key-workers and clients prior to the initial assessment and to ask if they would be willing to participate. A brief description of the research project was given and a time set to complete the instruments. Completion of key-worker and client schedules involved separate interviews on the same day in most cases by the same researcher. With clients, a psychiatric interview was conducted first, followed by the self-report assessment of need. Ratings on the BPRS were completed immediately after each interview in the absence of the patient. The REHAB and the key-worker perspective of client need was completed thereafter.

Methods of assessment.

This section consists of three parts. Part 1 introduces a detailed description of the development of a new schedule to assess self-reported need. Part 2 introduces an instrument to assess the levels of client dependency. Part 3 describes an instrument to assess client mental state.

Part 1: A new schedule to assess need.

There is much research to guide and recommend decisions about questionnaire design (e.g., Kidder and Judd, 1986; McDowell and Newell, 1987; Pedhazur and Schmelkin, 1991; Streiner and Norman, 1991). Briefly, the researcher is alerted to the following guidelines in relation to question content, wording and format. In terms of content, a primary

objective is the need to achieve a clear idea of what content is to be measured. In this sense, specific items need to take their lead from the literature, be expanded upon and added to as issues become apparent. Issues might include questions being too complex, socially undesirable, and analysis for reliability and validity. In relation to question wording, items should reflect conceptual clarity and necessitate a process of pre-test and revision. Finally, question format should ideally use closed-ended questions with open-ended questions to illustrate reasons for responses. At a more general level, it is recommended that the construction of a questionnaire includes a) asking respondents for comments item by item in relation to question wording, comprehension, question sequence, and administration and use of scales; and b) consideration of the number of questions asked, the time taken and the degree of detail required. In addition, it is suggested that drafts be pre-tested with a sample similar to the final target population and circulated amongst professionals for comment. In order to develop these points Part 1 of the 'Methods of Assessment' consists of two sub-sections: a) item selection, and b) principle, design and content of the new schedule.

Item selection.

The initial stages of this thesis began in the latter part of 1992. At that point no research instruments could be found which catered adequately for a self-report assessment of need in long-term mental illness. The aim therefore was to set about developing and piloting a new instrument in order to explore the needs of people with a long-term mental illness in a self-report situation. To do this, thirty-two need items were chosen which, according to a review of the mental health literature, appeared to reflect the needs of people with a long-term mental illness. In this section we look at the rationale for choosing the need items included in the new schedule. The reasons for doing this are to provide some independent evidence in support of item inclusion and also to establish a set of need items which might be considered as 'reasonably comprehensive' based on the mental health literature. Similarly we need to use the approach in an attempt to establish the reliability of the new schedule. The process of item selection was based on several sources: the Quality of Life literature; social and behavioural functioning literature and the assessment of need

literature. Samples from each of the sources is now reviewed in terms of item content and format. A final list of items for the new schedule is then presented.

Quality of Life

Lehman (1983; 1986) is one of the most widely used Quality of Life scales in mental health research in the USA. Interestingly, Lehman's approach to assessing Quality of Life is limited to the self-report of the person with a mental illness. Lehman's schedule assesses the life circumstances of people with long-term mental illness in terms of activities, experiences and feelings. Assessment includes eight life domains based on literature reviews: living situation, family relations, social relations, leisure, work, finances, safety and health. Lehman argues that the approach is justified in that, while different perspectives about Quality of Life may conflict, there is no evidence that the perspective of a person with a mental illness is invalid. Several authors have adapted the work of Lehman and his colleagues (e.g., Oliver, 1991; Crosby et al., 1993). By way of example, Crosby (1993) used Lehman's eight life domains in order to assess Quality of Life among long-term psychiatric patients being resettled into the community. The approach includes open and closed-ended response formats in order to assess self-report measures of life satisfaction and some objective measures with staff. Table 4.1 presents two items from Crosby et al., (1993).

Table 4.1. Quality of Life (Crosby et al., 1993).

Living situation	
Do you feel you belong here?	0 - No 1 - Yes 99 - Don't know/know response
Finances	
a) Do you manage your own money?	0 - No 1 - Yes 99 - Don't know/No response
b) How do you feel about the amount of money you have?	Very dissatisfied ---------- Very satisfied

Social and behavioural functioning

Several authors (e.g., McDowell and Newell, 1986; Peck and Shapiro, 1990) review scales that measure social and behavioural functioning of psychiatric patients in detail. Two points to emerge from these reviews include firstly, the observation that the presence of psychiatric symptoms is associated with impaired social functioning; and secondly, there are problems with defining optimal social and behavioural functioning. This is because of the issue of value judgements. For example, examination of mental state usually describes an expert judgement of the current state of the patient. The point is that although value judgements come into the assessment of mental illness, they are trickier in the assessment of social and behavioural functioning. In this sense, the measurement of social and behavioural function requires a different approach, for example, when a person with a mental illness feels they can cope and are coping well but someone close, for example, a member of staff, insists that they are not coping, which one is the more valid? Clearly, the choice of information has the potential to complicate the issue. One of the difficulties is that expectations about an individual's level of functioning can vary, and there is no absolute standard against which to judge performance, that is, it is difficult to prescribe normal behaviour. Therefore, it is important that measurement takes into account whether or not the individual wishes to perform up to a particular level. In order to address this issue, and in terms of methodology, McDowell and Newell (1986) and Peck and Shapiro (1990) point out that the measurement of social functioning usually includes the use of questionnaires and interview schedules, many of which are subject-completed. In this sense, the choice of scale depends on the aim of the measurement. Furthermore, many of the scales are predicated on the assumption that people with a mental illness have the same perception of social adjustment as staff. Such scales invariably relate to: employment, household tasks, money management, self-care, relationships, leisure activities and social networks. The form and content of two such scales used to assess functioning will now be presented, these include: the 'Social Functioning Schedule' (Remington and Tyrer, 1979) and 'The Task Motivation and Appraisal Schedule' (MacCarthy et al., 1986).

The 'Social Functioning Schedule' (Remington and Tyrer, 1979) is semi-structured interview where the interviewer summarises the patient's reports on a 10cm visual analogue

scale. Each item ranges from 'No difficulties in functioning' at one end to 'Severe difficulties in functioning' at the other. Ratings are based on the past four-weeks. The schedule includes sections related to employment, household chores, contribution to household, money, self care, marital relationships, social contacts, hobbies and spare time activities. Table 4.2 provides one example from the schedule which relates to 'Household chores':

Table 4.2. Item from The Social Functioning Schedule (Remington and Tyrer, 1979).

2. Household chores.

Now I would like to discuss household chores - cooking, shopping, the washing, cleaning, gardening, decorating, household repairs and so on. What household jobs do you usually do? (Give details).

Where necessary: does this mean you do something in the house every week? (Y/N).

2(a). Have you had any difficulties in managing the chores over the last month? Have you found that you cannot do as much as usual, or that others have had to take over/have you found it difficult to get things done? Have you been slow at doing things? Have you felt that you have done jobs well on the whole?

Rate problems with chores: Behaviour

None _____ Severe difficulties.

2(b). How do you feel about the chores? Have you found managing the chores a strain? Do the chores get you down or irritate you?

None _____ Severe difficulties.

MacCarthy et al., (1986) point out areas that many people with a long-term mental illness have problems with, these include: mixing with people; staying awake at night; staying in bed during the day; feeling low; neglect of appearance; not eating properly; taking longer than usual to do things e.g., jobs around the house; difficulty concentrating; difficulty shopping, making a meal, going to a cafe, household chores, using public transport, reading and writing, managing money, and finding work/occupation. Table 4.3 presents examples from the Camberwell High Contact Study (MacCarthy et al., 1986).

Table 4.3. Camberwell High Contact Study (MacCarthy et al., 1986).

What do you find most difficult or distressing in your life? Probe: What do you find most difficult to cope with?	
Have you ever tried anything that did seem to work, that is, make the problem go away or make you feel much better?	0 - No 1 - Yes
Do you sometimes neglect your appearance e.g., not change your clothes, not bother to shave or wash, comb your hair etc.	0 - No 1 – Yes
Have you been shopping on your own in the last year?	0 - No 1 – Yes
Have you been managing your personal money matters such as setting aside the amount of money you can spend each day, on your own, within the last year?	0 - No 1 – Yes

The assessment of need.

Measures of Quality of Life and functioning provide useful information on the adequacy of performance and satisfaction with various aspects of life. The limitation of such measures is that they do not provide an explicit self-report measure of need. One starting point for the measurement of need in long-term mental illness concerns the observation that the most basic human needs become an issue when the focus is on people who have difficulty getting such necessities for themselves (Doyal and Gough, 1984). For example, from a psychiatric rehabilitation perspective, arrangements for shopping can be complex (Watts and Bennett, 1991). A reasonably comprehensive approach to the assessment of need therefore requires a 'check' to see if 'basic' human needs are evident and being met. At the time the present schedule was under development two needs-assessment schedules could be identified. These were the 'Multifunction Needs-assessment Form (MFNA)' (Dellario et al., 1983) and the 'MRC Needs for Care Assessment' (Brewin and Wing, 1989).

The Multifunction Needs-assessment Form (MFNA) is made up of items related to self-care, mobility, household, personal appearance, community living, psychological functioning, work/school, family, social functioning, and leisure. Assessments are based on 'client observations' by professional members of the clinical treatment team in the main. Furthermore, assessments are based on the clients' typical functioning during the previous month, rather than specific functioning on the day of the assessment. The MFNA is able to

elicit practitioner-rated items and corresponding client self-report items. A sample item is illustrated in Table 4.4.

Table 4.4. The 'Multifunction Needs-assessment Form' (Dellario et al., 1983). Personal Appearance Item: Practitioner Assessment and Client Self-Report.

Practitioner Item	
With what type of assistance does this person currently perform all aspects of the maintenance of his/her appearance, including, but not limited to, cleanliness of hair, teeth, fingernails? Is the person able to maintain adequate and appropriate dress?	1. No assistance 2. Prompting/structuring 3. Supervision 4. Some direct assistance 5. Total assistance
Client item	
I can maintain a neat and appropriate personal appearance.	1. Without any assistance. 2. With little assistance 3. With a lot of assistance.

The content of the MRC Needs for Care Assessment (Brewin and Wing, 1989) is divided into two broad sections: clinical state (covering nine areas of functioning) and social role performance (covering basic skills and functional abilities regarded as necessary to live independently in society, for example, self-care skills, education, occupation, communication, money and household management). Table 4.5 presents a sample item from the MRC Needs for Care Assessment.

Table 4.5. The MRC Needs for Care Assessment (Brewin and Wing, 1989).

MRC NFCA Item.

Get meals (cook or buy them).

Rate LEVEL OF FUNCTIONING

....

Rate ITEM OF CARE if LEVEL OF FUNCTIONING = 1, 2. 3, 8

Assessment ....
Remedial training ....
Sheltered residence ....
Other (specify) ....

Rate PRIMARY NEED STATUS

Rate POSSIBLE NEED (LACK OF PERFORMANCE)

Rate OVER PROVISION (State item of care .....)

Rate FUTURE NEED (State item of care)

RATE LEVEL of FUNCTIONING as follows:

0 = Competence plus performance (skill demonstrated without prompting in past month)
1 = Currently shows competence plus performance but significant problem in recent past (usually within past 2 years) AND/OR threat of a significant problem
2 = Lack of competence (usually no evidence of skill at any time in the past year)
3 = Lack of performance (skill performed competently during past year, but not, or only with prompting, during the past month)
8 = Insufficient information to make a judgement
9 = Not applicable

Rate PRIMARY NEED STATUS

0 = No need
1 = Met need
2 = Unmet need (assessment)
3 = Unmet need (treatment)
4 = No meetable need
5 = Not applicable

Since the development of the instrument presented in this thesis two further needs-assessment tools have appeared in the literature. Namely the Camberwell Assessment of Need (The CAN) (Phelan et al., 1995) and the Cardinal Needs Schedule (Marshall et al., 1995). The CAN presents a method of assessing self-reported need for people with a severe mental illness. The instrument contains 22 items of need. These include items in

relation to: accommodation, food, looking after home, self-care, daytime activities, physical health, psychotic symptoms, information about condition and treatment, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, childcare, basic education, telephone, transport, money and benefits. Table 4.6 provides and example item and response format from the CAN.

Table 4.6. The Camberwell Assessment of Need (Phelan et al., 1995)

Does the person lack a current place to live? What kind of place do you live in? What sort of place is it?
0 = No Problem e.g., person does have an adequate home (even if in hospital currently).
1 = No/moderate problem because of continuing intervention e.g., Person is living in sheltered accommodation or hostel
2 = Serious problem e.g., Person is homeless, precariously housed, or home lacks basic facilities such as water and electricity.
If rated 0 or 9 go to question 2.

The Cardinal Needs Schedule (CNS) (Marshall et al., 1995) uses a semi-structured interview to elicit the views of patients – the Client Opinion Survey (COI). The COI determines for patients, their attitudes towards receiving help in a number of problem areas e.g., domestic skills, money; whether they wish to change their accommodation; and whether they are distressed by any current physical problem. Responses are coded numerically. Marshall et al., say that COI ratings of need take a systematic account of the views of patients. The COI approach tells the instructor *"... to begin the COI by explaining to the client that the interview concerns their views about what sort of help they require. You should first ask the client if there are any types of help which they need at present but are not receiving. You should record these needs in the space below. You should then explain to the client that you are now going to ask some questions about whether they would like certain particular types of help"*. Examples from the ten COI domains include: 1. General Question: *'How do you feel about your day-to-day life at the moment?'* Details are recorded by the questioner and ratings made on a Likert-type scale ranging from 1 = 'Bad' to 5 = 'Good'; with provision for 8 = 'Not known' or 9 = 'Not applicable'. A further example is '2. Accommodation'. Here the questioner asks *'How do you feel about where*

you are living at the moment?' Details are recorded by the questioner if the respondent wants to move. Further questions relating to 'Accommodation' include *'What sort of place would you like to move to?'* Ratings are made on a categorical scale in the form of '1 = Will move'; 2 = Will not move'; '8 = Not known'; and '9 = Not applicable'.

In conclusion, a number of problems are apparent with the instruments described which pre-date the development of the schedule developed for the purpose of this thesis. These include the observation that the SFS and Quality of Life (Crosby et al., 1993) do not indicate an explicit statement of need nor do they indicate the level of social support available to the patient, nor do they cover positive levels of functioning. Furthermore, the SFS has the potential for interviewer bias in translating responses into visual analogue scales. This difficulty is also a criticism of the approach to assessing need adopted by Brewin et al., (1987). Although, as Brewin and Wing (1989) say, the adoption of a normative approach is due to the uncertainty that all patients can equally express their needs. MacCarthy et al., (1986) offer an approach which includes the self-report of psychiatric patients in relation to what they might need, however it does not readily translate into an assessment of self-reported need, nor whether or not the need is being met, nor the type and levels of support required. On a more positive note some evidence exists which supports the assertion that people with a long-term mental illness can provide reasonably reliable information in response to questionnaires (Lehman, 1983; MacCarthy et al., 1986). However, as Lehman says, it is important to control for mental health effects on the Quality of Life data, especially anxiety and depression.

Principle, design and content of the new instrument.

The aim has been to set about developing and testing a new instrument where the object of the assessment is to examine the ability of people with a long-term mental illness to self-report need. In this sense, assessment means becoming aware of and understanding the needs a person with a long-term mental illness expresses, that is, establishing a client's self-reported need status. Naturally, such a development raises several issues: namely, what principle might underpin the development of such an instrument; what should the content

of an assessment of self-reported need include; and finally what should the format of a self-report assessment of need take?

The principle

The principle underlying the proposed self-report assessment of need schedule is allied to the policy notion of ordinary and independent living in the community for people with a long-term mental illness and the levels of help or support they require. The assumption is that most items in the new schedule refer to departures from normal functioning (see earlier). The principle, therefore, has been to focus on items of need which are considered important from the perspective of an individual with a long-term mental illness, and the professional mental health care perspective. This is because, as previous chapters have identified, people with a long-term mental illness have needs that are not only specific but also complex. Furthermore, such needs may be unrecognised by people with a long-term mental illness themselves as well as mental health professionals. In this sense, the approach to needs-assessment should be easily learned and 'user-friendly' from both patient and staff perspectives, particularly as this thesis is attempting to assess 'need' which is not defined by staff alone. In order to address this issue the initial approach to 'assessing need' is based on a subjective concept of 'need'. The advantage here is the potential to explore needs from differing perspectives. A disadvantage is potential for differing perspectives concerning the presence or absence of specific need. On this basis, and in order that a new instrument might be developed, careful attention has been given to the construction of the new schedule and the assessment process.

Content

In order that a reasonably comprehensive list of need items might be included in a self-report need schedule, a review of the mental health literature (PschLIT; MEDLINE; McDowell and Newell, 1987; Peck and Shapiro, 1990) shows that there are a large number of scales relating to social and behavioural functioning, user's attitudes, and Quality of Life. What is interesting is that the measurement of self-reported need in long-term mental illness has scarcely been documented i.e., a total of only three published academic articles (Dellario et al., 1983; Lynch and Kruzich, 1986; Lord, Schnarr and Hutchison, 1987) could

be found when the descriptors 'Need-Assessment-Mental-Illness-Psychiatric' were used at the outset of this thesis.

In view of what has been said so far, the content of the new schedule has taken its lead from an examination of the assessment of need literature, Quality of life literature and social functioning literature reviewed above. In addition to this source, items have been arrived at via discussion and consensus with experienced professionals in the mental health field, that is locally-based academics, health and social services personnel, personal consultation with representatives of MIND; and local mental health user groups. These various individuals were met informally and were asked to consider what might be the 'best' areas to consider in a needs-assessment and what might be the 'best' way of presenting such items. To this extent the initial version of the new schedule had eleven sections which contained 32 need items in total with provision for 'Other needs not mentioned' and a facility to rank the three most important needs. In short, items were chosen to reflect important aspects of need from a mental health key-worker perspective as well as a self-report persepective. Table 4.7 provides a list of need sections and need items assessed.

Table 4.7. Need sections and need items assessed.

1. Help with shopping
1. Help with cooking
2. Help with cleaning
4. Help with bathing
5. Help with washing self
6. Help with dressing self
7. Help with toileting
8. Help with getting up in the morning
9. Help with managing money
10. Help with using a telephone
11. Help with post
12. Help with getting out-and-about
13. Help with occupation
14. Type of accommodation
15. Help with a sense of belong
16. Help with feeling safe
17. Help with feeling accepted by the local community
18. Help with filling spare time
19. Help dealing with family difficulties
20. Needing more contact with people
21. Needing a club/centre/befriending service
22. Help with thoughts, feelings and behaviours
23. Help with protection from self
24. Help with medication
25. Needing someone who is skilled in talking to people about the way they might think, feel and behave
26. Help with motivation
27. Difficulties contacting mental health services
28. Needing a care plan
29. Needing help from the mental health services to cope with life
30. Advocacy
31. Help with physical difficulties
32. Help in the home
33. Other Needs
34 Ranking the three most important needs

Construction and mode of data collection

In relation to the construction and mode of data collection the methodology is to all intent and purpose a checklist of self-reported need. The justification for adopting this approach is that many assessments of this nature exist in the mental health and psychological literature (Streiner and Norman, 1991; Kline, 1993). In order to address this issue, the items included in the new self-report assessment of need schedule are typical of items used in the evaluation and study of, for example, Quality of Life and functioning in long-term mental illness. It has therefore been assumed that by providing a checklist of 'need items' it is possible to examine the reliability and validity of client self- reported need in an

assessment situation. Furthermore, comparison with the approaches to an assessment of need developed latterly by Marshall et al., (1995) and Phelan et al., (1995) would support this. To this end, the new schedule consists of a semi-structured questionnaire by personal interview which is intended to give a brief and simple indication of the self-reported need of people with a long-term mental illness. However, as previous chapters have indicated, getting a reliable and valid response in terms of needs is potentially the most difficult part of interviewing this population. This is what the present thesis sets out to explore. Importantly, this is examined by comparing measures of client self-reported need with those of key-workers. In order that this latter point might be achieved, and in recognition that the adoption of a normative approach to the assessment of need in mental illness is due to the uncertainty that all patients can equally express their needs, the instrument developed for key-workers is the same as that used with their clients.

Respondent instructions and response format for the new instrument

Prior to assessing need the following is said to the key-worker:

> *"The idea is for me to ask you a few questions to try and find out what you feel the needs are of the person you support; how important you feel those needs are for the person you support, and whether or not those needs are being met. I would like you to think about the person's situation over the last month. For example, if I ask you does the person you support need help with their shopping and you say "NO" then this means they can go about things independently of any help or support and in an 'ordinary' way. If you say "Yes", then perhaps you could tell me why it is you think help or support is needed. There are no right or wrong answers. Please remember it is important to think of the needs of the person you support in terms of the way you see the normal, independent everyday living of people at large".*

Prior to assessing need the client the following is said:

> *"The idea is for me to ask you a few questions to try and find out what you feel your needs are; how important you feel those needs are, and whether or not you feel those needs are being met. I would like you to think about your situation over the past month. For example, if I ask you if you need help with your shopping and you say "NO" then this means that you do it independently of any help or support. If you say "Yes", then perhaps you could tell me why it is you need help or support. There are no right or wrong answers".*

The items of need within each section have a standard format and follow the same basic structure for both key-worker and client instruments. The first part of each item asks for factual information, for example, from the key-worker perspective: 'Does ... need help with shopping?' and from a client perspective: 'Do you need help with your shopping?' Responses are rated categorically:

0 = No need present
1 = Need present
2 = Uncertain.

Need is scored:

a) present when an item falls below that which the person with a long-term mental illness or staff perceive to be normal or ordinary functioning; and
b) absent when a person with a long-term mental illness or staff perceives normal and independent functioning.

The second part of the assessment proceeds to find out qualitatively why help is needed. The third section asks respondents to rate the importance of a need.

Responses are rated on a five-point scale:

1 = Totally Unimportant
2 = Quite Unimportant
3 = Uncertain
4 = Quite Important
5 = Very Important.

The fourth section asks respondents to rate whether or not an identified need is being met. Responses are rated on a seven-point scale:

1 = Totally unmet
2 = Mostly unmet
3 = Partly unmet
4 = Uncertain
5 = Partly met
6 = Mostly met
7 = Totally met.

The fifth section asks respondents to categorise who meets the need or if unmet who should meet the need. Responses are coded as:

1 = Informal Carer
2 = Formal carer
3 = Other. Specify: ...
4 = Don't know.

Questions 22, 23, 25, 26, 29, 31 and 32 have identical formats but in addition ask about the severity of an identified need. Responses are coded

1 = Minor problem

2 = Mild problem

3 = Moderate problem

4 = Serious problem

5 = Very serious problem.

Table 4.8a and 4.8b provide one sample need item from the key-worker perspective and one sample self-report need item.

Table 4.8a. One example of a key-worker need item.

One rating only will be made by the key-worker. Ratings will be made as follows:-
If Need Absent Rate '0'; If Need Present Rate '1'; If Uncertain Rate '2'.

If Need present rate importance of support/help needed:
1= Totally Unimportant. 2 = Fairly Unimportant. 3 = Uncertain.
4 = Quite Important. 5 = Very Important.

If Need present rate whether or not need is met:
1 = Totally unmet. 2 = Mostly unmet. 3 = Partly unmet. 4 = Uncertain.
5 = Partly met. 6 = Mostly met. 7 = Totally met.

If met: rate who supports the need:

1 = Informal Carer e.g., family member, friend, neighbour.
2 = Formal Carer i.e., Someone paid e.g., CPN, Social Worker, Community Support Worker.
3 = Other. Specify:
4 = Don't know

If unmet: rate who should support/help need:
1 = Informal Carer e.g., family member, friend, neighbour.
2 = Formal Carer i.e., Someone paid e.g., CPN, Social Worker, Community Support Worker.
3 = Other. Specify:
5 = Don't know

Example of Assessment of Need by a Key-worker.

Q1. *Does ..... need help with their shopping?* '0' = Absent. '1' = Present. '2' = Uncertain
If Yes: What help/why does she/he need with his/her shopping?.....
If Yes: How important is it that she/he gets the help she/he needs?
If Yes: How well do you feel her/his need is met?
If met: who supports her/his shopping need?
If unmet: who should support her/his shopping need?

Table 4.8b. One example of a client self-reported need.

One rating only will be made by the client. Ratings will be made as follows:-

If Absent Rate '0'. If Need Present Rate '1'. If Uncertain Rate '2'.

If Need present rate importance of support/help needed:
1= Totally Unimportant. 2 = Fairly Unimportant. 3 = Uncertain.
4 = Quite Important. 5 = Very Important.

If Need present rate whether or not need is met:
1 = Totally unmet. 2 = Mostly unmet. 3 = Partly unmet. 4 = Uncertain.
5 = Partly met. 6 = Mostly met. 7 = Totally met

If met: rate who supports the need:
1 = Informal Carer e.g., family member, friend, neighbour.
2 = Formal Carer i.e., Someone paid e.g., CPN, Social Worker, Community Support Worker.
3 = Other. Specify:
4 = Don't know

If unmet: rate who should support/help need:
1 = Informal Carer e.g., family member, friend, neighbour.
2 = Formal Carer i.e., Someone paid e.g., CPN, Social Worker, Community Support Worker.
3 = Other. Specify:
4 = Don't know

Example of Assessment of Need - Client.

Q1. *Do you need help with your shopping?* '0' = Absent. '1' = Present. '2' =Uncertain.
If Yes: What help do you need with your shopping?.....
If Yes: How important is it to you that you get the help you need?
If Yes: How well do you feel your need is met?
If met: who supports your shopping need?
If unmet: who should support your shopping need?

In summary, an attempt has been made to arrive at an appropriate balance between detail, accuracy and effort not only in collecting data but also in how much time the person making an assessment of need has to give. In terms of method - and the use of a checklist approach to assessing need - if a question about fact is answered in the affirmative then this is followed by questions about views upon the fact. If the answer to the question is "No" there is no need for further investigation. One reason for using this approach is that it allows for a consistent pattern to emerge from 'Yes' and 'No' answers to different items. This is important for the reliability of responses, because as outlined earlier, people with a long-term mental illness may not easily understand all the questions or may have a tendency to reply "Yes" (or "No") to questions. Part of the notion is that such an approach

to gathering data will serve the dual purpose of informing reliability and validity of the new instrument. In this sense, the thirty-two items of need are designed to compare a person's present situation and functioning with what might be perceived as normal. Therefore, assessment focuses on patterns of need hypothesised to be associated with daily living in a group of people with a long-term mental illness.

Appendix 1 presents the new assessment of need schedule used to rate the self-reported need of people with a long-term mental illness. Appendix 2 presents the complementary assessment of need schedule used to rate the key-worker perspective.

Part 2: Levels of dependency.

Earlier discussion raised the point that the presence of psychiatric symptoms is associated with impaired social functioning (McDowell and Newell, 1986; Peck and Shapiro, 1990). In order that this issue might be addressed the REHAB (Baker and Hall, 1983; 1988) will be used. The REHAB has received wide currency in the literature and is a standardised, multi-purpose social and behavioural rating scale to assess the status of people with a major psychiatric illness from a staff perspective. Part 1 rates the frequency of seven difficult or embarrassing (deviant) behaviours (e.g., incontinence, violence, self-injury). Part 2 rates general social and everyday behaviours on a 10-point analogue scale for 16 general behaviours anchored with extremes at each end. The 16 items in the general behaviour scale provide five factor scores namely, social activity, speech disturbance, self care, community skills and speech skills.

Part 3: Measures of mental state

Lehman (1983) said, it is important to control for mental state effects on self-report data in mental health. Bowling (1995) suggests that when carrying out a study of outcomes in a psychiatric population a decision has to be made about whether or not to use a psychiatric diagnostic screening tool or a self-report symptom questionnaire. In relation to this thesis, psychiatric diagnosis will be obtained from case notes in order that comparisons might be made between diagnostic groups. In addition, whilst diagnosis can lead to the psychiatric classification of participants, and as has been highlighted in previous chapters, diagnosis

may not be as useful as looking at the relationship between mental illness and need status in terms of self-reported feelings, for example, of anxiety and depression. In this sense, the use of self-report questionnaires have the potential to provide the opportunity to analyse psychiatric state on a continuum. Details of one such method is presented next.

Brief Psychiatric Rating Scale (BPRS).

The Brief Psychiatric Rating Scale (BPRS) will be used as a measure of mental state (Overall and Gorham, 1962). The BPRS was originally developed by Overall and Gorham (1962) for use in recording clinical judgements based on information obtained in a brief semi-structured psychiatric interview. The BPRS has been widely used (Bowling, 1995) and has been subjected to a substantial amount of methodological development and testing (Headland and Viewing, 1980; Lukoff, Liberman, & Neuchterlein, 1986) covers much of the range of manifest psychopathology and provides a total score and a consistent factor structure (Rhodes and Overall, 1988). Mitchell et al., (1995) provide a modified version of the BPRS. The version consists of 21 symptom constructs each with explicit criteria for ratings of severity on a 7-point scale ranging from 0 ('not present') to 6 ('extremely severe') and five factors. In addition, Mitchell et al., provide probes for lead questions. For the purpose of this thesis, the author was trained in the use of the modified version of the BPRS (Mitchell et al., 1995) up to criterion. Ratings were made on the basis of a) a psychiatric interview devised by Mitchell et al., (1995); and b) observation. Appendix 5 contains the psychiatric interview and the BPRS. Due to resource constraints it was not possible to undertake independent ratings by two observers.

Conclusion.

What becomes clear is that there is an attempt in needs-assessment research to encompass 'all' circumstances of need, for example, accommodation needs, shopping needs, mental health needs etc. This is reminiscent of Maslow's (1962; 1970) hierarchy of need and the relationship of 'need' to 'Quality of Life' and an individual's ability to lead a 'normal life'. The point is that little attempt has been made to examine such assumptions critically; which moves on to the consideration that one possible starting point in an assessment of need in long-term mental illness is to examine the subjective accounts of people in need i.e., the

reports of long-term mentally ill patients themselves. This, from a phenomenological perspective, means that 'need' is dependent upon the interpretation and perception of the individual. Such a perspective provides one attempt at researching whether or not a 'simple listing' of needs-assessment items is a satisfactory way of assessing need in long-term mental illness. This is because it is unknown whether or not 'all' items have been included and whether or not a 'simple listing' works for its intended purpose. However, the difficulty here for needs-assessment research and the construction of 'need measures' lies in addressing need from competing perspectives. From the perspective of pragmatism, and to some extent the need to develop reliable and valid measures of need from the perspective of a long-term mentally ill person, necessitates compromise and the simplification of philosophical issues. For example, it might be argued that the translation of 'need' by patients themselves into numeric scores does not capture their subjectivity. However, and until a phenomenological approach to an assessment of need has been undertaken there will be little evidence to support such a thesis and counter-act the prevailing trend toward a pre-definition of 'need' which is normative. In this sense, several conclusions can be drawn from the present chapter. Firstly, more than one measurement perspective is required in the development of a self-report assessment of need schedule. This aspect of the methodology has support in the literature (Cook and Campbell, 1979; McKillip 1987). Secondly, what this means is that the methodological approach used in this thesis has the potential to consider need from the client's own perspective. This will include exaggeration and under-statement, because this is assumed to form an integral part of any given clients' need status. In this sense, one might argue that bias is inherent in the subjective judgements made by the person with a long-term mental illness and it does not threaten validity of the measurement process because need is as the person with a long-term mental illness assesses it. Thirdly, and in order to examine the counter argument to this approach i.e., that the approach provides a convenient simplification, which might be flawed because it contains potential biases, the methodology proposed will attempt to control for such bias by including firstly, the completion of a questionnaire or assessment by key-workers; and secondly with methods of statistical comparison e.g., Cohen's *Kappa*, Cohen (1960). The point is that by using a within-subjects design for establishing the reliability of each of the need schedules and then using a between-subjects design in order to check out the validity

of client responses using key-worker needs data provides one means of reliably and validly measuring the self-reported needs of people with a long-term mental illness.

In summary, the main objective of this thesis has been to find out whether or not people with a long-term mental illness can report their needs reliably and validly. Clearly, there is some evidence in the literature to suggest that some people with a long-term mental illness might be able to self-report their own needs reliably and validly and some not. In order to address this issue analysis will seek to relate mental illness characteristics and social functioning to an ability to respond reliably and validly. Several steps have been identified in order to address this question. The first step is to develop a self-report assessment of need schedule for clients and a perception of need schedule for key-workers and to test for their reliability. The second step is to refine the instruments on the basis of Stage 1 analysis. The third step is to use key-worker needs data to help verify the reliability and validity of client needs data and also to use measures of client mental state to help examine factors related to the reliability and validity of self-report need measures.

Statement of the research problem.

The research problem is stated in the form of a series of key questions.

Research question No 1.

Is it possible to devise a needs-assessment instrument for use in a sample of people with a long-term mental illness in a self-report situation?

The reason for asking this question relates to whether or not the form and content of a given needs-assessment approach is useable and comprehensive enough as an indicator of self-reported 'need' in a sample of people with a long-term mental illness.

Research question No 2.

Can people with a long-term mental illness reliably and validly report their own needs in a needs-assessment situation?

The reason for asking this question relates to the characteristics of people with a long-term mental illness examined in Chapters 1, 2 and 3, where it was suggested that respondents might have difficulties responding to a needs-assessment .

Research question No 3.

What is the relationship of a client's mental state to self-reported need?

The reason for asking this question relates to evidence in Chapter 3 and the suggestion that the researcher should consider the routine administration of an indicator of mental state.

Research question No 4.

Is the relative number of needs affected by whether or not someone lives independently or not?

The reason for asking this question is because it is assumed that environmental factors will have a relationship to the number of needs any given individual with a long-term mental illness might have. For example, those people living independently in the community would have fewer needs in relation to functioning, and would be more self-sufficient than those who lived in more dependent settings for example, 24 hour care.

Research question No 5.

Do diagnostic groups have similar needs?

Given the evidence indicating similarities in the daily living activities of people with a long-term mental illness by diagnosis (Shepherd, 1991), this question sets out to explore whether or not diagnostic groups have similar needs.

Chapter 5. Self-reported need in long-term mental illness: A Pilot Study.

Chapter overview.

Introduction.

The objective of this chapter is to see whether or not the self-report assessment of need methodology described in Chapter 4 works for its intended purpose.

Methodology.

Participants: Fifty-seven people with a long-term mental illness. Mean age 56.1 years. Mean number of admissions 7.9. Mean length of total time spent in hospital 18.05 years. 45 participants (86%) had a diagnosis of schizophrenia. In the main, respective key-workers were of charge nurse grade.

Design: Survey design with repeated measures.

Procedure: Completion of client and staff schedules involving separate interviews.
Twenty clients and staff randomly selected for test-retest.

Results.

Firstly, schedules proved acceptable to both key-workers and clients. Each clearly indicated that they understood the approach commenting consistently that it covered the range of 'need' items experienced by people with a long-term mental illness. Secondly, key-workers identified more needs than clients on average, and clients were more likely to regard needs as being unmet.

Discussion.

Data reflect a complex interaction between different perspectives of an assessment of need and raise issues with regard to reliability and validity of the client self-report need measures.

Conclusions.

In general, an assessment of self-reported need is not wholly appropriate for people with a long-term mental illness with the use of the present instrument. Suggestions for future modification and use of the self-report assessment of need schedule are made.

Introduction.

The objective of this chapter is to see whether or not the self-report assessment of need methodology described in Chapter 4 works for its intended purpose. In essence, this chapter gives consideration to:

a) reliability and validity of key-worker and client data;
b) use of key-worker needs data to help verify client needs data;
c) the use of measures of client mental state and levels of dependency to help examine factors related to the reliability of client's self-reported need; and
d) examination of potential refinement to the schedule based on results of its use.

Methodology.

This section describes study participants, study design, methods of assessment and procedure used.

Participants.

Participants were in the main part of a larger research project evaluating the closure of a local psychiatric hospital (Crosby and Barry, 1995). Due to clinical, administrative and time constraints random selection of participants was not feasible. Participants were selected for inclusion by approaching senior medical and nursing staff on all resettlement wards and senior medical, senior nursing, senior social services staff involved in the community. Being a participant was defined thus:

- 18 years of age and over;
- having a diagnosed serious mental illness (other than mental retardation, addiction to drugs and alcohol, or dementia);
- having currently or recently been hospitalised for a period greater than one year;
- in continued receipt of professional mental health services either in a psychiatric hospital or in the community; and
- psychologically capable of responding to a self-report assessment of need based on staff reports.

General characteristics.

Forty-three (75%) clients were male; 14 (25%) were female. The mean age of the client sample was 56.1 years (SD 14.5). The mean number of admissions was 7.9. The mean length of total time spent in hospital was 18.05 years (SD 14.9). Forty-five clients (86%) were diagnosed as having schizophrenia. The remainder were diagnosed as having a personality disorder or asocial behaviour based on available case-notes. The living situation of clients was: 13 (23%) 'Independent'; 24 (42%) 'Supported living'; and 20 (35%) 'Long-term psychiatric hospital'. All participants had spent a long-time in a psychiatric hospital and most were undergoing rehabilitation during the study period either in the community (as part of a resettlement and hospital closure programme) or the

rehabilitation ward in a psychiatric hospital (awaiting resettlement to the community). The data compared well with the most commonly accepted definition of long-term mentally illness i.e., duration of admission of over one year and having a diagnosis of a major mental illness (for example, Wykes et al., 1982; MacCarthy et al., 1986; O'Driscoll and Leff, 1993).

Design.

Survey design with repeated measures at approximately one month apart.

Methods of assessment.

Methods of assessment include:

a) measurement of client and key-worker need using the schedules described in Chapter 4;
b) measurement of client levels of dependency using the REHAB (Baker and Hall, 1983; 1988); and
c) measurement of client mental state using the Brief Psychiatric Rating Scale (Overall and Gorham, 1962).

Procedure.

Key-workers and clients were contacted approximately one week prior to the initial assessment and asked if they would be willing to participate. A brief description of the research project was given and a time set to complete the instruments. All 57 clients and their respective key-workers agreed to participate in the research. Having agreed consent, case-notes were used to derive background information. This included information on age, sex, diagnosis, length-of-time in hospital, number and duration of previous admissions. Completion of the key-worker and client schedules involved separate interviews on the same day in most cases by the same researcher. With clients, a semi-structured psychiatric interview was conducted first, followed by the self-report assessment of need. This procedure took about forty-five minutes. Ratings on the BPRS were done after each interview in the absence of the client. Completion of the REHAB by key-workers and the

key-worker perception of client need took approximately thirty minutes. When it came to responding to questions about the importance of need and whether or not need was being met participants were given a card with the response categories written on it if they needed it for reference. Similarly, when it came to 'ranking need' clients and key-workers were shown the list on a card. Twenty clients and their key-workers were randomly selected for test-retest and were asked whether or not they would be willing to be re-interviewed approximately four weeks later.

Data analysis: General information.

General information is provided in three parts: data storage and statistical analysis; data reduction procedures and the choice of reliability criteria.

Data storage and statistical analysis.

Each subject was given an identification number and separate databases were created for staff and client responses to the assessment of need questions; REHAB and BPRS using FoxBASE+ (Fox Software, 1988). All data were subsequently transferred to the University of Wales, Bangor UNIX computer called 'Thunder'. The SPSS-x (SPSS Inc., 1988) package was used for analyses.

Data reduction procedures.

For the purpose of analysis of key-worker 'needs data' and client self-report needs data, items have been analysed individually and as a total need score. REHAB data and BPRS data have also been analysed as total scores. BPRS and REHAB scores have been further reduced by computing factor scores.

Table 5.1 presents the BPRS item composition of each factor score. Five items in the 21-item version of the BPRS (Mitchel et al., 1995) did not contribute to BPRS factor scores. These included Disorientation, Motor hyperactivity, Elevated Mood, Distractibility and Incomprehensible Speech. These were analysed separately from the factor scores.

Table 5.1. BPRS item composition and five factors.

BPRS factor	**BPRS factor items**
Anxiety- Depression	Somatic Concern Anxiety Guilt Feelings Depressive Moods
Anergia	Emotional Withdrawal Motor Retardation Blunted Affect
Thought Disturbance	Conceptual Disorganisation Grandiosity Hallucinatory Behaviour Unusual Thought Content
Activation	Tension Mannerisms and Posturing
Hostility-Suspiciousness	Hostility Suspiciousness Uncooperative

Factor Score = Sum of composite items/Number of composite items

Baker and Hall (1983) provide a means of computing a 'Total General Behaviour' score for the REHAB. Furthermore, these authors report five factors based on a sample of 508

long stay patients. These, along with items which loaded on each factor, are presented in Table 5.2.

Table 5.2. REHAB factor and item composition.

REHAB factor	REHAB factor items
Social Activity	Mixing on Ward Mixing off Ward Use of Spare Time Level of Activity Amount of Speech Imitation of Speech
Speech Disturbance	Sense of Speech Clarity of Speech
Self Care	Table Manners Washing Self Dressing Self Looking after Possessions Amount of Prompting
Community Skills	Use of Money Use of Public Facilities
Speech Skills	Amount of Speech Initiation of Speech

Factor Score = Sum of Composite Items.

Total General Behaviour (TGB) = 1 + 2 + 3 + 4 + Overall Rating.

Reliability.

Because this thesis is attempting to develop a new schedule to measure self-reported need in a sample of people with a long-term mental illness, issues of reliability will need to be addressed in order that suitable criteria might be defined. As stated earlier, use is being made of a 'checklist' approach to the assessment of self-reported need. With this approach the literature (e.g., Kreiner, 1993) suggests, a) reliability should proceed on the basis of an item by item analysis and b) the use of one score based on the simple addition of items which yield a total or summary score. This latter approach is useful because it is helpful to

compare responses which might report more or less needs. Clearly, there are considerations which need to be made in terms of drawing criteria for testing the reliability of individual items and the total number of items. However, before this is done one disadvantage of this approach requires discussion. The limitation of this approach is that the only information which can be obtained from such analysis resides in the items themselves and/or total scores. This sort of situation it should be noted is far different from the case where one is striving to demonstrate that, for example, a set of personality items are sampled from a common domain of items where the assessment exercise is to show that the assessment items are related. The point is that if this latter type of assessment is valid, scores will reflect a wider set of behaviours beyond the assessment items. In the case of assessing need with the use of a checklist approach, it might be argued that items do not refer to any variable beyond the assessment itself. In this instance, it does not make sense to talk about 'internal consistency reliability' and factor analysis with the variables being measured because the need items are simply collections of 'similar' items. In this sense, what the self-report assessment of need schedule under development in this thesis amounts to is essentially a quantified interview. Such an approach has strong appeal in applied social sciences research (McDowell and Newell, 1987; Streiner and Norman, 1991; Breakwell et al., 1995). Therefore, to establish reliability of the key-worker and client assessment of need schedules requires specific criteria.

Guyatt (1993) has pointed out that questionnaire design can be problematic and that question wording can be fraught with difficulties. Items and scales need to be adequately tested for their reliability and validity. In essence, the development of an assessment of need tool has had to consider possible threats to the tool's reliability and validity. For example, ambiguous or vague definitions. In terms of setting reliability criteria, traditionally agreement has been presented as a percentage index. However, as Harrop et al., (1989) suggest "...there is obviously an awareness that overall percentage agreement can mislead, but there appears to be no consensus on alternative ways of examining the data". Hopkins and Hermann (1977) have argued that agreement should be quoted together with levels of chance agreement and should receive greater attention in the psychological

and psychiatric literature. In an attempt to introduce more rigour in the calculation of reliability in this study, the measure of agreement has been examined with the use of

a) percentage agreement; and
b) *Kappa* for nominal data (Cohen, 1960).

Fleiss (1971) and Landis and Koch (1977) have characterised different ranges for *Kappa* with respect to the degree of agreement. Values of K range from 1.0 for 'perfect agreement', through 0.0 for 'chance agreement'; to negative values for less than chance. These authors have suggested that for most purposes values equal to or greater than 0.7 may be taken to represent 'excellent agreement beyond chance'; values less than 0.4 may be taken to represent 'poor agreement beyond chance; and values equal to or greater than 0.4 and less than 0.7 may be taken to represent 'fair to very good agreement beyond chance'.

Therefore, results are presented in terms of a) reliability of staff needs data and then b) reliability of client self-report needs data. The rationale for doing this is to examine how reliable the instrument is with key-workers and then to compare this with how reliable the instrument is for clients. In order to achieve this test-retest reliability measures will be examined in relation to levels of agreement by need items, that is, firstly, are key-worker perceptions of need by need items stable over time; and ii) are client self-reports of need by need items stable over time. The main justification for taking this approach is that one might predict that stability of client reported need would differ from that of key-workers. That is, given the characteristics of people with a long-term mental illness there would be a higher level of stability for key-worker need items over time compared to clients.

Results.

Results are presented in four main sections. Section 1 presents clinical and demographic characteristics of the test-retest group. Section 2 reports on test-retest of need items for key-workers and clients with the *Kappa* group of statistics and percentage agreement. Section 3 reports on inter key-worker:client agreement by need items. Section 4 presents data for key-workers (n=57) and clients (n=57) as a whole in relation to need, mental state and social and behavioural functioning

Section 1. Characteristics of the test-retest group

Table 5.3 shows client characteristics of the test-retest group (n=20). The measures shown did not differ significantly from those of the non test-retest group (n=37). Three clients were unable to complete the test-retest. Data show that in comparison to the remainder of the test-retest group these three participants were younger; having had more previous psychiatric hospital admissions, having spent less time in a psychiatric hospital and having been known to the services for less time. In addition, the three participants had a significantly higher mean REHAB total 'Deviant Behaviour Score'; a significantly higher mean REHAB 'Total General Behaviour Score' (suggesting that it is doubtful they live outside of a psychiatric hospital; Baker and Hall; 1988) and a significantly higher mean total BPRS score.

Table 5.3. Comparison of the test-retest group.

Variables	Group (n=37)	Test-retest (n=20)	Non-participants(n=3)
Mean Age	56	56.3	40.5
Previous admissions	7.7	8.3	12
Time in hospital	18.5	17.5	6.5
Time known to services	29.5	28.6	18
REHAB deviant Behaviours	2.4	1.4	4.5
REHAB TGB	46	56.3	78
Total BPRS	18.3	16.3	24

Section 2. Test-retest for need items

Table 5.4 presents test-retest measures of agreement as the proportion of responses for key-workers (N=20) and clients (N=17) for the thirty-two individual need items. In this instance *Kappa* measures the degree of agreement as the proportion of responses for the 32 need items at Time 1 and Time 2. Thereby allowing a comparison of the measure of agreement for each of the 32 need items over time. The result of cross-tabulating the presence or absence for individual need item ratings for key-workers (N=20) shows that seven of the thirty-two (22%) items for key-workers had a *Kappa* values <0.4 representing 'poor agreement beyond chance'. Fifteen of the thirty-two (47%) items for key-workers had *Kappa* values ≥ 0.4 and < 0.7 representing 'fair to very good agreement beyond chance'. Ten of the thirty-two (31%) items for key-workers had *Kappa* values ≥0.7 representing 'Excellent agreement beyond chance'. Ratings for clients (N=17) shows that thirteen of the thirty-two (40%) items had *Kappa* values <0.4. Representing 'poor agreement beyond chance'. Ten of the thirty-two (31%) items for clients had *Kappa* values ≥0.4 and < 0.7 representing 'fair to very good agreement beyond chance'. Nine of the thirty-two (29%) items for clients had *Kappa* values ≥0.7 representing excellent agreement beyond chance.

Table 5.4. Test-retest measures of agreement for key-workers and clients by individual need items.

Need item	*Kappa* (%) Key-workers	*Kappa* (%) Clients
1. Shopping	**0.65 (84)**	0.26 (66)
2. Cooking	**0.59 (80)**	**0.57 (79)**
3. Cleaning	**0.73 (79)**	**0.45 (79)**
4. Bathing	**0.46 (79)**	**1.00 (100)**
5. Washing	0.06 (70)	-0.05 (89)
6. Dressing	**1.00 (100)**	**1.00 (100)**
7. Toilet	-0.05 (90)	**1.00 (100)**
8. Getting up	**0.62 (80)**	**0.40 (72)**
9. Money	**0.67 (85)**	**0.57 (79)**
10. Phone	**1.00 (100)**	0.36 (79)
11. Post	0.30 (79)	0.22 (61)
12. Out & about	**0.80 (90)**	0.20 (66)
13. Occupation	**0.45 (74)**	**0.50 (71)**
14. Move accommodation	**0.55 (80)**	**0.44 (72)**
15. Location	**0.78 (90)**	**0.77 (89)**
16. Safety	-0.05 (89)	0.38 (79)
17. Acceptance	**0.62 (90)**	-0.06 (88)
18. Spare time	**0.47 (75)**	0.22 (79)
19. Family	**0.57 (79)**	**0.76 (93)**
20. Contact	**0.68 (84)**	0.16 (65)
21. Club	**0.55 (80)**	0.05 (52)
22. Thoughts	**0.45 (78)**	**0.82 (94)**
23. Protection	**0.40 (68)**	**1.00 (100)**
24. Medication	**0.83 (95)**	0.3 (61)
25. Counselling	**0.89 (94)**	**0.55 (82)**
26. Motivation	0.32 (68)	**0.48 (84)**
27. Contact Services	**1.00 (100)**	**1.00 (100)**
28. Care-plan	0.02 (65)	0.25 (66)
29. Coping	**1.00 (100)**	**0.42 (70)**
30. Advocacy	**0.68 (89)**	0.20 (64)
31. Physical	0.16 (75)	**0.64 (89)**
32. Trouble in the home	**1.00 (100)**	**1.00 (100)**

Section 3. Inter-rater agreement by need items.

Table 5.5 presents *Kappa* and percentage agreement as an index of inter key-worker:client agreement by need items. The mean *Kappa* value is 0.21 (Mean percentage agreement 66%). Examination of key-worker:client agreement by need items suggests 'poor agreement' for 24 of the 32 (75%) need items (i.e., *Kappa* values < 0.4). The remaining eight items showed 'fair to very good agreement beyond chance' (Fleiss, 1971; and Landis and Koch, 1977).

Table 5.5. Key-worker and client agreement by need items.

Need item	*Kappa*	Percentage agreement
1. Shopping	0.12	53%
2. Cooking	**0.5**	75%
3. Cleaning	0.08	49%
4. Bathing	0.37	69%
5. Washing	-0.04	69%
6. Dressing	0.23	91%
7. Toilet	-0.06	86%
8. Getting up	**0.45**	79%
9. Money	0.3	63%
12. Phone	0.46	78%
13. Post	0.23	69%
12. Out & about	**0.45**	73%
13. Occupation	-0.001	47%
14. Move accommodation	**0.64**	82%
15. Location	**0.6**	81%
16. Safety	-0.07	67%
17. Acceptance	0.21	78%
18. Spare time	**0.41**	78%
19. Family	**0.4**	81%
20. Contact	0.02	64%
21. Club	0.09	55%
22. Thoughts	0.25	55%
23. Protection	-0.06	62%
24. Medication	0.03	52%
25. Counselling	0.33	69%
26. Motivation	0.05	40%
27. Contact Services	0.17	85%
28. Care-plan	0.13	52%
29. Coping	-0.16	59%
30. Advocacy	0.21	72%
31. Physical	0.23	69%
32. Trouble	-0.07	84%
Mean *Kappa* 0.21 (66% agreement)		

Section 4. Need, mental state and social and behavioural functioning.

General introduction.

Interviews with key-workers (n=57) took approximately thirty minutes and approximately forty-five minutes with clients (n=57). Four clients completed the self-assessment of need but failed to complete the psychiatric interview. In general, key-workers reported higher mean total need scores compared to the clients. At first interview the mean total number of needs identified by key-workers was 13.2 (SD 4.9) and the mean total number of needs identified by the clients was 8.6 (SD 4.6). Key-workers perceived a total of 751 needs and clients expressed a total of 491 needs. This represents a ratio of 1 client expressed need : 1.5 key-worker perceived needs. The mean REHAB deviant behaviour score was 2.8 (SD 1.6). The mean REHAB Total General Behaviour Scores (TGB) score was 60.1 (SD 30.7). Baker and Hall (1988) provide the following clinical judgement about the meaning of the TGB: 41 to 50 suggests the need for "... extensive training and experience" in relation to living in the community; 51 to 60 means "Could only live out if supervised"; 61 to 70 means "Could only live out with much tolerance and supervision". The mean total BPRS score was 17.4 (SD 13.2).

Need.

Table 5.6 shows the frequency of need present, the importance of need, and the frequency of need being unmet for each item of self-reported need and key-worker perceptions of client need. Needing help to 'cope with life' (Item number 29) and needing help with 'post' (Item number 15) rated as the most frequent needs for clients. Needing help to 'cope with life' (Item number 29) and needing help with 'medication' (Item number 24) rated as the most frequent needs for clients identified by key-workers. The least number of clients expressing a need occurred with the items related to self-care i.e., washing, dressing and using the toilet; items 3, 4,and 5 respectively. The item clients needed least help with as identified by key-workers was 'help with getting in touch with mental health services' (Item number 20). The need items to exhibit the largest discrepancy between need expressed by clients and need identified by key-workers concerned the need items 'Thoughts, feelings and behaviours' (Item number 22) and 'Motivation' (Item number 26).

Table 5.6. Frequency of key-worker identified client need and client expressed need by need items.

Need item	Need present (%)		Importance (%)		Unmet (%)	
	Staff	Clients	Staff	Clients	Staff	Clients
1. Shopping	35 (61)	22 (39)	31 (89)	18 (81)	3 (9)	1 (5)
2. Cooking	32 (56)	27 (47)	29 (91)	20 (74)	0	2 (7)
3. Cleaning	38 (67)	20 (35)	37 (97)	17 (85)	3 (9)	2 (10)
4. Bathing	26 (45)	15 (26)	26 (100)	14 (93)	2 (8)	0
5. Washing	16 (28)	1 (1.7)	16 (100)	1 (100)	0	1 (100)
6. Dressing	13 (23)	2 (3)	12 (92)	2 (100)	0	0
7. Toilet	6 (11)	2 (3)	5 (3)	2 (100)	0	1 (50)
8. Getting up	14 (25)	13 (23)	11 (79)	9 (70)	0	3 (23)
9. Money	33 (57)	23 (40)	33 (100)	22 (96)	3 (9)	0
14. Phone	14 (25)	14 (25)	14 (100)	12 (86)	0	1 (7)
15. Post	43 (75)	37 (66)	42 (98)	33 (89)	0	0
12. Out & about	27 (47)	17 (30)	27 (100)	15 (88)	2 (7)	0
13. Occupation	30 (53)	17 (30)	29 (97)	16 (96)	8 (27)	7 (41)
14.Move accomm	19 (33)	23 (40)	16 (84)	21 (91)	8 (42)	18 (78)
15. Location	19 (33)	25 (44)	16 (84)	21 (84)	8 (42)	18 (72)
16. Safety	8 (14)	14 (25)	5 (62)	13 (97)	2 (25)	5 (35)
17. Acceptance	10 (17)	9 (15)	7 (70)	7 (78)	1 (10)	5 (55)
18. Spare time	16 (27)	11 (19)	15 (94)	8 (73)	5 (31)	3 (27)
19. Family	14 (25)	7 (12)	13 (93)	5 (71)	3 (21)	4 (57)
20. Contact	21 (37)	16 (29)	18 (86)	11 (69)	7 (33)	5 (31)
21. Club	25 (44)	24 (42)	21 (84)	21 (86)	11 (44)	11 (46)
22. Thoughts	40 (70)	13 (23)	36 (90)	12 (92)	2 (5)	4 (31)
23. Protection	17 (30)	5 (1.7)	17 (100)	4 (97)	0	1 (20)
24. Medication	43 (75)	23 (40)	40 (93)	18 (78)	0	2 (9)
25. Counseling	23 (40)	12 (21)	22 (96)	9 (75)	5 (22)	5 (41)
26. Motivation	40 (70)	11 (19)	37 (93)	8 (73)	0	2 (18)
27.Contact Services	1 (1.7)	9 (16)	1 (100)	9 (100)	0	3 (33)
28. Care-plan	42 (74)	18 (32)	40 (95)	17 (94)	2 (5)	1 (6)
29. Coping	47 (83)	38 (67)	43 (92)	31 (82)	1 (2)	1 (6)
30. Advocacy	13 (23)	10 (18)	13 (100)	9 (90)	8 (62)	6 (60)
31. Physical	20 (35)	10 (18)	14 (70)	9 (90)	1 (5)	6 (60)
32. Trouble	6 (11)	3 (5)	5 (83)	3 (100)	0	0

For present purposes the 'importance of need' has been expressed by combining the categories of 'quite' and 'very' important (Table 5.6). Almost all need items rated as being quite or very important. The mean importance score for clients was 4.6 (Scale range 1-5). The mean importance score for key-workers was 4.6 (Scale range 1-5).

In terms of client and key-worker responses to whether or not need which was said to be present was 'met' or 'unmet' yields the following results. Clients reported 71% (n=350) of their expressed needs were being 'partly', 'mostly' or 'totally' met and 20% (n=98) were being 'partly', 'mostly' or 'totally' unmet. Nine percent (n=43) of client responses were 'Uncertain'. This yields a ratio of 3.6 met:1 unmet need. Key-workers reported that 88% (n=659) of identified needs were being 'partly', 'mostly' or 'totally' met and 10% (n=77) were being 'partly', 'mostly' or 'totally' unmet. Two percent (n=15) of key-worker responses were 'Uncertain'. This yields a ratio of 8.6 met:1 unmet need. Table 5.6 presents the results of combining the categories of needs being 'partly unmet', 'mostly unmet' or 'totally unmet' into one 'unmet' need category for ease of presentation. With regard to need being unmet, the most frequently unmet need expressed by clients concerned needing help to 'move accommodation'. Needing help with some sort of club or befriending service (Item 21) was the most frequently unmet need perceived by key-workers. Neither clients nor key-workers reported unmet need in relation to three need items - help with dressing, help with post and help in the home. Need items to exhibit the largest discrepancy between unmet need expressed by clients and unmet need identified by key-workers concerned the item 'help to move accommodation' (Item number 14). Seventy-eight percent of clients reported the need to be unmet compared to 42% of key-workers.

By combining ratings of need severity for the seven need items where a severity rating was applicable 'Thoughts and feelings'; 'Protection from self'; 'Counselling'; 'Motivation'; 'Coping with life'; 'Physical need' and 'Physical need in the home' (Item numbers 22, 23, 24, 25, 26, 31, and 32 respectively) results in a mean need severity rating of 3.5 (range 2.8 to 4.5. Scale range 1-5) for clients and 3.5 (range 3.0 to 3.8. Scale range 1-5) for key-workers. All need items which included a need severity rating scored a mean of ≥3.0

('Moderate' to 'Serious') apart from the need item 'Need help to cope with life' (Item number 29) for clients which had a mean rating of 2.8.

In relation to client responses to the need item 'Do you need help to move from where you are living at the moment?' (Item number 15) and for those clients who responded "Yes", asking 'Where do you feel you belong?' resulted in 50% of responses indicating 'Independent living'. The remaining responses included 'A larger town', 'A rural area' and 'Closer to friends'. Similarly, for the need item 'Do you need help to occupy yourself during the day?' (Item number 13) and clients who responded "Yes", asking 'Where do you think you should be occupied?' resulted in most responses indicating "Don't know". In comparison to clients, key-worker responses (65%; n=13) indicated 'Closer to family' for the item 'Where do you feel they belong?'. For the need item 'Does ... need help to occupy themselves during the day?' (Item number 13) and for those key-workers who responded "Yes", asking 'Where do you think they should be occupied?' resulted in 63% (n=12) of responses stating 'Day centre'. The remaining responses included 'Sheltered work' and 'Open employment'.

Finally, in terms of needs being met, clients reported that 85% of their identified needs were met by formal carers; 9% by voluntary services and the remaining needs were either met by informal carers or were 'Unknown'. Similarly, key-workers reported that the vast majority of needs were being met by 'Formal carers' (91%). Six-percent of needs were being met by the voluntary services and the remainder were being met by informal carers. In 3% of needs the key-workers did not know who was meeting the need. In terms of the question 'Are there any other needs we have not mentioned that you think are important?' no additional areas were identified by more than two respondents. When asked to rate the most important need clients rated 'Money' (37%) and key-workers rated 'Mental health' (47%).

Total key-worker perceived need scores and total client self-reported need scores.

Correlating levels of total key-worker perceived need scores and total client expressed need scores yields a correlation coefficient of r 0.36, p.01. Any interpretation of this relationship should be made cautiously due to the difficulties outlined earlier with regard to indices of reliability. One way of examining the relationship is to look at where any 'differences' lie. In order to do this a 'Need Difference Score' has been created. This has been done by subtracting total key-worker need scores from total client expressed need scores. Figure 5.1 shows the frequency distribution of 'Need Difference Score'

Figure 5.1. Frequency distribution of 'Need Difference Scores.

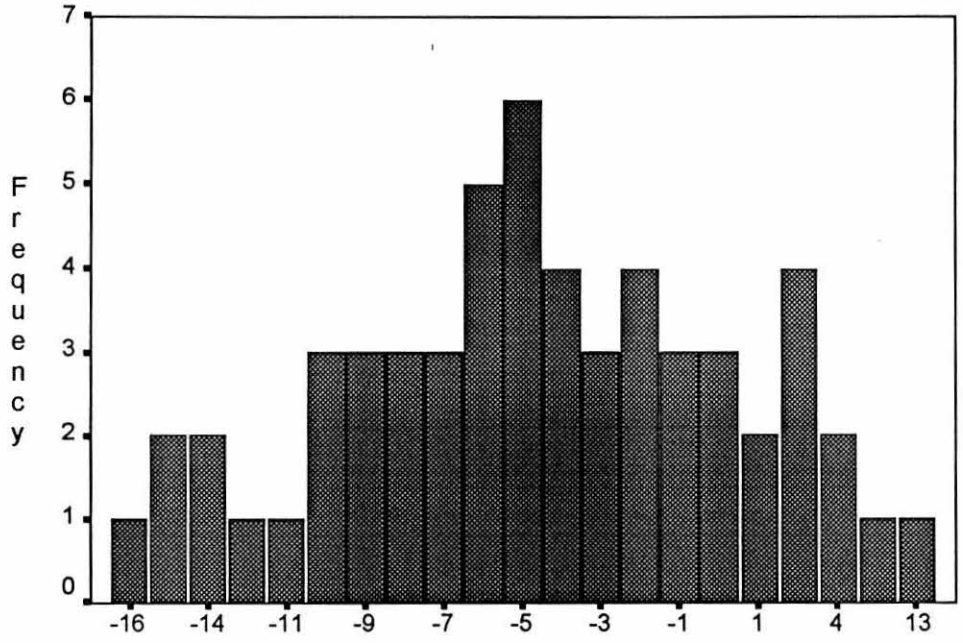


Figure 5.1 has three adjacent peaks with mid-point values of -4, -5 and -6 (Mean -4.6, SD 5.6). What Figure 5.1 shows is that the majority of client total need scores disagree with staff total need scores (range -1 to - 16) suggesting that the under-reporting of need by clients is somewhat more probable than over-reporting. For example, 44 (77%) clients under-reported need whilst 10 (17%) over-reported need compared to key-workers. The remaining 3 (8%) agreed. What these data indicate is a difference in perspective. Further examination of the data shows a strong positive correlation between total client expressed

need scores and the 'Need Difference Score' (r 0.56) and a strong negative correlation exists between total key-worker need scores and 'Need Difference Score' (r - 0.62). This observation will be discussed later.

Need and demographic variables.

Table 5.7 shows the correlation of total key-worker need scores and total client need scores with demographic variables. The only statistically significant result, although weak, was total number of previous psychiatric hospital admissions with total key-worker perceived need scores.

Table 5.7. Correlating total client and key-workers need scores with demographic variables.

Demographic Variables	Total key-worker need scores	Total client need scores
Age	r - 0.20	r - 0.20
Previous psychiatric hospital Admissions	**r 0.3**	r 0.22
Time spent in psychiatric hospital	r - 0.19	r - 0.03
Time known to services	r - 0.21	r 0.008

Coefficients in bold type are significant at the p 0.05 level.

Needs and levels of dependency.

Table 5.8 shows correlations of total key-worker need scores and total client need scores with REHAB Total General Behaviour (TGB) scores, REHAB deviant behaviour scores and REHAB factor scores. A statistically significant relationship was found when total need scores for key-workers are compared with the TGB scores of the REHAB. A modest association was found between total key-worker perception of need scores and the REHAB factor score 'Social activity'. Other, significant associations were found between total key-worker perception of need scores self-care and community skills. No statistically significant relationship was found between total client self-report need scores and REHAB total general behaviour scores. Furthermore, no statistically significant relationship was found between client total expressed need scores and REHAB factor scores.

Table 5.8. Total key-workers and total client need scores correlated with REHAB scores.

REHAB variable	Total key-worker need	Total client need
Deviant behaviour	r 0.15	r -0.12
Social Activity	**r0.45**	r 0.04
Speech skills	r 0.15	r -0.07
Disturbed speech	r 0.21	r 0.06
Self-care	r 0.3	r 0.08
Community skills	**r 0.24**	r 0.09
TGB	**r 0.40**	r 0.06

Coefficients in bold type are significant at the p 0.05 level.

Mental State

Table 5.9 shows a reasonable correlation between total key-worker perceived need scores and total BPRS scores and total client self-reported need scores and total BPRS scores. The strongest association found between total key-worker perception of need scores and BPRS factor scores was 'Anxiety-depression'. Other associations were found in relation to BPRS factors 'Anergia', 'Thought disturbance', and 'Hostility-suspiciousness'. The strongest association found between client total need scores and BPRS factor scores was 'Anxiety-depression'. The association can only be described as modest. Other associations were found in relation to BPRS factors 'Thought disturbance' and 'Hostility-suspiciousness'.

Table 5.9. Total need scores correlated with total BPRS and BPRS factor scores.

BPRS variable	Total Key-worker need	Total client need
Anxiety- depression	**r 0.42**	**r 0.44**
Anergia	**r 0.27**	r - 0.17
Thought disturbance	**r 0.27**	**r 0.30**
Activation	r 0.11	r 0.19
Hostile-suspicious	**r 0.28**	**r 0.33**
Total BPRS	**r 0.44**	**r 0.31**

Coefficients in bold type are significant at the p 0.05 level.

Table 5.10 presents correlation coefficients of a) client total need scores and BPRS items Disorientation, Motor hyperactivity, Elevated Mood, Distractibility, Incomprehensible Speech and b) total key-worker need scores need scores and BPRS items 'Disorientation', 'Motor hyperactivity', 'Elevated Mood', 'Distractibility', 'Incomprehensible Speech'.

Table 5.10. Correlation of need scores with BPRS items disorientation, motor hyperactivity, elevated mood, distractibility and incomprehensible Speech.

BPRS items	Total key-worker need	Total client need
Disorientation	**0.28**	0.12
Motor hyperactivity	0.04	0.12
Elevated mood	**0.38**	**0.34**
Distractibility	**0.28**	- 0.05
Speech	0.002	0.08

Coefficients in bold type are significant at the p 0.05 level.

Three BPRS items were found to be significantly related to key-worker total need scores. These were 'Disorientation', 'Elevated mood' and 'Distractibility'. The only item found to be statistically significant for clients in relation to total self-reported need scores was 'Elevated mood'.

Table 5.11 shows the results of a) correlating total BPRS scores for items 1-12 (i.e., ratings based on client answers to the questions (Mean 12.4 SD 11.9 N=53) with total key-worker and total client and need scores and b) correlating total BPRS scores for items 13-21 (ratings based on client behaviour during the interview. Mean 5.0 SD 4.4 N=53) with total key-worker and total client and need scores.

Table 5.11. Correlation of BPRS items 1-12 and 13-21 with total need (n=53).

BPRS	Total Key-worker need	Total client need
Items 1-12	**0.39**	**0.35**
Items 13- 21	0.25	0.03

Coefficients in bold type are significant at the p 0.01 level.

The result of a) correlating total BPRS scores for items 1-12 with total key-worker need scores and total client need scores yields a moderate positive correlation. Correlating total BPRS scores for items 13-21 with total key-worker need scores and total client need scores showed no statistically significant relationship.

There were no significant differences in total need scores by living situation i.e., participants who lived independently in the community (n=13), in a supported living

situation in the community (n=24) and those who were long-term psychiatric in-patients awaiting resettlement (n=20). The mean number of needs expressed by clients was 8.7, 8.4 and 8.9 respectively; obtained F.05 (2,55) = 0.06 (p >.05). This compares to mean needs scores of 11.7, 13.6 and 13.6; obtained F.05 (2,55) = 0.7 (p >.05) respectively by key-workers. Measures of client total expressed need scores and measures of key-worker total perceived need scores revealed no difference by broad diagnosis i.e., schizophrenia versus non-schizophrenia.

Discussion.

Main findings.

At a most simple level schedules proved acceptable to both key-workers and clients. Each clearly indicated that they understood the approach - commenting consistently that it covered the range of 'need' items experienced by people with a long-term mental illness. Thus, providing some evidence to support the concept of 'face validity'. Leading on from this, descriptive data show three main points. Firstly, clients appear to mirror samples used in other studies of long-term mental illness and may very well be 'representative' of the population in terms of demographic characteristics, psychiatric history, and clinical profiles Wing, 1975; Angelini, 1982; Wykes et al., 1985; Baker, and Hall, 1988; Brewin et al.,1988; Bennett, 1991; Bennett and Morris, 1991). In this sense, those clients who participated in this study are a dependent group who are psychiatrically disabled, requiring support. Secondly, clients varied widely in terms of their self-reported needs, perceived needs by key-workers, mental state, and levels of social and behavioural functioning. Thirdly, a description of the needs data in general shows the following main features: key-workers identified more needs than clients on average, and key-workers were more likely to regard client needs as being met. Clearly, before any conclusions can be drawn from the data, discussion of the reliability of the data has to be made.

Reliability.

The main criterion for examining the value of the new schedule has been the test-retest of need items. Results indicated better levels of agreement for key-worker responses compared to client responses. By using the available data it is possible to explore a number of factors in relation to the reliability of the need scores presented thus far. For example, 'How might the indices of *Kappa* and percentage agreement interpreted?'; 'How satisfactory are the methods of testing for agreement for what is essentially a judgmental task?'; 'What is reliability really concerned with in the present study?' As Levy (1973) points out, it is very easy in a search for scientific respectability to become diverted from the substance of an investigation. Essentially, the question of reliability is concerned with a matter of judgement, i.e., do key-workers and clients agree sufficiently within and between

themselves in terms of the investigation undertaken. That is, are the statistical summaries of value? The point is that the absolute level of agreement can only be one hundred percent (or *Kappa* 1.00) when both clients and key-workers assign the same need items to the same categories both within and between themselves. What the data show is a) that there is poor agreement by need items overall between clients and key-workers (see Table 5.5) and b) that there is better agreement by need items by key-workers than clients in a test-retest situation (see Table 5.4). However, before any confidence can be placed in the data a key question which has to be answered concerns what can be done in order to explain the poor levels of test-retest agreement (defined as *Kappa* <0.4) by need items for key-workers and clients? Need items which showed poor levels of test-retest agreement for key-workers included: needs for

'5. Washing';
'7. Going to the toilet';
'11. Post';
'16. Safety';
'26. Motivation';
'28. Needing a care plan'; and
'31. Needing help with physical difficulties'.

Need items to show poor levels of test-retest agreement for clients included:

'1. Shopping';
'5. Washing';
'10. Using a phone';
'11. Post';
'12. Getting out and about';
'16. Safety';
'17. Local acceptance';
'18. 'Spare time';
'20. Contact with other people';

'21. Needing a club to use';

'24. Medication';

'28. Needing a care plan'; and

'30. Advocacy'.

Items where key-workers and clients each showed poor test-retest agreement included

'5. Needing help with washing';

'11. Post';

'16. Safety'; and

'28. Needing a care plan'.

Results: possible explanations.

In general, several explanations are possible for these results. In the first instance we need to examine the possibility of 'response error' due to the design of the assessment of need schedule. For example, not only was there poor agreement for some need items by clients but also by key-workers. Clearly, we also need to look at Cohen's (1960) idea that disagreement may be real in that it simply is disagreement. A third possible explanation might be related to a response bias which concerns the fact that it might be foolhardy to expect client and key-worker test-retest agreement to be high for needs which require high levels of inference and which may be subject to different frames of reference and value judgements in terms of what is 'ordinary' over time (Carter et al., 1995). In addition *Kappa* coefficients can be very low compared to levels of percentage agreement due to a substantial skew in the distributions of the ratings (Feinstein and Cicchetti, 1990). For example, examination of Table 5.4 shows *Kappa* values for 'Washing' (*Kappa* -0.5, percentage agreement 89%) for clients; and 'Needing help to feel safe' (*Kappa* -0.5, percentage agreement 89%) for key-workers; to be very low compared to levels of percentage agreement. This difficulty with misleading *Kappa* coefficients is partly related to the situation where for example, the presence of need is infrequent. The resultant skew in a test-retest situation being caused by a change in response by one individual, thereby undervaluing *Kappa*. For example, examination of the raw data shows that the one client

who rated a need for help with washing at Time 1 was concerned with the delusional idea that fungi in the bathroom had a significance related to the Devil. The need for help with this item was rated as very important. At Time 2 the client reported that no need existed for this item, providing some evidence for real change in a client's subjective need status. In this sense, and without the benefit of more detailed data, test-retest might interpret true change as measurement instability. This suggests clear reason to examine the relationship of client self-reported need with key-worker perceptions of need, client mental state and levels of dependency.

Client need, key-worker perceptions of client need, mental state and levels of dependency.

A fairly moderate positive relationship was found between levels of total key-worker perceived need scores and levels of total client expressed need scores (r 0.36, p .001). The derivation of a 'Need Difference Score' (Figure 5.2) provides potential for several possible interpretations including concerns that of the majority of 'Need Difference Scores' which seem to represent an under-reporting of need by clients compared to key-workers. One possible explanation for this finding is that under-reporting might be related to a general social undesirability of expressing need in a self-report situation. A second interpretation relates to clients who over-report or inflate their needs for attention, representing what might be described as a 'complaints' bias. Additionally someone might not know what their needs are because of time or disorientation - that is a client might not be able to recall whether or not they needed support. Table 5.10 shows that correlating BPRS item 'Disorientation' with the total need scores for key-workers and clients shows a relationship for key-workers but no relationship for clients. Although weak, the data does offer some support for this view. A fourth interpretation has to do with the observation that the sample consists of long-term mentally ill people who have a diagnosis of schizophrenia and the finding that schizophrenics lack insight into their illness (for example, David, 1990). Following on from this, and by using what data there is available, it seems reasonable to interpret the 'Need Difference Score' as 'quasi insight' in the sense that clients seem to have less insight into their needs compared to key-worker perceptions of those same needs. Further evidence of this latter view point is found by examining data in relation to levels of

client dependency. REHAB total general behaviour scores were not associated with total client need scores. However, a significant relationship was found between total key-worker need scores and individual levels of client functioning. However, it must be noted that such an interpretation needs to be made cautiously. This is because key-workers were rating need and levels of client social and behavioural functioning at the same time. What this seems to suggest for clients is that total expressed need scores are not associated with levels of social and behavioural functioning whereas they are for the key-workers.

Summary

Data seems to reflect a complex interaction between different perspectives of an assessment of need. This raises issues with regard to reliability and validity of the need measures. This is hardly surprising given the points made in Chapter 3 where it was stated that people with a long-term mental illness may not easily understand all the questions or may reply at random or may have problems with defining or identifying need because of differing value judgements. Two difficulties here are firstly, that expectations about an individual's level of functioning might vary, and secondly, that there is no absolute standard against which to judge performance, that is, it is difficult to prescribe normal behaviour. This is partly borne out, not only by the needs data, but also by the data which related to levels of dependency. Notwithstanding these comments, rating client self-reported need has to be regarded as a methodological problem using the instrument in its present form and using measures of reliability which compare key-worker perceptions of client need with client self-reported need. As Brewin (1992) has suggested, user participation is a potentially useful data source in the assessment of need. However, quantifying and qualifying participation which is 'a potentially useful data source' seems inconclusive. What the present chapter suggests is that while different perspectives about need may conflict in general, there is some evidence to suggest that the perspective of a person with a mental illness might be no less valid. For example, when asked to rank their most important need clients rated 'Finances' whereas key-workers rated 'Mental health'. In this sense, lack of agreement between clients and key-worker assessments of need should not be dismissed as being due to inadequacies on the part of clients (Babiker and Thorne, 1993) nor in assuming that the values of key-workers are the same as those of clients (Scheff, 1961; Szasz, 1971; Littlewood and

Lipsedge, 1982). What this suggests is that the reliability of a self-report assessment of need has to consider the sample from which the needs data is obtained. As Kline (1993) points out, schizophrenics are notoriously difficult to test. Eighty-six percent of the client sample had a diagnosis of schizophrenia. In this sense, and in relation to the client reliability data, it can be speculated that what the data represent are a 'uniqueness' of need and long-term mental illness which ultimately express themselves as anomalies of self-reported need.

Conclusions.

The development of a self-report assessment of need schedule has lead to i) an attempt being made to establish whether or not people with a long-term mental illness can reliably and validly report their own needs; and ii) an attempt being made to investigate need which has been by-and-large defined normatively. Interpretation of indices of reliability by need items has not been necessarily straight-forward. Explanations have included the possibility that low levels of agreement may be real; the observation that some *Kappa* coefficients can be very low compared to levels of percentage agreement due to a substantial skew in the distributions of the ratings; the possibility that test-retest reliability might interpret true change as measurement instability; and the possibility that poor levels of test-retest agreement for both key-workers and clients might be due to some technical fault with the instrument or with the use of the instrument. Naturally, conclusions and suggestions for future use and modification of the assessment of need schedule are required if it is to work in the most basic of ways and be reliable for its intended use.

It is in relation to these points several conclusions exist in relation to Stage 1 of this thesis. The first conclusion relates to indices of reliability. Results show that an assessment of need is reported more reliably by key-workers than clients, that is key-workers are more stable over time compared to clients. The finding that only two-thirds of the client self-report need items met criteria appropriate for this type of instrument is hardly surprising given that previous chapters have indicated getting a reliable and valid response in terms of needs is potentially the most difficult part of interviewing this population. This might lead one to be sceptical about the value of the self-reported need of clients. This brings weight to the second conclusion that, in general, an assessment of expressed need is not wholly appropriate for people with a long-term mental illness compared to key-workers with the use of the present instrument. This conclusion is supported by mental state data and the finding that the BPRS factor 'Anxiety-depression' is related to total need scores for both key-worker and client groups. Such symptoms can include lack of motivation, poor concentration and indecisiveness which can adversely affect relationships and have an negative impact on role performance, (Huber et al., 1980; Braun et al., 1981; Sturt, Wykes and Creer, 1982; Bennett and Morris, 1991; O'Driscoll, 1993). Clearly, this pilot study

needs to be supplemented by further work in order to explore the qualities of a self-report assessment of need schedule. This is because it is essential to examine several questions in relation to the need items which had poor indices of test-retest reliability. For example, is poor agreement due to the sample of need items; flaws in the design of the instrument itself; a reflection of changing needs between assessments or response error due to a client's mental state? In this sense, the issue of whether or not people with a long-term mental illness can reliably and validly report their needs is far from clear-cut. Clearly, this leads to a third conclusion that it is necessary to not only refine the set of need items but also to establish further indices of reliability based on stated criteria. Several approaches exist which might help inform this situation. The first relates to refinement of the self- report assessment of need schedule, that is, amendments need to be made based on the reported results. For example, *Kappa* values may be improved by either the modification, combination or exclusion of some items based on low *Kappa* values; and an examination of need items where there has been a low response rate. The second approach has to do with the observation that overall results are complex in that correlations are not enough in themselves. Clearly, the issue of client insight is important in relation to measures of self-reported need. In this sense, if poor insight into need among a sample of long-term mentally ill is important then a better measure of insight is required if one is to attempt to establish the appropriateness of a self-report assessment of need in long-term mental illness. What this means for this thesis is that it can be hypothesised that different levels of insight might enter into the self-reporting of need. The third approach includes introducing measures of psychiatric symptomatology which rate items 1-12 of the BPRS from the perspective of the interviewer and allow self-reported measures of need to be correlated with measures of psychiatric symptomatology which incorporate an interviewer rating and do not solely rely on what the client says. As a first stage to addressing these questions, Chapter 6 describes modification of the assessment of need schedule.

Chapter 6. Modification of the approach to assessing self-reported need in long-term mental illness.

Chapter overview.

Introduction.
This chapter presents modification of the self-report assessment of need schedule.

Methodology.
Participants: Thirty-three clients from the initial sample of 57 and their respective key-workers.

Design: Survey design with repeated measures. Methods of assessment:

1) A modified schedule to assess need.
2) The Brief Psychiatric Rating Scale (Overall and Gorham, 1962).

Procedure: Completion of key-worker and client schedules involving separate interviews.

Results.
Thirty-three key-workers and clients completed the test-retest. Data show

i) Improved *Kappa* values for both key-workers and client schedules in terms of indices of test-retest reliability.
ii) No difference in total BPRS scores over time.

Discussion.
Results are discussed in terms of there being:

a) Clearer evidence in support of both the reliability of client and key-worker need schedules.
b) An base from which to further examine the reliability and appropriateness of self-reported need in people who have a long-term mental illness.
c) A platform to more usefully explore and interpret the issue of levels of agreement between key-worker and client measures of need.

Conclusions.
It is concluded that results add confidence firstly, to the use of the self-report assessment of need schedule; secondly, confidence in the hypothesis that it is appropriate to ask people with a long-term mental illness to report their own needs and thirdly, a clearer measure for further research purposes. Chapter 7 provides further examination of measures of self-reported need and gives consideration to the relationship of measures of client insight to measures of self-reported of need.

Introduction.

Chapter 5 described the first stage in the development of a new 32 item self-report assessment of need schedule. It was concluded that further work was needed in order to explore the qualities of a self-report assessment of need schedule in relation to need items which had poor indices of inter and intra reliability. The present chapter provides such an exploration.

Methodology.

Refinement of content and format.

This section presents a rationale and justification for refining the assessment of need schedule. The section is made up of two parts: Part 1 relates to the modification of content and Part 2 relates to modification of format. The final list of items for the modified schedule is then presented.

Part 1: modification of content.

This part will consider modification based on a) low *Kappa* values; and b) what respondents had to say. Consideration is also given to modification of sub-sections and item wording.

Content: Modification based on low *Kappa* values.

Need items where there was poor 'intra' and 'inter' agreement included Item 5 'Needing help with washing'; Item 11 'Post'; Item 16 'Safety'; and Item 28 'Needing a care plan'. One course of action might be their elimination. However, and because of the several explanations considered in Chapter 5 their elimination may not be wholly correct. In view of this what has been decided is the inclusion of Item 5 'Needing help with washing' and Item 28 'Needing a care plan' into other items. The decision to include Item 5 in another item was based on comments from both key-workers and clients. Comments are expanded upon in the next section 'Content: Modification based on what respondents had to say'. The inclusion of Item '28. Needing a care plan' in another item was based on comments from key-workers who felt that the item asked about something important but was under-

developed as a part of care provision, thereby leading to possible inconsistency in terms of key-worker and client responses. In terms of comments from clients in relation to Item 28 the report by most was that they did not really know what a care plan was, let alone whether or not they needed one. A decision to retain Item 13 'Post' and Item 16 'Safety' has been made on the suggestion by key-workers and clients that examples be given in order to help clarify the nature of the need. This point is developed later.

Content: Modification based on what respondents had to say.

Examination of both key-worker and client comments on need items suggested that it is possible to modify and reduce the number of need items.

Self-care.

Four need items (that is, needing help '4 Bathing', '5 Washing', '6 Dressing and '7 Using the toilet') have been combined into one 'self-care' need item. This has been done in order to try and address firstly, the 'subjective' nature of the items from key-worker and client perspectives in terms of 'value judgements'; and secondly on the basis of low levels of client responses. Qualitative statements have helped support item modification and inclusion. For example, a large number of key-workers and clients said that each of the items were 'subjective' and that it was difficult to decide 'normal standards' in terms of every-day living. However, the 'self-care' items were felt to be important. For example, in relation to 'bathing' a key-worker commenting on a client said "He needs the occasional reminder ..." and the respective client said "I need the occasional reminder". A further client said "I need help bathing if I am unwell mentally". The statement was supported by the key-worker's reply. Replies also included statements in relation to key-workers saying that clients needed 'prompts' and 'reminders' in relation to self-care from time to time. Such statements were again supported by client comments in relation to their own self-care. The new item for key-workers now reads "Does ... need help with their self-care? For example, bathing, washing or dressing?" For clients the item now reads "Do you need help with your self-care? For example, bathing, washing or dressing?"

Living situation.

Item 14 which had to do with 'the type of accommodation someone lives in' and Item 15 which asked about someone 'living where they feel they belong' were felt to ask about the same type of need. Similarly, Item 20 which had to do with clients 'needing more contact with people' and Item 21 which had to do with clients 'needing to go to a club or centre to meet people' produced the same comments. Based on these considerations Item 15 'Does ... need help to move from the type of accommodation they are in at the moment?" and "Does ... need/want to live in another area?" and the complementary item from the client assessment of need, now reads "Does ... need help to move from where they are living at the moment?" for key-workers, and "Do you need help to move from where you are living at the moment?" for clients. Analysis of key-worker and client qualitative data helped inform this modification in the following way. For example, in response to the question "Does ... need help to move from the type of accommodation they are in at the moment?" and the complementary question asked of clients, replies included reasons also applicable to the question "Do you need to live in another area?" e.g., "She has no family here". "I want the company of people my own age". "He wants to go home and live with his parents - even though this is not possible at the moment". "I don't like it here. Providing I can get a job and can pay for myself that is where I belong. I desperately want to move". "The reason I want to move is because Rhyl is noisy ... shouting and bad language. My dream has always been to live in a cottage in the country". "I am lonely where I am at the moment". Quantitative analysis showed statistically significant associations between Items 14 and15 for key-workers (Chisq 12.51, df 1, p.001) and for clients (Chisq 29.07, df 1; p.001). The same was found for Item 20 and Item 21 (key-workers, Chisq 9.9, df 1, p.001; clients, Chisq 9.0, df 1, p.001).

Physical needs

Infrequent responses and comments in relation to Item 31 'Physical needs' and Item 32 'Needing help in the home' results in the two items being combined into one single item. For key-workers the item now reads "Does ... have any physical difficulties with which they need help/support?" For clients the item now reads "Do you have any physical difficulties with which you need help/support?"

Content: Modification to sub-sections

Questions in the original needs-assessment schedule contained sub-sections which invited the key-workers and clients to rate (i) the importance, and (ii) for some items the severity of an identified need. By correlating a 'total key-worker need score' with a 'total key-worker need importance score' and a 'total client need score with a total client need importance score' yields the following results: for key-workers $r = 0.9$ (p .001) and for clients $r = 0.93$ (p .001). It can be concluded that there is a statistically significant positive correlation between the two variables for each group. Correlating a 'total key-worker need score' with a 'total key-worker need severity score' and a 'total client need score' with a 'total client need severity score' produced the following results: for key-workers $r = 0.7$ (p .001) and for clients $r = 0.78$ (p .001). Similarly, it can be concluded that there is a statistically significant positive correlation between the two variables for each group. These findings, combined with analysis of the qualitative data from both key-workers and clients, has led to the questions of importance and severity being dropped and the items of need now being scaled in terms of severity. Both key-workers and clients commented that although it was possible to say whether or not a need was present it was more useful to discriminate a 'need present' in terms of 'severity' as opposed to 'importance', particularly in relation to functioning and the level of support required. For example, key-worker comments included:

- "He needed some assistance and support with his shopping. Although at the time it was only mild".

- "She needs direct support and supervision. She cannot manage alone. Her level of need is quite severe at the moment and has been for some time".

- "His needs are moderate at the moment - although they can become severe."

Client comments included:

- "Its important that I get help occupying myself during the day. As it is, I'm not capable of holding a job down. My nerves go because of the pressure. It can get severe."

- "Counselling from my key-worker or support worker is very important. It depends how severe I am. I go up and down a lot."

- "Sometimes I can't go out shopping. That's when things get bad. I need a lot of help then".

The new scale of severity is presented in Part 2 'Modification of response format'.

Content: modification of item wording.

Some items in the original schedule have had their wording slightly altered based on responses from key-workers and clients. By-and-large modification of item wording has meant that questions have been followed with examples for the purpose of clarity. This has been done on the basis of key-worker and client feed-back. For clients, for example, the question:

- "Do you need help with cooking?" now reads "Do you need help preparing a meal?"
- "Do you need help from other people to manage your money?" now reads "Do you need help to manage your money? For example, budgeting from week-to-week?"
- "Do you need help with your post?" now reads "Do you need help with your post? For example, filling in forms?"

Further alterations to the schedule include the need item "Do you need help filling your spare time?" being moved to appear after the need item concerning 'occupation'. In order

that the item concerning 'care plans' from the original schedule might be retained it has been combined with the question concerning 'Needing help to cope with life'. This now reads "Do you need help from the mental health services for example, a CPN or a Social Worker - to help you cope with life? For example, to help you develop a plan for your daily life?" The question concerning "Do you ever feel that you need protection from yourself?" has been has been included in the item asking about 'coping' in the form of a probe.

In summary, the number of need items has been reduced. To this extent the modified version of the self-report assessment of need schedule contains 24 need items in total. The strongest case presented for modification has been key-worker and client comment based on the use of the schedules. Where possible and appropriate this has been supported by quantitative analysis. Table 6.1 provides a list of need sections and need items. The changes apply to both the key-worker needs-assessment schedule. It must be noted that the principle underlying the design of the modified schedule and the approach to constructing the modified schedule has remained the same as that described in Chapter 4.

Table 6.1. Sections and need items contained within the modified schedule.

Domestic needs

1. Help with shopping
2. Help with preparing a meal
8. Help with cleaning where someone lives

Self-care needs

9. Help with self-care e.g., bathing, washing self, dressing self, and toileting
10. Help with getting up in the morning

Financial needs

11. Help with managing money

Communication needs

12. Help with using a telephone
13. Help with post

Travel needs

9. Help with getting out-and-about

Employment/occupation needs

10. Help with occupation. Including asking someone where they would like to be employed

Leisure and recreation needs

11. Help with filling spare time

Accommodation /living situation needs

12. Type of accommodation someone lives in
13. Help with feeling safe where currently living
14. Help with feeling accepted by the local community

Social networks

15. Help dealing with family difficulties
16. Needing more contact with people

Mental health care needs

17. Help with thoughts, feelings and behaviours
18. Help with medication
19. Help from someone skilled in talking to people about the way they think, feel and behave
20. Help with motivation
21. Difficulties contacting mental health services
22. Needing help from the mental health services to cope with life
23. Advocacy and having someone to help make informed choices

Physical health care needs

24. Help with physical difficulties

Other needs

25. Other Needs not mentioned

Ranking of need

26. Ranking the three most important needs.

Part 2: modification of response format

The modified schedule has items of need which have a standard format and follow the same basic structure. The first part of each item continues to ask for factual information. For example, 'Do you need help with your shopping?' However, responses are now rated in terms of severity on a four-point scale. 0 representing 'No need' and 3 'Severe need', Appendix 3 defines the ratings for clients. Appendix 4 defines ratings for key-workers. As with the original schedule need is scored:

a) present when an item falls below that which a key-worker or client perceive to be normal or ordinary functioning; and
b) absent when a key-worker or a client perceives normal and independent functioning.

The second part of the assessment proceeds to find out qualitatively why help is needed.
The third section asks respondents to rate whether or not an identified need is being met. Responses are rated on a four-point scale ranging from 0 'Need not met' to 3 'Need totally met'. Appendix 3 defines the ratings for clients. Appendix 4 defines ratings for key-workers. The fourth section asks respondents to categorise who 'meets the need' or if 'unmet' who should 'meet the need'. Responses are coded categorically as:

1 = Informal Carer e.g., family member, friend, neighbour.
2 = Formal Carer i.e., Someone paid e.g., CPN, Social Worker, Community Support/Worker.
3 = Other. Specify: ....
4 = Don't know

Questions 10 and 12 have identical formats but in addition ask the respondent to indicate where the client is or might be occupied and where someone should move to, respectively. Appendix 3 presents the modified self-report assessment of need schedule.

In summary, as with the original schedule, an attempt has been made to arrive at an appropriate balance between detail, accuracy and effort not only in collecting data but also

in how much time the person making an assessment of need has to give. In terms of method - and the use of a checklist approach to assessing need - if a question about fact is answered in the affirmative then this is followed by questions about views upon the fact. If the answer to the question is "No" there is no need for further investigation. The next section examines issues of reliability in relation to the development of the modified schedule.

Reliability.

In terms of drawing criteria for testing the reliability of the modified schedule, and the continued adoption of a checklist methodology for the assessment of need, criteria are defined as they were in Chapter 5. Therefore, to find out whether or not the schedules are reliable the following test-retest reliability measures will be examined in relation to levels of agreement as the proportion of:

i) key-worker perceptions for individual need items i.e., are key-worker perceptions for individual client need items stable over time; and

ii) client self-report responses for individual need items i.e., are client self-reports for individual need items stable over time;

Participants.

For the purpose of testing the modified version of the assessment of need schedule the sample consisted of attempting to get in touch with the original fifty-seven people with a long-term mental illness described in Chapter 5 of this thesis. This was done some eighteen months later. Of the original fifty-seven clients, thirty-three agreed to participate. Respective key-workers of the 33 clients agreed to participate also. Of those clients who did not participate 5 had deceased, 3 had been resettled due to the closure of the local psychiatric hospital, 1 was in a general hospital long-term due to physical illness; 5 were not seen on the advice of their key-worker because the clients were psychiatrically unwell; 5 had left the area; and 5 refused to be interviewed.

Clearly, it might have been advantageous to have selected a new sample. However, this was not possible due to resource limitations placed on the researcher whilst the study was under way. Potential methodological problems in terms of sample selection as a consequence include 'learning effects' and 'self-selection'. In relation to the first problem it might be argued that the same subjects should not have been used because reliability may have been improved by learning effects. This, it is argued, may be limited by the eighteen months time interval between assessments. The interval would seem long enough to reduce the risk of inflating consistency due to recall of previous responses. With regard to the second problem it might be argued that the 'less reliable' subjects may have been more likely to drop out, thus inflating reliability. However, and although the assumption cannot be tested the only method available in order to address this issue concerns a comparison of the general demographic and clinical characteristics of the client sample who did not participate. This is presented in the next section.

General demographic and clinical characteristics.

The mean age of the thirty-three participants who provided self-report data was 57.6 years (SD 14.05). The mean length-of-time spent in a psychiatric hospital was 19.06 years. The mean number of admissions was 7.0 (SD 8.0), the mean length of total time known to the mental health services was 30.5 years (SD 13.6). Twenty-nine participants (88%) were diagnosed as having schizophrenia, the remainder were diagnosed as having a personality disorder or asocial behaviour based on available case-notes.

Table 6.2 shows characteristics of the 33 clients who participated compared to those who did not. It must be noted that these data are based on measures obtained at the time the original assessment of need schedule was used, and therefore, may be limited in their generality for present purposes. Measures of those people who did participate (n=33) did not differ to a statistically significantly degree from those who did not participate (n=24). However, non-participants did have a lower mean level of self-reported need, a higher mean REHAB total deviant behaviour score; a higher mean REHAB total general behaviour score and a higher mean total BPRS score. For the purpose of defining the sample, to all intent and purpose the data suggests that participants continue to be

consistent with the most commonly accepted definition of long-stay i.e., duration of admission of over one year (O'Driscoll and Leff, 1993).

Table 6.2. Comparison of participant group with non-participant group.

Variable (Mean Values)	Participant group (n=33)	Non-participant Group (n=24)
Age (Years)	57.6	56.7
Previous admissions	7.0	9.2
Time in hospital (years)	19.0	16.7
Time known to services (years)	30.5	27.3
Key-worker perceived needs	13.0	13.3
Self-reported needs	9.3	7.6
REHAB Deviant Behaviour Score	2.4	3.0
REHAB Total General Behaviour Score	54.8	64.9
Total BPRS Score	16.0	19.1

Design.

The design adopted for examining the reliability of the modified assessment of need schedule is the same as that described in Chapter 5, that is, a survey design with repeated measures (Breakwell et al., 1995). In this sense, examination of the reliability of the modified schedule has a within subjects design which involves a comparison of an assessment of key-worker and client need between two different administrations separated by time. However, two differences exists in the present study. The first difference is that in order to strengthen the design of the test-retest situation a decision was made to not only measure client mental state at Time 1 but also at Time 2. A major advantage of doing this was to see whether or not measures of client mental state differed over time compared to measures of self-reported need. A second difference was due to limited resources and that the test-retest period was reduced to approximately one week. Clearly, a disadvantage of this decision was the potential for some loss of comparability with regard to test-retest in Chapter 5 and the possible increase in agreement by artefactual means. As a general comment the difficulty here concerns the concept of 'test-retest reliability' as the one corresponding most closely to a view of reliability as consistency or repeatability of

measurement i.e., external reliability. In this approach to reliability the same measure is applied to the same group of subjects, under similar conditions, at two different points in time. The rationale is that if the measure is assessing the characteristic consistently, those who score high (or low) on the first occasion should score high (or low) on the second. However, as Streiner and Norman (1991) say there is no standard interval between the administrations of the measurement. The individual researcher is left to decide a time period that is long enough to reduce the risk of inflating consistency. Such risk might include recall of previous responses, major fluctuations in the characteristic being measured, actual changes in symptoms, behaviour and attitudes, or because of the introduction of new interventions. Clearly, a compromise has to be reached. The position is that an interval of one week is unlikely to have encountered changes in interventions, symptoms, behaviour and attitudes. Furthermore, it is recall of previous responses is unlikely. The only guidance available in the literature where test-retest has been used in the assessment of need in mental illness comes from Marshall et al. (1995) and Phelan et al. (1995). Each of these studies used an interval of one week.

Method of assessment

Methods of assessment included the modified schedule to assess the key-worker perception of client need; a modified schedule to assess self-reported need; an instrument to assess the mental state of the client making the self-report of need.

Procedure.

Key-workers and clients were contacted approximately one week prior to the initial assessment and asked if they would be willing to participate. A brief description of the research project was given and a time was set to complete the modified schedules. Completion of the key-worker and client schedules involved separate interviews on the same day by the same researcher. With regard to clients, the psychiatric interview was conducted first, followed by a self-report assessment of need. This procedure took about forty-five minutes. Ratings on the BPRS were completed immediately after each interview in the absence of the client. When it came to responding to questions about the severity of need and whether or not need was being met clients and key-workers were given a card

with the response categories written on it if they needed it for reference. Similarly, when it came to ranking need clients and key-workers were shown the list. All thirty-three clients and respective key-workers agreed to participate in the test-retest approximately one week later.

Results.

Results are presented in terms of general information, data reduction procedures, indices of reliability and some basic descriptive statistics. For the purpose of this Chapter and indices of reliability, results will be limited to an examination of the key-worker perception of client need data and client self-reported need data and total BPRS scores.

General Information.

Each subject was given an identification number and separate databases were created for key-worker and client responses to the assessment of need questions using FoxBase+ (Fox Software, 1988). All data were subsequently transferred to the University College of North Wales UNIX computer called 'Thunder' for statistical analyses. The SPSS-x (SPSS Inc., 1988) package was used for analyses. In terms of data reduction, and for the purpose of analyses of the key-worker perception of need and self-report need, items have been analysed independently and as respective total need scores. In order that this might be done, and for ease of presentation as well as comparability with data generated with the use of the original schedule, 'Need present' based on the modified schedule has been calculated by combining the categories of 'Mild', 'Moderate' and 'Severe'. In this sense, for the purpose of reliability, scores have been dichotomised as follows: 0 = 'Need absent' and 1 = 'Need present'.

Reliability: Test-retest for need items

Table 6.3 presents test-retest measures of agreement as the proportion of responses for key-workers and clients (N=33) for the twenty-four individual need items. In this instance *Kappa* measures the degree of agreement as the proportion of responses for the 24 need items at Time 1 and Time 2 with the use of the modified schedules; thereby, allowing a comparison of the measure of agreement for each of the 24 need items over time in a within-subjects design.

The result of cross-tabulating the presence or absence for individual need item ratings for key-workers (N=33) shows that seven of the twenty-four (29%) items had *Kappa* values ≥ 0.4 and < 0.7. Representing fair to very good agreement beyond chance. Seventeen of

the twenty-four (71%) items for key-workers had *Kappa* values >0.7 representing 'Excellent agreement beyond chance'. No items had *Kappa* values <0.4. Results for client self-reported need shows that twenty-three of the twenty-four (96%) items had a *Kappa* value >0.4. This compared to eighteen of the thirty-two (56%) items for the clients with use of the original self-report assessment of need schedule. Fifteen of the twenty-four (63%) items had *Kappa* values ≥0.4 and < 0.7 representing fair to very good agreement beyond chance. Eight of the twenty-four (33%) items had *Kappa* values >0.7 representing excellent agreement beyond chance. One item (13. Acceptance) had a *Kappa* value <0.4.

Table 6.3. Test-retest measures of agreement for key-workers and clients by individual need items.

Need item	***Kappa* (%) Key-workers**	***Kappa* (%) Clients**
1. Shopping	**1.0 (100)**	**0.81 (91)**
2. Preparing a meal	**0.8 (94)**	**0.6 (81)**
3. Cleaning	**0.67 (91)**	**0.5 (78)**
4. Self-care	**0.64 (87)**	**0.46 (74)**
5. Getting up	**0.74 (88)**	**0.6 (81)**
6. Money	**0.4 (78)**	**0.5 (75)**
7. Phone	**1.00 (100)**	**0.6 (83)**
8. Post	**0.84 (97)**	**0.5 (75)**
9. Out & about	**0.86 (94)**	**0.8 (91)**
10. Occupation	**0.53 (78)**	**0.77 (90)**
11. Move accommodation	**0.87 (97)**	**0.54 (80)**
12. Safety	**0.8 (94)**	**0.43 (87)**
13. Acceptance	**1.00 (100)**	0.14 (81)
14. Spare time	**0.87 (94)**	**0.67 (91)**
15. Family	**0.9 (97)**	**0.64 (94)**
16. Contact	**0.74 (92)**	**0.71 (90)**
17. Thoughts	**0.71 (87)**	**0.63 (86)**
18. Medication	**0.71 (87)**	**0.69 (84)**
19. Counselling	**0.6 (81)**	**0.59 (87)**
20. Motivation	**0.73 (88)**	**0.7 (86)**
21. Contact Services	**0.65 (97)**	**1.00 (100)**
22. Coping	**0.65 (97)**	**0.61 (92)**
23. Advocacy	**0.89 (97)**	**0.89 (97)**
24. Physical	**0.86 (94)**	**0.72 (88)**

Basic descriptive data

Table 6.4 shows that key-workers reported higher mean total need scores when compared to clients. At first interview, using the modified schedules, the mean total number of needs identified by key-workers was 12.6 (SD 3.5) and the mean total number of needs expressed by clients was 7.6 (SD 4.9). Key-workers reported 37% more total need than clients. This represents a ratio of 1 client expressed need to 1.7 key-worker perceived needs. This compares to a ratio of 1 client expressed need to 1.5 key-worker perceived needs reported in Chapter 5. The mean total BPRS score was 20.1 (SD 10). This compares to a mean of 17.4 in Chapter 5. There was no statistically significant difference between total BPRS scores on test-retest.

Table 6.4. Needs identified by key-workers and expressed by clients.

Group	Mean (SD)	Min-Max	Sum
Key-workers	12.6 (3.5)	2-17	398
Clients	7.6 (4.5)	0-19	251

Table 6.5 shows that Item 22 'Needing help to cope with life' rated as the most frequent need perceived by key-workers. Item 22 'Needing help to cope with life' rated as the most frequent need reported by clients. Item 22 'Needing help to cope with life' rated as the most frequent need reported by key-workers and clients with the use of the original schedule. The least number of needs perceived by key-workers with the modified schedule occurred with the item related to Item 21 'Getting in touch with mental health services'. This need item was the same as that reported by key-workers using the original schedule. The least number of clients expressing a need with the modified schedule occurred with the item related to Item 21 'Getting in touch with mental health services'. With the use of the original schedule the least number of clients expressing a need occurred with the items related to self-care.

Table 6.5. Frequency of individual need items for key-workers and clients (N=33).

Need item	Key-workers (%)	Clients (%)
1. Shopping	25 (76)	15 (45)
2. Preparing a meal	27 (82)	15 (45)
3. Cleaning	25 (76)	18 (58)
4. Self-care	25 (76)	11 (36)
5. Getting up	14 (42)	10 (30)
6. Money	24 (72)	17 (51)
7. Phone	11 (48)	8 (30)
8. Post	27 (88)	17 (51)
14. Out & about	20 (51)	10 (33)
15. Occupation	21 (77)	10 (30)
16. Move accommodation	5 (18)	10 (29)
17. Safety	7 (24)	3 (12)
18. Acceptance	9 (30)	5 (15)
19. Spare time	15 (45)	5 (18)
20. Family	8 (24)	4 (15)
16. Contact	7 (21)	7 (24)
17. Thoughts	22 (70)	7 (21)
18. Medication	21 (67)	17 (51)
19. Counselling	14 (42)	7 (27)
20. Motivation	20 (60)	10 (33)
21. Contact Services	2 (6)	1 (3)
22. Coping	31 (97)	27 (85)
23. Advocacy	5 (24)	7 (27)
24. Physical	11 (33)	10 (30)

Discussion.

The objective has been to modify the original self-report assessment of need schedule in order to further obtain data from key-workers and clients so that indices of test-retest can be made on the presence and absence of need. In general, results suggest improved indices of test-retest agreement for key-workers and for clients as described by Landis and Koch (1977). This was set against a situation where there was no significant difference between total BPRS scores over time. This finding a) provides a different result in terms of the modified schedule's reliability to measure need over time; b) shows that people with a long-term mental illness can report their needs reliably in a test-retest situation; and c) suggests that the use of the modified schedule is appropriate for this sample. Only one client need item showed a poor level of agreement, namely, Item 13 'Needing help to feel accepted by the local community'. This item related to a low *Kappa* coefficient compared to a high level of percentage agreement due to a substantial skew in the distributions of the ratings (Feinstein and Cicchetti, 1990).

In the main, by addressing the issue of refinement of the sample of need items and flaws in the design of the original schedule itself as possible explanations for poor test-retest indices of agreement, has resulted in a finding more in line with that of MacCarthy et al., (1986) from a client perspective. That is, there is some evidence to support the idea that people with long histories of serious psychiatric disorder can respond to a structured interview with questionnaire type measures in a reliable way over time. However, a number of points are worth noting. Firstly, indices of key-worker test-retest agreement (Mean *Kappa* 0.77 for the 24 need items) show proportionately better mean levels of agreement compared to people with a long-term mental illness (Mean *Kappa* 0.63 for the 24 need items). This suggests that key-workers are 'more reliable' than clients in terms of reporting perceived client needs over time. Secondly, a disadvantage of the sampling procedure is that it excluded those who might have been in more need e.g., some were too unwell psychiatrically. Whether or not such an exclusion would have altered the results of this study remains an untested assumption. Thirdly, it might be argued that changes to the schedule seemed to improve indices of test-retest agreement by artefactual means. For example, by using the same subjects and reducing the test-retest to one week etc. Although

plausible, whether or not such an approach has altered the results of this study remains an untested assumption and is partly mitigated against by comments made earlier in this chapter. However, whilst acknowledging these points, data do seem to provide:

a) clearer evidence in support of the self-report of need schedule's reliability, that is, the instrument seems to provide a reliable measurement of self-reported need in that clients were able to respond consistently over time;
b) an empirical base from which to further examine the reliability and validity of self-reported need; and
c) a platform to more usefully explore and interpret the issue of levels of poor agreement between client and key-worker measures of need.

Based on these results it would seem that the method used to gather test-retest reliability data is satisfactory for what has earlier been described as essentially a 'judgmental task'. In this sense, there is some evidence to support the view that the sample of key-workers and people with a long-term mental illness do agree sufficiently well within themselves in terms of the investigation undertaken. However, the abiding issue remains that of asking 'Do people with a long-term mental illness and their respective key-workers agree sufficiently between themselves in terms of an assessment of need?' The point is that the level of agreement achieved with the modified assessment of need schedule for key-workers and people with a long-term mental illness provides a set of items which can be accepted as evidence of very good within key-worker and within client test-retest agreement. The issue is now what use can be made of it, particularly in terms of why are people with a long-term mental illness indicated as 'less reliable' in a test-retest situation? The reader will recall from Chapter 5 that indices of within client reliability showed poor levels of agreement for 13 of the 32 items of self-reported need and that inter client:key-worker agreement was reported as poor. Three possible explanations offered for this were firstly, clients and key-workers having different value judgements; secondly, the hypothesis that what the data represented were 'anomalies' of client self-reported need which were related to client mental state; and thirdly, that modifications be made to the instrument in order that any flaws might be identified. Having focused on the latter of these three possible explanations

it would seem that amendments based on the modification, combination or exclusion of some need items has improved reliability in a test-retest situation.

Conclusion.

These results add firstly, confidence to the use of the modified schedule for the purpose of this thesis; secondly, confidence in the assumption that people with a long-term mental illness can report their own needs reliably over time and c) a clearer measure for further research purposes. In this sense, the numerical quality of the scores and the interpretation of the various analyses is more straight forward. However, there still remain both conceptual and methodological issues in establishing a rating of what 'need' might be with respect to key-worker and client perspectives. What seems crucial to further analysis is how an assessment of need which is defined normatively relates to a measure of self-reported need by people with a long-term mental illness. Based on the results of this chapter and in order to address these questions, Chapter 7 gives consideration to the following issues:

a) the relationship of measures of client insight to measures of self-reported of need;
b) the introduction of measures of psychiatric symptomatology which incorporate an interviewer rating and do not solely rely on what the person with a long-term mental illness says; and
c) examination of the validity of measures of self-reported need in people with a long-term mental illness.

Chapter 7. The Validity of Self-reported Need in Long-term Mental Illness.

Chapter overview.

Introduction.
The objective of this chapter is to see whether or not people with a mental illness can report their own need validly.

Methodology.
Participants: Clients (N=160) and their respective key-workers. Mean age 42 years. Forty percent female. Most frequent diagnosis schizophrenia. Eighty percent known to the services for more than five years.

Design: Survey approach.

Methods of assessment:

i) key-workers and client assessments of need;
ii) REHAB (Baker and Hall, 1983);
iii) Brief Psychiatric Rating Scale (Overall and Gorham, 1962);
iv) The Krawiecka Rating Scale (Krawiecka et al.,1977); and
v) The Insight Scale (Birchwood et al., 1994).

Procedure: completion of key-worker and client schedules involving separate interviews.

Results.
Results indicate:

- a moderate correlation between the key-worker assessment of client need schedule scores and measures of social and behavioural functioning;
- a positive relationship between levels of total key-worker perceived need scores and total client expressed need scores;
- a moderate correlation of key-worker perception of client need scores with measures of mental state; and
- a moderate correlation of client self-report assessment of need scores with measures of mental state.

Discussion.
Overall, results provide some support for the idea that the need schedule is firstly, construct valid and secondly, that it is psychometrically sound to use the need schedule. However, although the results are encouraging, they do not go without qualification. Consideration is given to the validity of the self-report needs of people with a long-term mental illness in relation to key-worker needs data, measures of insight and measures of mental state.

Conclusions.
The main conclusions to be drawn from the results are

- that under-reporting of need by people with a long-term mental illness is more probable than over-reporting;
- establishing the validity of a self-reported assessment of client need has to be regarded as a methodological problem;
- data reflect a complex interaction between different perspectives of an assessment of need and raise a number of issues with regard to validity of client's self-report need measures.

Introduction.

Chapter 6 established that the need items employed are reliable for key-workers on test-retest and that the same need items are reliable for people with a long-term mental illness on test-retest. The objective of the present chapter is to see whether or not people with a long-term mental illness can report their own need validly. This is because it cannot be assumed that because people with a long-term mental illness can report their needs reliably in a test-retest situation that they can do so validly. Indeed, there are two points at issue for this thesis. The first concerns the potential for levels of poor agreement by need items between key-workers and people with a long-term mental illness. The second concerns the observation that some people with a long-term mental illness do not recognise that they are suffering from such an illness (Amador et al., 1994).

If one accepts that people with a long-term mental illness are 'unaware' of their illness then it seems reasonable to assume that they will also be unaware of their needs. Hence, for example, the requirement for rehabilitation of the long-term mentally ill and the identification of needs by mental health professionals (Watts and Bennett, 1991). Although contentious, one argument for the identification of needs by mental health professionals, is the assumption that the self-report of needs by people with a long-term mental illness might be questionable and invalid (see Chapter 3 of this thesis). In order to try and address this issue the basic approach of this thesis is to continue to use a normative perspective due to the uncertainty that all clients can equally self-report their needs (Brewin, 1992). In this sense, the first step is to examine the concurrent validity of the key-worker needs assessment schedule. The second step is a test of client validity using key-worker needs data. The third step is an examination of those characteristics which distinguish the more valid clients responses from the less valid responses in a self-report assessment of need situation. In order that this might be done this chapter gives consideration to:

a) issues of validity;
b) the use of key-worker needs data to help verify the validity of client needs data; and
c) the use of measures of client mental state and insight to help examine factors related to client self-report need measures.

Validity

Chapter 3 showed that there is no one validity coefficient. The point was made that it is never sufficient to demonstrate that a test or assessment is reliable and then assume that it must be valid. One approach to validating a new measure is to correlate the new measure against other scales that purport to measure the same construct. The difficulty with this approach is that of finding a suitable convergent or concurrent measure. Therefore, for the purpose of this thesis, it is necessary to find a suitable convergent or concurrent measure and to describe what criteria might be used appropriately. However, before this task is undertaken, and by way of a reminder, two points need to be made. Firstly, testing for validity in relation to 'need' in mental health may be limited because 'need' involves making value judgements. Secondly, validity is limited by cultural and social factors which determine the appropriateness of skills. For example, domestic needs and self-care needs in long-term mental illness. Therefore, what criteria can be used in order to validate an assessment of need schedule in long-term mental illness?

Validity: criteria for the new schedule.

In order to strengthen confidence in any conclusions about the validity of client self-report assessments of need this thesis seeks to examine four approaches. These include: face validity, content validity, convergent (concurrent) validity and construct validity.

Face validity and content validity.

Face validity and content validity have been discussed in Chapter 3 of this thesis.

Convergent (concurrent) validity.

Because one of the approaches to establishing the validity of client self-report assessments of need is to use key-worker needs data, the validity of the key-worker needs assessment schedule requires examination. Several authors (e.g., Streiner and Norman, 1991; Kline, 1993) who write in the area of instrument development suggest that in attempting to establish convergent (concurrent) validity the most common practice is to correlate the new instrument with another instrument which comes close to measuring the same underlying construct. Convergent validity is defined as the correlation of a scale with some other

measure of the hypothesised construct under study, ideally, a 'gold standard' which has been used and accepted in the field. Moderate correlations of around 0.4 to 0.5 are considered acceptable (Vogt, 1993). In order to address this issue the REHAB (Baker and Hall, 1983) has been used. The decision to use the REHAB relates to the fact that the design of the needs-assessment schedule is based on the concept of functioning, and at the time of the present study the REHAB was possibly the only instrument in the literature which approximated an assessment of a key-worker's perception of functioning whose reliability and validity were well enough documented to provide a 'gold standard'.

Construct validity.

In order to establish the construct validity of self-reported need three approaches are possible. The first approach is to consider the use of *Kappa* (Cohen, 1960). This involves the proposition by Wackerly and Robinson, (1983) and Feinstein and Cicchetti (1990) that the use of *Kappa* be extended as an index of construct validity. The second approach is an exploration of the relationship between total key-worker perceived need scores and total client self-reported need scores. The third approach is an examination of total need scores in relation to ratings of mental state and insight. The benefit of this latter approach to construct validity would be that it can be hypothesised that the higher the mental state and insight scores, the higher the need scores will be associated with them.

Mental state.

Chapter 5 said that psychiatric symptomatology which incorporates an interviewer rating is an important variable in determining a clearer understanding of self-reported client need. One limitation of the BPRS concerns items 1-13. In order to address this issue this section describes an instrument intended to provide a more accurate picture of psychiatric symptomatology which incorporates a more explicit measure of an interviewer rating.

Psychiatric symptomatology: rater observation.

Mitchell et al., (1995) recommend the Krawieka Rating Scale (Krawiecka, Goldberg and Vaughan, 1977) as a measure of psychiatric symptomatology which incorporates an interviewer rating. Like the BPRS (Overall and Gorham, 1962) the KRS is used by a

trained interviewer who rates each scale from the interviewees' behaviour and verbal reports. Ratings are based on explicit criteria for assigning subjects to one of the five points on the eight scales. Although there is considerable overlap in the symptom constructs covered by the BPRS, KRS ratings do not only include information based on what the client has said but also include the actual behaviour observed at interview. This is different to the BPRS, when behaviours observed by the interviewer are rated separately for a limited number of items i.e., 13-21 and do not include items like 'Depression' and 'Anxiety'. The KRS is more fully described in the Method section of this chapter.

Insight.

The concept of insight will be introduced by focusing firstly, on the importance of insight in mental illness and secondly, on self-report measures of insight. The reason for doing this is to examine the relationship of insight to measures of self-reported need. If a relationship is found it can be argued that such a measure might inform the issue of the validity and appropriateness of self-reported measures of need.

The importance of insight in mental illness.

One of the earliest definitions of insight in mental illness is that of Lewis (1934) which states that insight is 'a correct attitude to morbid change in oneself'. Other, and more recent definitions include 'the acknowledgement of some awareness of emotional illness' (Carpenter; Strauss and Bartko, 1973); a 'Yes' response to questions about needing to be in a hospital or see a doctor (Lin; Spiga and Fortsch, 1979); ratings based on whether or not in-patients vigorously denied they were disturbed (The World Health Organisation; 1978); knowledge or awareness of being ill (Freud, 1981) and 'the patient's ability, during the early phase of decompensation, to recognise that he or she is beginning to suffer a relapse of his or her psychotic illness' (Heinrichs; Cohen; Carpenter, 1985). These definitions highlight different understandings of insight in mental illness, ranging from psychological defence mechanisms to cognitive deficits.

Measures of insight.

Several studies have used a multidimensional approach to measuring insight. For example, McEvoy, Freter, et al. (1989a) observed that involuntarily committed schizophrenic patients demonstrated significantly less insight compared to voluntary patients. Furthermore, McEvoy, Apperson, et al. (1989b) found that degree of insight was not consistently related to severity of acute psychopathology and that changes in insight during hospitalisation did not vary consistently with changes in acute psychopathology. David et al., (1992) examined insight in a mixed sample of psychotic patients; concluding that a total insight score was inversely correlated with a global measure of psychopathology. Age, gender and patient diagnosis having little effect on levels of insight. More recently, Michalakeas, Skoutas, Charalambous and Peristeris (1994) examined insight in relation to acute exacerbation's of schizophrenia, mania, and depression. Psychopathology was assessed using the BPRS (Overall and Gorham, 1962) and insight was assessed with the ITAQ (McEvoy et al., 1989b). The study found that the more severe symptoms in the schizophrenic group were related to poorer insight only on assessment at discharge from hospital, whereas the manic group showed a consistent negative correlation between severity of symptoms and degree of insight on admission, 15th, 30th, and discharge day. The depressive group showed a non-significant relationship between insight and psychopathology ratings throughout. From these results, one can speculate that factors other than psychopathology may be responsible for changes in awareness in the schizophrenic group (such as neuropsychological deficits), whereas psychopathology may be implicated in the changes in insight observed in the manic group.

In view of these points, several authors have argued for a continuum of insight (David, 1990; Markova & Berrios, 1992; Amador et al., 1993; Birchwood, Smith, Drury and Healy, 1994). This approach to the definition and measurement of insight in mental illness is seen as being necessary if, for example, one is to take account of the patient who acknowledges the presence of some symptoms (e.g., poor social relationships) but not others (e.g., anhedonia) or who denies being disturbed or ill but accepts pharmacotherapy because he or she feels that it is helpful (Amador et al., 1993). In order to address this issue David (1990)

has proposed a modality-specific approach to insight. The model consists of three distinct, overlapping dimensions of insight:

1) the recognition that one has a mental illness;
2) the need for treatment; and
3) the ability to re-label unusual mental events (delusions and hallucinations) as pathological.

In essence, the approach attempts to acknowledge that people with a mental illness might have insight into some signs or symptoms of their illness but not others. Examples of self-report measures of insight include Markova and Berrios (1992) and Birchwood et al., (1994).

Markova and Berrios (1992) examined insight in 43 patients with diagnoses of either schizophrenia or depression in relation to: hospitalisation; mental illness in general; perception of being ill; changes in the self; control over the situation; perception of the environment; and wanting to understand one's situation. Measures of psychopathology were rated with the use of the BPRS (Overall & Gorham, 1962). Results suggest a difference in the nature of insight shown in patients with a diagnosis of schizophrenia compared to depression. Poor insight was related to more severe psychopathology on admission to hospital in patients with a diagnosis of schizophrenia whereas for the depressive group, more severe symptoms were correlated with poor awareness of illness on discharge. The self-report assessment of insight developed by Birchwood et al., (1994) contains items designed to measure the three dimensions of insight proposed by David (1990): awareness of illness, re-labelling of symptoms, and need for treatment. The instrument has been shown to have good reliability both for single administrations and test-retest evaluations and to be valid and sensitive (Birchwood et al., 1994). The authors claim the instrument to be acceptable to seriously disturbed patients who could complete the questionnaire both quickly and reliably. Moreover, the instrument has been found to discriminate individual differences and individual change over time with regards to levels of insight.

In summary, the objective of this chapter is to see whether or not people with a mental illness can self-report need validly. This introduction has discussed how measures of self-reported need might be validated. Consideration has been given to the development of a key-worker assessment of need schedule as a means of validating a client assessment of need schedule; and issues of mental state and insight. The rationale is to use measures of insight to explore the uncertainty that all patients can equally self-report their needs. In view of this comment a decision has been made to use the instrument developed by Birchwood et al., (1994). This is because the scale has been shown to be firstly, both reliable and valid as a measure of self-reported insight; secondly, acceptable to people with a serious mental illness; and thirdly, contains items designed to measure three hypothesised dimensions of insight into mental illness namely: 'Awareness of illness', 'Re-labelling of symptoms', and 'Need for treatment'. Finally, the instrument is reported to be quick and easy for respondents to complete. In relation to psychiatric symptomatology and an interviewer rating a decision has been made to use the Krawieka Rating Scale (Krawiecka, Goldberg and Vaughan, 1977) in order to gain more information in relation to an interviewer rating of a client's mental state. Both the Insight scale developed by Birchwood et al., (1994) and the KRS (Krawieka et. al., 1977) are described more fully in the Methodology section of this chapter.

Methodology.

This section describes participants, design, procedure and instruments used in order to examine the validity of the self-report needs data.

Participants.

In order to examine the validity of the modified self-report assessment of need schedule data will be analysed using a sample of 160 clients who have a long-term mental illness and their respective key-workers. In the main key-workers were Community Psychiatric Nurses. Some key-workers were either Approved Social Workers, Social workers, Occupational therapists or psychiatrists. All people with a long-term mental illness were cases on four established Community Mental Health Team caseloads in North Wales. The client sample was selected according to the following criteria:

- a diagnosis of long-term mental illness;
- living in the community;
- receiving continuing mental health care and support from the team; and
- had a mental health service key-worker.

It must be noted that at the time of data gathering for the purpose of the present chapter, the local large psychiatric hospital had closed down and considerable mental health service re-organisation had taken place. The sample can best be described as a 'purposive sample' (Kidder and Judd, 1986).

General demographic and clinical characteristics

Table 7.1 shows that the mean age was 42 years. Forty percent of the sample were female. Almost eighty percent of the sample had been known to the services for more than five years. By-and-large it was not possible to determine the mean number of admissions nor the mean length-of-total time spent in hospital from case-notes.

Table 7.1. A comparison of participant demographic and clinical characteristics (n=160).

Variables	Sample
Mean Age	42 (SD 12.5)
Gender	
Female	64 (40%)
Male	96 (60%)
Diagnosis	
Schizophrenia	94 (59%)
Depression	34 (21%)
Personality	6 (4%)
Other	9 (6%)
Missing	17 (10%)
Time known to services	
Less than 2 yrs	19 (12%)
3-5 yrs	14 (9%)
6-10 yrs	39 (24%)
10 yrs plus	88 (55%)
Living situation	
Independent	72 (45%)
With family	34 (21%)
With staff	52 (33%)
Mean Total BPRS scores	15.8 (SD9.8)

Design.

Survey design.

Methods of assessment

- The modified schedule to assess self-reported (Appendix 3);
- The modified schedule to assess key-worker perception of need (Appendix 4);
- The BPRS (Overall and Gorham, 1962);
- The REHAB (Baker and Hall, 1983);
- The Krawiecka Rating Scale (Krawiecka et al.,1977); and
- The Insight Scale (Birchwood et al., 1994).

Krawiecka Rating Scale (Krawiecka et al.,1977).

The Krawiecka Rating Scale (Krawiecka et al.,1977) provides a method for making a rating of psychiatric symptomatology which incorporates an interviewer rating. The instrument comprises eight 5 point scales rated from 0 'Absent' to 4 'Severe'. The scales are shown in Table 7.2. The full instrument can be found in Appendix 6.

Table 7.2. KRS scales

1. Depressed	5. Incoherence of speech
2. Anxious	6. Poverty of speech
3. Coherent delusions	7. Flattened affect
4. Hallucinations	8. Psychomotor retardation

The Insight Scale (Birchwood et al., 1994).

The Insight Scale (Birchwood et al., 1994) is a self-report structured questionnaire comprising of eight questions related to the respondents' insight into their mental illness. The scale provides a total score of 12. There are three possible answers for each question: 'agree', 'disagree', or 'unsure'. Each question is scored with a 0, 1, or 2, depending on which of the three possible responses the subject chooses. Factor analysis provides three sub-scales: items 1 and 8 contribute to the 'Attribution of symptoms' sub-scale; items 2 and 7 make up the 'Awareness of illness' sub-scale and items 3, 4, 5 and 6 contribute to the 'Need for treatment' sub-scale. A higher total score indicates more insight, with a maximum possible score of 12. Birchwood et al., (1994) suggest that a score of 9 represents a cut-off point indicative of having insight. One slight, but necessary modification to the wording of one item of the original scale has had to be made. This has had to be done because this chapter has focused on people with a long-term mental illness living in the community as opposed to being in hospital. To address this issue question 4 of the scale developed by Birchwood et al., (1994) has been changed from 'My stay in hospital is necessary' to say 'My seeing someone from the CMHT is necessary'. In order to maintain comparability with Birchwood et al., (1994) the coefficient alpha (Cronbach, 1951) has been calculated as an index of reliability based on a single administration of the test. The alpha coefficient is high 0.78 (n=160). This compares to an alpha coefficient of 0.75 (n=133) (Birchwood et. al., 1994). In this sense, and with the slight change to the wording of one of the items in the original scale, it may be concluded that the scale is assessing a stable characteristic that

underlies client's responses to the individual items. Appendix 7 provides a copy of the amended scale and how it is scored.

Procedure.

The procedure follows that described in Chapter 4. Briefly, key-workers were required to complete the assessment of need and the REHAB. Interviews with clients included a psychiatric assessment being made at each interview, followed by an assessment of self-reported need, followed by completion of the self-report assessment of insight.

Results.

Results are presented in terms of:

- general information;
- convergent (concurrent) validity;
- raw needs data provided by key-workers and clients;
- the relationship of key-worker and client needs data;
- the relationship of key-worker and client needs data to mental state; and

General Information

Each subject was given an identification number and separate databases were created for each measurement instrument using FoxBase+ (Fox Software, 1988). All data were subsequently transferred to the University College of North Wales Thunder mainframe for statistical analyses. The SPSS-x (SPSS Inc., 1988) package was used.

Data reduction

Key-worker needs data and client self-report needs data have been analysed by individual items and as total scores. REHAB, BPRS data and the self-report assessment of insight data have been analysed as total scores and by computing factor or sub-scale scores. Five items that do not contribute to BPRS factor scores include: Disorientation, Motor hyperactivity, Elevated Mood, Distractibility, and Incomprehensible Speech. Four composite scores were also computed for the KRS. These included: Anxious-Depressed (anxiety and depression), Thought Disorder (hallucinations, delusions, and incoherent speech), Poverty (poverty of speech, flattened affect, and motor retardation), and a total score.

Interviews

Interviews with key-workers took approximately twenty minutes to complete and forty-five minutes for clients. All clients (n=160) completed the self-assessment of need and Birchwood et al's., (1994) Self-report Insight Scale. Three clients failed to complete the psychiatric interview.

Convergent (concurrent) validity.

In order to examine the convergent validity of the key-worker assessment of need schedule, key-worker measures of total need have been correlated with scores on the REHAB (Baker and Hall, 1983). The mean 'Total General Behaviour Score' was 33 (SD 23.2) suggesting that the client sample as a whole ranged from having "... a need for training and experience in relation to living in the community" to "Could only live out if supervised". Indicating that the group as a whole is dependent in terms of measures of social and behavioural functioning. The correlation of key-worker total need scores with REHAB total general behaviour scores provides some support for the convergent validity of the key-worker assessment of need schedule, r 0.42, p .001. This suggests 'total key-worker need scores' are significantly associated with levels of social and behavioural functioning as measured by the REHAB. On this basis it can be concluded that there is some evidence to support the idea that the key-worker assessment of need schedule has convergent validity. That is, the correlation coefficient falls within the range 0.4 - 0.5 described by Vogt (1993) as acceptable. This suggests that key-workers seem to perceive need in terms of individual levels of client functioning. However, one limitation of the approach is that key-workers not only provided information in relation to client need but also the REHAB. Clearly, there is potential for response bias. This may therefore limit the interpretation of the result.

Raw needs data: key-workers and clients.

Key-workers reported a higher mean total need score compared to clients. The mean total number of needs identified by key-workers was 9.2. The mean total number of needs expressed by people with a long-term mental illness was 6.3. This represents a ratio of 1 client expressed need : 1.4 key-worker perceived needs. An independent two-tailed t-test showed a statistically significant difference between measures of client and key-worker perceived total need scores (t = -6.58, df 159, p .001).

Table 7.3 provides a comparison of the number and percentage of key-workers and clients reporting need by individual items. Item 22. 'Needing help to cope with life' and Item 17. 'Needing help with Thoughts, feelings and behaviours' rated as the most frequent needs for both key-workers and clients. The item rated least by key-workers was Item 21.

'Contacting mental health services. The item rated least by clients was Item 4. 'Self-care'. The need item to exhibit the largest discrepancy between need perceived by key-workers and need expressed by clients was Item 17.' 'Thought, feelings and behaviours'.

Table 7.3. Number and percentage of needs rated present by key-workers and clients (n=160).

Need item	Key-workers (%)	Clients (%)
1. Shopping	63 (40)	55 (34)
2. Preparing a meal	58 (36)	41 (26)
3. Cleaning	56 (35)	44 (28)
4. Self-care	45 (28)	16 910)
5. Getting up	45 (28)	29 (18)
6. Money	59 (36)	43 (27)
7. Phone	12 (7)	17 (11)
8. Post	78 (49)	63 (40)
9. Out & about	53 (33)	39 (24)
10. Occupation	72 (45)	49 (32)
11. Spare time	26 (16)	15 (9)
12. Move accommodation	54 (34)	31 (20)
13. Safety	14 (9)	24 (15)
14. Acceptance	22 (14)	24 (15)
15. Family	56 (35)	26 (16)
16. Contact	55 (34)	56 (35)
17. Thoughts	104 (65)	68 (43)
18. Medication	67 (42)	41 (26)
19. Counselling	83 (52)	64 (40
20. Motivation	80 (50)	61 (38)
21. Contact Services	8 (5)	15 (9)
22. Coping	126 (79)	105 (66)
23. Advocacy	44 (28)	44 (28)
24. Physical	31 (29)	37 (23)

Table 7.4 shows the frequency and percentage of need for each item by whether or not the need was rated as being 'Absent', 'Mild', 'Moderate' or 'Severe'. Comparison is given for key-workers and clients. In relation to scaling 'need present' in terms of need severity, key-workers rated 33% of needs as 'Mild'; 36% as 'Moderate' and 31% as 'Severe'. Clients rated 21% of self-reported needs as 'Mild'; 36% as 'Moderate' and 42% as severe. Needing help in relation to 'Coping' (Item 22) rated as the most frequent 'Severe' need for key-workers (32%) and clients (29%).

Table 7.4. Comparison of key-worker and client need scores by severity (n=160)

	Number (%) by severity							
	Key-workers				Clients			
Item	**Absent**	**Mild**	**Mod.**	**Severe**	**Absent**	**Mild**	**Mod.**	**Severe**
1. Shopping	96 (60)	16 (10)	27 (17)	20 (13)	105 (65)	9 (6)	23 (14)	23 (14)
2. Preparing a meal	99 (63)	18 (12)	17 (11)	23 (14)	119 (71)	9 (6)	11 (7)	21 (13)
3. Cleaning	104 (64)	16 (10)	15 (9)	25 (16)	116 (73)	7 (4)	23 (14)	14 (9)
4. Self-care	115 (73)	25 (15)	10 (6)	10 (6)	145 (90)	6 (4)	6 (4)	3 (2)
5. Getting up	115 (73)	24 (15)	12 (8)	9 (6)	131 (82)	13 (8)	10 (6)	6 (4)
6. Money	101 (63)	10 (6)	24 (15)	25 (16)	117 (73)	6 (4)	15 (9)	22 (14)
7. Phone	148 (93)	1 (0.6)	4 (3)	7 (3.4)	151 (94)	2 (1)	7 (4)	2 (1)
8. Post	82 (51)	22 (14)	32 (20)	24 (15)	97 (61)	11 (7)	19 (12)	33 (20)
9. Out & about	107 (69)	16 (10)	19 (12)	18 (11)	121 (76)	5 (3)	14 (9)	20 (12)
10. Occupation	88 (55)	17 (11)	32 (20)	23 (14)	110 (70)	10 (6)	24 (15)	15 (9)
11.Move accommodation	144 (92)	2 (1)	7 (4)	5 (3)	136 (86)	2 (1)	9 (6)	13 (8)
12. Safety	138 (86)	11 (7)	7 (4)	4 (3)	136 (85)	5 (3)	11 (7)	8 (5)
13. Acceptance	134 (84)	12 (7)	9 (6)	5 (3)	145 (91)	3 (2)	8 (5)	4 (2)
14. Spare time	106 (66)	25 (16)	20 (13)	9 (5)	129 (81)	10 (6)	15 (9)	6 (4)
15. Family	104 (65)	14 (9)	28 (18)	14 (8)	134 (83)	4 (3)	10 (6)	12 (8)
16. Contact	105 (66)	28 (18)	9 (6)	6 (4)	104 (64)	14 (9)	22 (14)	20 (13)
17. Thoughts	56 (35)	31 (19)	40 (25)	33 (21)	92 (58)	11 (7)	24 (15)	33 (21)
18. Medication	93 (58)	22 (14)	18 (11)	27 (17)	119 (74)	6 (4)	11 (7)	24 (15)
19. Counselling	77 (48)	23 (14)	40 (25)	20 (13)	96 (60)	8 (5)	28 (18)	28 (18)
20. Motivation	80 (50)	31 (19)	18 (11)	28 (19)	99 (62)	25 (16)	16 (10)	20 (12)
21.Contact Services	152 (95)	2 (1)	4 (3)	2 (1)	145 (91)	2 (1)	7 (4)	6 (4)
22. Coping	34 (12)	28 (18)	47 (29)	51 (32)	55 (35)	21 (13)	37 (23)	47 (29)
23. Advocacy	116 (73)	23 (14)	16 (10)	5 (3)	116 (74)	15 (9)	15 (9)	14 (9)
24. Physical	129 (81)	12 (8)	12 (8)	7 (3)	123 (77)	12 (8)	13 (8)	12 (6)

Table 7.5 presents key-worker and client responses to whether or not need which was said to be present was unmet, partly met, mostly met or totally met. Key-workers reported that 92% of perceived needs were being partly, mostly or totally met and 8% were being unmet. This yields a ratio of 11 met : 1 unmet need. Clients reported 76% of their expressed needs were being partly, mostly or totally met and 24% were being unmet. This yields a ratio of 3.2 met : 1 unmet need. Overall clients reported proportionately more unmet need compared to key-workers.

Table 7.5. Proportion of key-worker and client need being met for the sample as a whole.

Group	**Total Needs**	**No. Unmet**	**No. Part met**	**No. Mostly met**	**No. Totally met**
Key-workers	1311	8%	18%	16%	58%
Clients	1007	24%	11%	13%	52%

Table 7.6 shows the number and proportion of needs present which were reported to be unmet, partly met, mostly met and totally met by key-workers and people with a long-term mental illness. Item 10. 'Needing help with Occupation' was the most frequently unmet need perceived by key-workers. 31% of key-workers reported the need to be unmet compared to 28% of clients. The most frequently unmet need expressed by clients concerned Item 16. 'Needing more contact with other people'. Fifty-one percent of clients reported the need to be unmet compared to 19% of key-worker responses. The need items to exhibit the largest percentage difference between unmet need perceived by key-workers and unmet need expressed by clients concerned: Item 16. 'Contact with services' (Key-workers 0% Clients 61%); and Item 20. 'Motivation' (Key-workers 4% Clients 62%). In relation to key-worker responses to Item 13 'Accommodation' and for those key-workers who responded "Yes", asking "Where do you feel they belong?" resulted in 42% of responses indicating "Supported group home". The remaining responses included "A larger town", "A rural area" and "Closer to friends". For Item 10. 'Occupation' and for those key-workers who responded "Yes", asking "Where do you think they should be occupied?" resulted in 32% of responses stating "Day centre". The remaining responses

included "Sheltered work" and "Open employment". In comparison to key-workers, client responses (44%; n=13) indicated "Supported group home" for the sub-section of Item 10 "Where do you feel you belong?". For Item 13. 'Occupation' and clients who responded "Yes", asking "Where do you think you should be occupied?" resulted in most responses indicating "Day centre". In terms of the question 'Are there any other needs we have not mentioned that you think are important?' no additional areas were identified by more than two respondents. When asked to rate the most important need, key-workers (44%) and clients (22%) rated 'Mental health'.

Table 7.6. A comparison of key-workers and client need scores by need met (n=160).

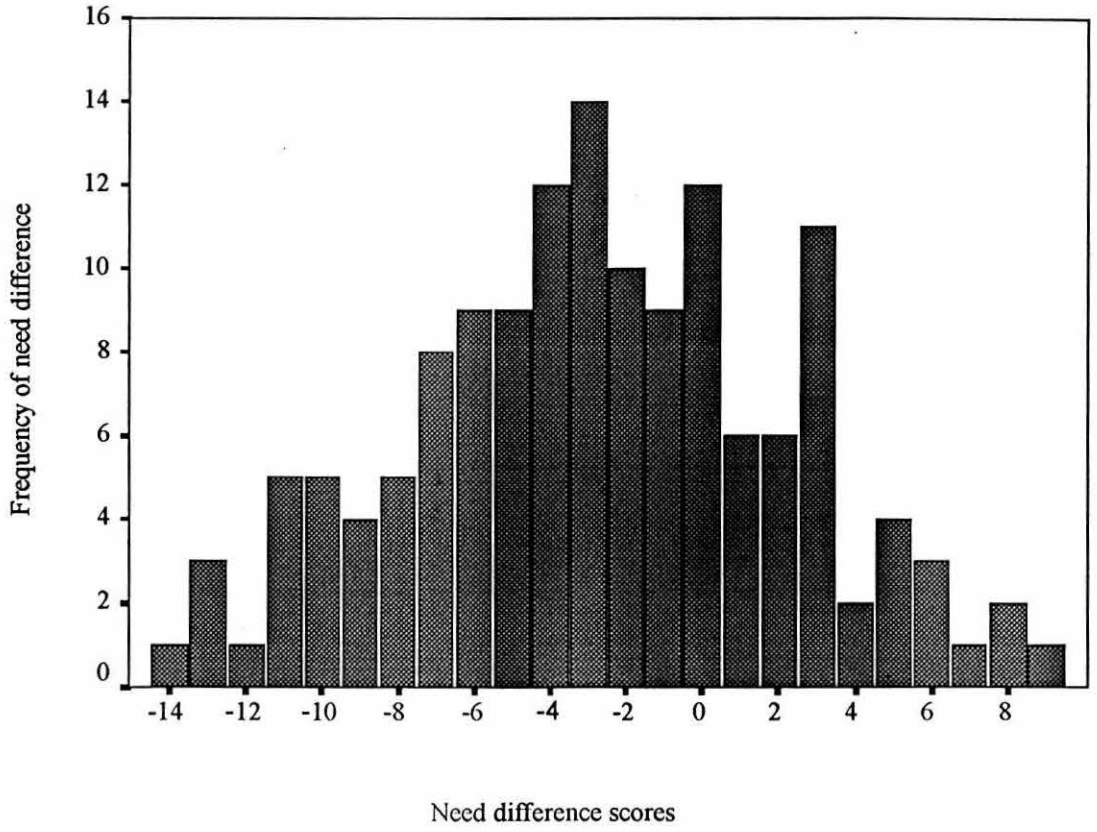
	Number (%) of Needs Met							
	Key-workers				Clients			
Item	**Unmet**	**Partly**	**Mostly**	**Totally**	**Unmet**	**Partly**	**Mostly**	**Totally**
1. Shopping	0 (0)	3 (5)	8 (13)	52 (83)	1 (2)	3 (5)	5 (9)	48 (84)
2. Preparing a meal	2 (3)	4 (7)	2 (3)	51 (86)	6 (15)	0 (0)	5 (12)	30 (73)
3. Cleaning	3 (5)	6 (11)	2 (4)	46 (81)	4 (10)	1 (2)	6 (14)	31 (74)
4. Self-care	1 (2)	6 (13)	3 (7)	36 (78)	2 (12)	1 (6)	0 (0)	14 (82)
5. Getting up	4 (9)	5 (11)	8 (18)	28 (62)	2 (7)	1 (3)	3 (10)	23 (79)
6. Money	3 (5)	8 (13)	10 (17)	39 (65)	2 (5)	1 (2)	6 (14)	34 (79)
7. Phone	2 (14)	0 (0)	2 (14)	10 (72)	1 (6)	2 (12)	0 (0)	14 (82)
8. Post	1 (1)	3 (4)	9 (12)	65 (83)	5 (8)	1 (2)	6 (10)	51 (10)
9. Out & about	4 (8)	8 (15)	11 (21)	30 (57)	6 (15)	5 (13)	3 (8)	25 (63)
10. Occupation	22 (31)	18 (25)	16 (22)	16 (22)	14 (28)	12 (24)	8 (16)	16 (32)
11.Move accommodation	5 (40)	1 (8)	0 (0)	7 (54)	13 (54)	0 (0)	0 (0)	11 (46)
12. Safety	2 (9)	3 (14)	5 (23)	12 (55)	12 (48)	3 (12)	7 (28)	3 (12)
13. Acceptance	2 (8)	9 (35)	8 (31)	7 (27)	4 (25)	4 (25)	2 (13)	6 (38)
14. Spare time	11 (20)	17 (31)	9 (16)	18 (33)	14 (44)	9 (28)	3 (9)	6 (18)
15. Family	11 (20)	17 (30)	8 (14)	20 (36)	13 (50)	7 (27)	3 (12)	3 (12)
16. Contact	0 (0)	3 (5)	8 (13)	52 (83)	1 (2)	3 (5)	5 (9)	48 (84)
17. Thoughts	10 (19)	28 (53)	9 (17)	6 (11)	28 (51)	15 (27)	4 (7)	8 (15)
18. Medication	2 (3)	1 (2)	6 (9)	58 (87)	4 (10)	1 (2)	5 (12)	32 (76)
19. Counselling	3 (4)	11 (13)	21 (25)	48 (58)	23 (38)	12 (19)	6 (9)	24 (37)
20. Motivation	3 (4)	31 (39)	18 (23)	28 (35)	23 (62)	7 (11)	12 (19)	20 (32)
21.Contact Services	0 (0)	2 (29)	1 (14)	4 (57)	10 (61)	1 (7)	3 (18)	1 (7)
22. Coping	0 (0)	4 (3)	19 (15)	102 (82)	8 (8)	5 (5)	17 (16)	77 (71)
23. Advocacy	15 (35)	9 (21)	2 (5)	17 (40)	20 (47)	7 (16)	3 (7)	13 (30)
24. Physical	0 (0)	4 (13)	3 (10)	24 (77)	9 (22)	3 (9)	10 (27)	16 (42)

The relationship of key-worker and client needs data.

In Chapter 6, *Kappa* values established that the need items employed were reliable for key-workers and people with a long-term mental illness in that responses were stable over time. Wackerly and Robinson (1983) and Feinstein and Cicchetti (1990) point out that *Kappa* values can also be used as an index of validity. In this sense, one interpretation of the *Kappa* values (Table 6.3) is that key-worker responses and the responses of people with a long-term mental illness are valid. *Kappa* values in general, were higher for key-workers compared to people with a long-term mental illness. This suggests that key-worker responses are not only more reliable compared to people with a long-term mental illness but also more valid. However, such an interpretation needs to be supported by other evidence of validity. One source of evidence is an examination of the relationship of total key-worker perceived need scores with the total self-reported need scores of people with a long term mental illness.

Correlating levels of total key-worker perceived need scores and total client expressed need scores yields a statistically significant correlation coefficient (r 0.43, p.001). This result suggests that the more needs people with a long-term mental illness report the more needs their key-workers report. One interpretation of this result is that people with a long-term mental illness appear to have some insight into their total needs. However, this finding provides only a partial answer to the question of what the nature of that need might be. By making use of other aspects of the data, this issue can be further developed in two ways. Firstly, cross-tabulating the responses of each key-worker with their respective client by the number of needs for the sample as a whole resulted in almost one-third of key-worker and client *Kappa* values being ≥0.4. Representing fair to good agreement beyond chance. Secondly, the calculation of a 'Need Difference Score' i.e., the subtraction of total key-worker need scores from total client need scores, allows for quantifying the extent of error in terms of key-worker and client need scores and what might be considered 'inaccurate' responses or 'poorer' insight. Figure 7.1 shows the frequency distribution of the need difference scores.

Figure 7.1. Frequency distribution of need difference scores (n=160).



The distribution of the need difference scores has a mean of -2.7 (SD 4.9). This suggests that under-reporting is more probable than over-reporting, with 66% of people with a long-term mental illness under-reporting and 21% over-reporting need compared to key-workers. The remaining 11% of people with a long-term mental illness agreed with key-workers. Almost 41% of people with a long-term mental illness expressed their needs to within 2 needs either side of the mean value. In summary, the distribution of the difference scores suggests that response error exists. This might be interpreted as 'poorer' insight for people with a long-term mental illness compared to key-workers in terms of identifying need.

Table 7.7 provides an indication of where such differences lie. This has been done by presenting *Kappa* and percentage agreement values as an index of inter key-worker:client agreement by need items. What the table shows is 'poor agreement' for 17 of the 24 (70%) need items i.e., criterion *Kappa* values <0.4; and 'fair agreement' for the remaining seven items (Fleiss, 1971; Landis and Koch, 1977).

Table 7.7. Key-worker and client need levels of agreement by need items.

Need item	*Kappa*	**Percentage agreement**
1. Shopping	0.44	72
2. Preparing a meal	0.32	68
3. Cleaning	0.44	74
4. Self-care	0.17	71
5. Getting up	0.26	71
6. Money	0.45	73
7. Phone	0.4	81
8. Post	0.32	66
9. Out & about	0.46	76
10. Occupation	0.24	61
11.Move accommodation	0.5	88
12. Safety	0.18	77
13. Acceptance	0.02	76
14. Spare time	0.17	65
15. Family	0.37	77
16. Contact	0.11	58
17. Thoughts	0.13	54
18. Medication	0.22	62
19. Counselling	0.22	62
20. Motivation	0.25	61
21.Contact Services	0.03	86
22. Coping	0.12	72
23. Advocacy	0.07	60
24. Physical	0.44	81

The relationship of key-worker and client needs data to mental state.

Comparisons of the coefficients in Table 7.8 show statistically significant correlations for total key-worker and total client need scores with total BPRS scores. What data reveal is that the total self-reported need scores of people with a long-term mental illness is more strongly associated with total BPRS scores (r 0.6) than are key-worker total need scores (r 0.43). The strongest association found between client total need scores and BPRS factor scores was 'Anxiety-depression' (r 0.61). The strongest association found between total key-worker perception of need scores and BPRS factor scores was 'Activation' (r 0.37).

Two points are worthy of note. The sample of people with a long-term mental illness who have higher BPRS scores self-rated more need than key-workers. Bearing in mind that key-workers reported higher mean total need scores overall, this would seem to suggest that key-workers rated needs as 'present' independently of BPRS scores.

Table 7.8. Total need scores correlated with total BPRS and BPRS factor scores.

BPRS	Total key-worker need	Total client need
Total BPRS	**.43**	**.6**
Anxiety-Depression.	.15	**.61**
Anergia	**.26**	.12
Thought Disturbance	**.29**	**.42**
Activation	**.37**	**.23**
Hostility-Suspiciousness	**.22**	**.43**

Coefficients in bold type are significant at the p 0.05 level.

Table 7.9 shows that the result of a) correlating total BPRS scores for items 1-12 with total key-worker need scores and total client need scores yields a stronger positive correlation for people with a long-term mental illness (r 0.63) compared to key-workers (r 0.27). This would seem to suggest that people with a long-term mental illness who have higher BPRS scores on items 1-12 (verbal reports) self-rated more need than key-workers; suggesting that key-workers rated needs as 'present' independently of BPRS items 1-12.

Correlating total BPRS scores for items 13-21 with total key-worker need scores and total client need scores shows a stronger relationship for key-workers (r 0.41) compared to people with a long-term mental illness (r 0.21). This suggests that people with a long-term mental illness who have higher BPRS scores on items 13-21 are rated as having more need by key-workers; suggesting that people with a long-term mental illness rated needs as present 'independently' of BPRS items 13-21.

Table 7.9. Correlation of BPRS items 1-12 and 13-21 with total need.

	Key-workers	Clients
BPRS items 1 - 12	**0.27**	**0.63**
BPRS items 13 - 21	**0.41**	**0.21**

Coefficients in bold type are significant at the p 0.05 level.

Psychiatric symptomatology: rater observation.

In an attempt to examine further the finding in the last section from a different perspective, one attempt to make clear any interpretation has been to introduce 'The Krawieka Rating Scale' (Krawiecka et al., 1977). This measure of psychiatric symptomatology incorporates more of an interviewer rating. The rationale has been that although there is considerable overlap in the symptom constructs covered by the KRS and the BPRS, KRS ratings do not only include information based on what the client has said but also include the actual behaviour observed at interview. This it was stated is different to the BPRS where for example, items 1-12 which include Depression, Suspiciousness, Grandiosity and Hallucinations are based " ... on the patient's answer to the interviewer's question" alone

(see Appendix 6). Table 7.10 presents the correlation of total need scores with KRS scores for key-workers and people with a long-term mental illness. Examination of KRS scores suggests a relationship for both key-worker total need scores with total KRS scores (r 0.46) and client total need scores (r 0.55). This finding is consistent with that of the BPRS. In general, use of the KRS supports the findings of the BPRS in that client self-reported need is more strongly associated with mental state compared to key-worker measures of client need. These data offer further support to the finding that a) people with a long-term mental illness who have higher mental state scores self-reported more needs, particularly in relation to the symptoms related to anxiety and depression; and b) that key-workers rated less needs in relation to total KRS scores.

Table 7.10. Correlation of need scores with KRS items with total key-worker and total client need scores.

	Key-worker	Client
Total KRS	0.46	**0.55**
Anxious-depressed	0.24	**0.51**
Thought disorder	0.29	**0.39**
Poverty of speech	0.2	0.08

Coefficients in bold type are significant at the p 0.05 level.

Table 7.11 shows the correlation of total key-worker and total client self-report need scores with Birchwood et al's (1994) total insight score and insight factor scores. Significant correlations were found with total client need scores. Significant correlations were also found with 'Awareness of illness' and 'Attribution of symptoms' sub-scale scores. No significant correlations were found with total key-worker need scores. One interpretation of this finding is that people with a long-term mental illness who rate higher self-report measures of insight self-report more need and that key-workers rate need independently of measures of insight. What these data suggest is that measures of insight can be used in order to explore and define the characteristics of people with a mental illness who are 'better' able to report their needs compared to those who are 'less' able. The rationale for doing this is that it might help inform where a self-report assessment of need might be most usefully and appropriately deployed in a sample of people with a long-term mental illness. This issue is examined next.

Table 7.11. Correlation of need scores with Birchwood et al's., Insight Scale scores.

	Key-workers	Clients
Total Insight score	0.12	**0.33**
Attribution of symptoms	0.07	**0.25**
Awareness of illness	0.11	**0.33**
Need for treatment	-0.01	**0.11**

Coefficients in bold type are significant at the p 0.05 level.

Differences by self-reported insight.

Two groups have been created by using Birchwood et al's (1994) suggested score of 9 to represent a cut-off point indicative of insight. In this sense, Group 1 (n=97, 61%) represents respondents who scored below 9 and Group 2 (n=63, 39%) represents respondents who scored 9 or more. A score of 9 or above indicating insight (Birchwood et al., 1994). The mean self-reported insight score for Group 1 was 5.3 (SD 2.3) and for Group 2 was 10.4 (SD 1.1).

Table 7.12 shows the mean total BPRS score, mean number of needs perceived by key-workers, and mean number of self reported needs by clients. Statistically significant differences were found in relation to BPRS scores (t = -2.71, df 156, p .01); KRS scores (t = -2.52, df 156, p .01); key-worker needs (t = -3.0, df 156, p .01); and client self-reported needs (t = -2.6, df 156, p .01) by group. Data show that not only did Group 2 have insight into their mental illness but also that they had higher mean scores in relation to the BPRS, KRS, key-worker perceptions of client needs and self-reported needs by clients. Some light is shed on these difference when BPRS scores and total key-worker and client need scores are examined. It is interesting to note that clients in both Group 1 and Group 2 under-report need compared to key-workers.

Table 7.12. Mean comparison of Group 1 and Group 2 BPRS, KRS, total key-worker and total client need scores (n=157).

	Group 1 (Insight <9)	Group 2 (Insight ≥9)
BPRS	12.8 (SD 8.0)	17.3 (SD 10.3)
KRS	5.4 (SD 3.8)	7.4 (4.7)
Total key-worker need scores	7.9 (SD 4.9)	9.9 (4.9)
Total client need scores	4.9 (4.0)	6.9 (4.8)

Table 7.13 shows the total key-worker and total client need scores correlated with total BPRS scores for Groups 1 and 2. Overall, comparisons show a statistically significant correlation for total key-worker need scores with total BPRS scores for the Group 1 but not Group 2. This would seem to suggest that more need is associated with higher BPRS scores for Group 1 and not Group 2 for key-workers. In other words, although clients are perceived by key-workers as having a mean of 9.9 needs and a mean BPRS score of 17.3 there is no statistically significant relationship between the two variables. In this sense, a key-worker perception of client need in Group 2 is independent of mental state. Correlations for total client need scores with a total BPRS score for Group 1 and Group 2 are not only significant but also stronger. This suggests that more need is associated with higher BPRS scores for both Group 1 and Group 2 in relation to the self-reports of people with a long-term mental illness.

Table 7.13. Total need scores correlated with total BPRS scores for Groups 1 and 2 (n=157).

	Total key-worker need		Total client need	
	Group 1	**Group 2**	**Group 1**	**Group 2**
Total BPRS	**0.52**	-0.09	**0.68**	**0.51**

Coefficients in bold type are significant at the p 0.05 level

In summary, results can be shown to indicate six main points. Firstly, a moderate correlation was found between the key-worker assessment of client need schedule and the REHAB (Baker and Hall, 1983). When indices of convergent (concurrent) validity are considered in combination with indices of reliability for key-workers in Chapter 6 this suggests that the schedule designed to measure key-worker perceptions of client need meets the necessary criteria appropriate for this type of schedule. Secondly, having established that there is some evidence to support the validity of the key-worker assessment of need schedule this has allowed the examination of client self-report needs data with that of key-workers. A positive relationship was found between levels of total key-worker perceived need scores and total client expressed need scores (r 0.43, p .001). Thus providing some

support for the validity of clients' self-report needs data. The third point is that this finding is further supported by examining face and content validity in that both key-worker and client schedules have proved acceptable to both groups who clearly indicated that they understood the approach to the assessment of need. Fourthly, both key-worker and client assessment of need schedules seem to be sensitive to individual differences in the reporting of need. Descriptive data show that both groups of respondents varied widely in terms of perceived need by key-workers and self-reported need by clients. Fifthly, both key-worker and client assessment of need scores correlated moderately well with measures of mental state. This suggests that the more need reported the higher the mental state score. Finally, measures of insight showed a significant relationship with client measures of self-reported need and no significant relationship with measures of key-worker perceptions of total client need.

The procedure and criteria used in this chapter have several implications for establishing the validity of self-reported need in a sample of people with a long-term mental illness. The task is to examine now, from the data, why it is that people with a long-term mental illness vary in their ability to self report need reliably and validly in the assessment of need procedure developed for the purpose of this thesis. The basic question is what factors characterise those people with a long-term mental illness who are reliable and valid from those who are not? In order to address this question discussion is now given to client self-report needs data in relation to key-worker needs data, measures of insight and measures of mental state.

Discussion.

The aim of this chapter has been to establish whether or not people with a long-term mental illness can self-report their own need validly. This has been done because although there is evidence to support the hypothesis that people with a long-term mental illness can report their needs reliably over time (see Chapter 6 of this thesis) it cannot be assumed that they can do so validly. This assumption is supported by

a) data in Chapter 6 which showed poor levels of agreement by need items between the perceived needs of key-workers and the self-reported needs of clients;
b) the observation that people with a long-term mental illness do not recognise that they are suffering from such an illness (Amador et al., 1994) and may also be unaware of their needs, thereby rendering the self-reporting of their needs questionable; and
c) historically, the identification of needs by mental health professionals (Watts and Bennett, 1991).

In view of these points, the basic approach to an examination of validity has been to use a normative perspective. The first step in order to address these issues was to examine the concurrent validity of the key-worker needs assessment schedule with the use of REHAB. The rationale, as a second step, was to then use key-worker needs data to help verify the self-reported needs data of people with long-term mental illness. A highly significant association was found between total key-worker need scores and REHAB total general behaviour scores, thus providing some support for concurrent validity of key-worker need measures. There was a non-significant relationship between total client need scores and REHAB total general behaviour scores. A limitation of the approach to concurrent validity might have been that key-workers were asked to complete the REHAB before making a 'need' rating and may explain why key-worker total need scores correlated with total REHAB general behaviour scores. One future solution to addressing this issue would be to counter-balance the presentation of both schedules in order to avoid order effects. However, and although this is a methodological consideration, a positive association was found between key-worker and client total need scores. In this sense, the more need key-

workers perceived the more need clients self-reported. This finding is important in three ways. Firstly, it adds some weight to the hypothesis that a self-report assessment of need in people with a long-term mental illness is valid. Secondly, the finding relates to how key-workers perceive a person with a long-term mental illness in terms of functioning. Thirdly, the finding relates to how a person with a long-term mental illness perceives (or has insight into) their illness and how this impacts on their life in terms of functioning. The difficulty with this finding is that, although significant, correlations are not enough in themselves. This is because one is left with asking what factors distinguish the 'more valid' client responses from the 'less valid' responses in a self-report assessment of need situation?

What data in this thesis seem to be suggesting is that self-reporting of need in a sample of people with a long-term mental illness is both reliable and valid in a test-retest situation using *Kappa* as an index of reliability and validity (Wackerly and Robinson, 1983; Feinstein and Cicchetti, 1990). This is set against the following background:

- higher *Kappa* values for items of need reported by key-workers compared to clients on test-retest;
- higher levels of total key-workers need compared to levels of total client need;
- poor levels of inter key-worker:client agreement for 17 of the 24 (70%) need items; and
- a statistically significant relationship between levels of total client and total key-worker need scores.

One interpretation of these findings is that key-worker responses were not only more reliable compared to clients but also more valid. However, before any conclusions can be drawn such an interpretation would need to be supported by other evidence of validity. For example, as a whole clients reported proportionately more unmet need compared to key-workers. If one accepts the position that 'key-workers know best' this suggests what might be described as a 'complaints' bias in the self-reporting of need by people with a long-term mental illness in this thesis. This leads to a situation where, taken together, these results raise the interesting situation where the sample of people with along-term mental illness in

the present study on the one hand appear to be able to report their own needs both reliably and validly and on the other show a statistically significant relationship with key-worker total need scores but show poor levels of agreement by need items. In other words, some people with a long-term mental illness have, what might be described as 'good insight' into their own individual needs over time and their own total needs compared to key-workers, but are 'poorer' at judging individual needs compared to key-workers. The net result is that data show that the question of self-reported need is complex. Possibly the simplest explanation as far as this thesis is concerned is that the under-reporting of need by people with a long-term mental illness is more likely compared to key-workers. Thus suggesting that response error exists and that such error might be interpreted as 'poorer insight' for people with a mental illness compared to key-workers in terms of an assessment of need. However, the 'simplest explanation' has to be balanced against the finding that people with a long-term mental illness self-report need consistently over time in a test-retest situation. Clearly, such issues raise a number of questions, the answers to which will depend on the nature of other factors in the self-assessment of need. For example, What are the influences of mental state?

Mental state.

The introduction to the present chapter suggested that there has been no attempt in the literature to examine the relationship of self-reported need to insight in long-term mental illness. Data in the present chapter showed a significant relationship between total client need scores and insight and a non-significant relationship between key-worker perceptions of client need and insight. It was hypothesised that the more insight a person with a long-term mental illness had the higher would be their self-report need scores and that if a relationship was found it might be argued that such a measure may inform the issue of the validity of self-reported measures of need. By taking the issue of self-reported need first, it would seem that people with a long-term mental illness having more insight rate more need. This raises the interesting corollary that the rating of self-reported need in people with a long-term mental illness who have 'poor insight' might be inappropriate. This situation represented approximately two-thirds of the sample in the present study using Birchwood et al's., cut-off score of nine. By taking the issue of perceived need by key-

workers next it would seem that a lack of association between key-worker perceptions of client need and insight scores suggests that key-workers continue to rate needs when a person with a long-term mental illness has no insight.

At the outset of this thesis it was pointed out that the main approach to an assessment of need has been predominantly normative. The indication was that few studies have developed or adapted a client-centred approach to needs-assessment which takes the self-reported view of the client themselves as its basis. Reasons for this were seen to be related to a) the difficulty in conceptualising need and need assessment; and b) the cognitive and social difficulties of the long-term mentally ill as outlined in Chapter 1, suggesting that giving weight to clients' own accounts of their needs is questionable. In this sense, 'professionals' identify needs and determine plans to meet those needs and in so doing assume the mantle of lead agents in the assessment of need. This is because it is assumed that key-worker perceptions are not confounded by mental illness and are probably the more accurate source of information. The difficulty was that a normative approach may not in itself provide sufficient information about need, particularly when the expressed needs of the individual with a long- term mentally illness have not been taken into account. The upshot was that the systematic identification of basic self-reported needs in the long- term mentally ill presented little data in the mental health literature. This gave rise to three key questions for this thesis. Firstly, do people with a long-term mental illness and their key-workers agree on the presence of need? If they disagree, where do the disagreements lie? and Why do disagreements exist? Clearly, it is possible to make a number of conclusions in relation to these questions in terms of the data presented in this thesis.

Conclusions.

The main conclusion is that the self-reporting of need in people with a long-term mental illness seems questionable for some clients, in relation to some needs compared to key-workers. This conclusion is supported by the finding that *Kappa* values were higher for key-workers compared to clients in a test-retest situation. This suggests that key-worker responses are not only the more reliable compared to clients but also the more valid. This conclusion is further supported by the finding that response error existed in client's total self-report need scores compared to key-worker total need scores. The net result, in general, is that under-reporting by clients is more probable than over-reporting. The simplest interpretation of this finding is that respondents with a long-term mental illness had 'poorer insight' into their own needs compared to key-workers. Insight used in this way leads to the conclusion that for some clients poor insight was related in the majority of cases to an under-estimation of self-reported need and an over-estimation of self-reported need in the remainder. However, arriving at any firm conclusion about the nature of insight in relation to the self-reporting of need is complicated. This is because on the one hand client insight into their needs is supported in the first instance by test-retest values for clients reported in Chapter 6 which were very good; secondly, inter key-worker:client agreement for seven need items (see Table 7.7); and thirdly, by the relationship of measures in insight to levels of self-reported need. These findings provide some support for the view that a person's self-reported need status can in some cases be reported both reliably and validly. However, and in general, the answer to the question 'Do people with a long-term mental illness and their key-workers agree on the presence of need?' would seem to be 'No'. Answering the question 'Where do the disagreements lie?' seems to be in relation to the majority of the needs items used in this thesis. The simplest explanation as to 'Why do disagreements exist?' would seem to be related to insight.

In summary, compared to the assessment of reliability, the assessment and interpretation of validity is more difficult. As data on validity indicate, there are both conceptual and methodological issues establishing a rating of 'objective' need with respect to key-worker and client perspectives. What data in this chapter lead one to conclude is that they reflect a complex interaction between different perspectives of an assessment of need and raise a

number of issues with regard to validity of client's self-report need measures. The reader will recall from the introduction that testing for validity is limited firstly, because need involves making value judgements, and secondly, validity is limited by cultural and social factors which determine the appropriateness of skills in relation to, for example, domestic needs and self-care needs. Nevertheless, for the purpose of validity three important conclusions are:

i) that an attempt has been made to establish the construct validity of measures of self-reported need;

ii) that an attempt has been made to investigate need which has been by-and-large defined normatively;

iii) that the evidence for validity is to all intent and purpose inferential.

In view of these points, the findings of the present chapter are useful in that they can add to the understanding of an assessment of self-reported need in long-term mental illness. Chapter 8 provides a detailed discussion of the findings of this thesis.

Chapter 8. General discussion and conclusions.

Chapter overview

This chapter discusses the ability of people with a long-term mental illness to self-report their own needs in a needs-assessment situation. Factors include levels of agreement with key-workers, psychiatric symptomatology, insight, cognitive deficits, motivational processes and a social desirability response bias. The relationship of policy to practice is also discussed. It is concluded:

a) that people with a long-term mental illness require a thorough assessment of their mental state and verification of their needs with key-workers in a self-report assessment of need situation; and

b) until further research is available assessments of self-reported need of in long-term mental illness are best taken in combination with their key-workers.

Limitations of the present thesis are described and ideas for future research in the assessment of self-reported need are given.

Introduction.

The objective of this thesis has been to examine the ability of people with a long-term mental illness to self-report their own need in a needs-assessment situation. The context is an increased emphasis on mental health service user participation as an important variable in the assessment of need (Welsh Office, 1989; HMSO, 1990; Welsh Office, 1991). This discussion proceeds by considering:

a) the main findings of this thesis;
b) explaining where client and key-worker differences exist in relation to client need;
c) controversies in the definition and assessment of need; and
d) the relationship of policy to practice.

Main findings

This thesis shows that it is possible to take account of the views of people with a long-term mental illness using an assessment of need schedule in an assessment of need situation. However, being an active participant, assumes in the first instance that people with a long-term mental illness can reliably report their own needs and in the second that an assessment of need schedule improves the accuracy with which need might be reported. Results showed four main findings. Firstly, individuals with a long-term mental illness did not say that they have no needs at all. Secondly, a moderate positive relationship was found between client total self-report ratings of need and total key-worker ratings of client need. This implies that there was a tendency toward the more need key-workers reported the more need people with a long–term mental illness reported. Thirdly, in a test-retest situation people with a long-term mental illness and key-workers were able to report need reliably. This implies that responses were not random because responses were stable over time. Fourthly, the main difference between key-workers and clients was an under-reporting of total need by clients. These findings suggest that although there is moderate agreement between clients and key-workers on an underlying dimension of 'client need', clients and key-workers may be providing different information relative to their individual perspectives. Such a finding points to potential difficulties in an assessment of need. It is therefore necessary to try and explain where and why such differences exist.

Explaining where and why differences in need exist.

There are several possible explanations as to why clients and key-workers provided different information relative to their individual perspectives concerning 'client need' using the methodology adopted in this thesis. However, before any possible explanations are examined 'need items' where key-workers and clients agreed will be discussed briefly.

Agreement by need items.

There was better agreement between key-workers and clients in relation to seven need items, namely, Items 1 'Shopping; 3 'Cleaning'; 6 'Money'; 7 'Phone'; 9 'Getting out-and-

about'; 11 'Moving accommodation' and 24 'Physical'. Explaining why inter key-worker:client agreement should exist for these items may be due to key-workers and clients having 'identified' a need that is well-defined and poses a 'risk' to the client. In this sense, help with 'Shopping' or 'Accommodation' might be described as needing help with a 'basic need' and might be easier to identify and agree on. Whereas, help with 'Self-care' or 'Motivation' is more difficult because of the subjective nature of the former and possibly a lack of insight by clients in relation to the latter.

Poor agreement by need items.

Problems where 'poor agreement' occurred may be examined best in relation to two broad categories, namely, 'client factors' and 'key-worker' factors.

Client factors.

Data in the present study seem to indicate that BPRS scores are only partly relevant in terms of explaining poor levels of client agreement with key-workers. A more important factor seems to be that a lack of insight into need. However, other possible explanations exist. These include ideas related to motivation; an inability to change a given situation; and the perception that meeting a need might be too difficult.

Chapter 7 showed that clients reported proportionately more unmet need compared to key-workers (see Table 7.6). The highest proportion of unmet self-reported need related to the item 'Motivation'. If unmet need is taken as an index of Quality of Life (e.g., Lehman, 1983) in long-term mental illness and the meeting of need is mediated by motivation, then assuming that the resources and means to fulfil unmet need were available, why did the self-reported needs of individuals in the present study remain unmet? Three explanations are possible. Firstly, self-reported unmet need might reflect a 'complaints bias', the function of which might be to attract attention. Secondly, a given need may remain unmet because it has little relevance to those areas of life that people with a long-term mental illness in this thesis think are important. Thirdly, meeting an unmet need may be too complex due to the client's mental and physical state. What this seems to suggest is that if

Quality of Life is measured in terms of self-reported unmet need, individuals in the present study may be failing to meet their own needs because a) a lack of motivation and/or b) a perception that they have no control over the resources necessary to meet those needs. Such an hypothesis might be related to the finding that clients who believe that they cannot determine outcomes, tend also to be passive, apathetic, easily persuadable and conformist (Lefcourt, 1981; Wing and Morris, 1981; Brugha et al., 1988; Wing, 1990). What this suggests is that if an individual has difficulty changing their situation themselves or does not believe that they can influence what happens to them they will tend to acquiesce with regard to their general state of affairs. Thus, one might speculate resulting in an underestimation of need. Beyond this, there is also the possibility that people with a long-term mental illness might not identify a need because meeting that need might be perceived as being too difficult. In this sense, a client might not say that they have a need because meeting that need involves complex functions in terms of cognitive and or physical factors.

Key-worker factors.

Several key-worker factors can be identified that might account for poor levels of key-workers and client agreement. These include: institutional practices and how well key-workers 'know' their clients.

The idea of institutional practice describes the situation where key-workers identify and meet client need i.e., 'do things for clients' as opposed to 'do things with clients'. In this sense, key-workers might over-estimate need compared to clients. Related to this idea is the possibility that poor agreement might be a function of key-workers possibly operating a bias of their own in terms of over-rating levels of client need. This might include the phenomenon of attribution (Aronson, 1988) and the tendency among individuals to try and attribute causes to behaviours. The Fundamental Attribution Error (Ross, 1977) has to do with the situation when an individual's behaviour is so compelling to an observer that they take it at face value and give insufficient weight to the circumstances surrounding it. For example, it is possible to underestimate the situational causes of behaviour, thus drawing conclusions about the dispositions of the person. A good example of this is whenever a person is labelled as mentally ill any behaviours such individuals exhibit are commonly

attributed to their 'illness'. Situational factors that would normally be taken into account for other individuals who display the same behaviours are ignored. Thus, once the label 'mentally ill' is attached to a person, observers act as if all attribution problems are solved (Goffman, 1961; Rosenhan, 1973). Any behaviour that is not thought to be ordinary is attributed to 'the illness'. This brings into question the issue of how well key-workers know their respective clients and their clients' needs? What this points to is the situation where key-workers may be in 'less agreement' with clients due to a lack of a 'full knowledge' of the client due to a possible key-worker bias.

In summary, the meaning of 'need' and the assessment of need is complicated in relation to three factors. The first factor concerns long-term mental illness as a confounding variable in a self-report assessment of need. The second factor concerns value judgements. This is the situation where key-workers might consider 'need' in terms of mental healthcare services that they can 'supply', whilst people with a long-term mental illness may have a different view of what they 'need' – for example, a job, or more money. The question here is should the principle criterion be the need as seen by a key-worker or the person with a long-term mental illness? The difficulty here concerns the priority attached to different needs from the two different perspectives. This situation raises philosophical as well as practical problems in the assessment of need. For example, not only might key-workers and people with a long-term mental illness 'disagree' on the presence of need but the situation may also arise where people with a long-term mental illness might be rated as having a 'need' for support they do not want or vice-versa.

The second factor concerns the definition of need. For example, need can be considered as a problem or deficit, a desire, a demand, or a solution. Mental health services tend to define needs normatively or comparatively in terms of the services available in order to meet need. Thereby, assessment becomes a process of establishing a given client's eligibility for mental health services. This can cause problems for clients. This is because it can be difficult for people to construct a picture of their needs without knowing what services are available. This raises problems for an assessment of need in the sense that

what people with a long-term mental illness personally define as needs, and those they present as demands, will be influenced both by their expectations of the resources available through their key-workers and their expectations of their quality of life. The difficulty here for key-workers is the job of exploring the long-term mentally ill person's situation with them without taking an overly narrow view of need or raising expectations. The up-shot is that an assessment of need cannot simply be a process of listening to people with a long-term mental illness or relying on key-worker experience. Therefore, if one accepts that the majority of needs, in general, are assessed differently by key-workers and clients, this gives rise to controversies in the definition and assessment of need.

Controversies in the definition and assessment of need.

It is probably accurate to say that most key-workers and mental health practitioners are used to 'assessing need' in individual clients. In this sense, an assessment of need can indicate a form of 'intervention' or support that might meet an identified need. The ideology behind an assessment of need assumes that needs identified by key-workers and needs identified clients would be in agreement. Such a notion is attractive because it seems a simple way of identifying a 'problem' and evaluating objectives. However, things are not that straight-forward. This is because there is widespread uncertainty about how need should be defined and how an assessment of need should be done (Bradshaw, 1972; Shapek, 1975; Stewart and Poaster 1975; Siegal et al., 1978; Doyal and Gough, 1984; Stevens and Gubbay, 1991; Brewin and Wing, 1993; Liss, 1993; Marshall, 1994; Carter et al., 1995). Furthermore, official policy is complex (e.g., The Welsh Office, 1991) with concepts of 'health' and 'social' needs being relatively new phrases. The root of the complexity centres on two key questions. Firstly, 'What is meant by need?' and secondly, 'How can need be assessed?' In order to try and answer these questions discussion will proceed by looking at the definition of need used in this thesis, the method of assessment used in this thesis, the way measurement is defined, and the key controversies in defining and assessing need.

Defining measurement.

In terms of measurement or assessment Stevens (1951) defines measurement as the "... assignment of numbers to objects or events according to rules". In this sense, measurement is a process involving both theoretical as well as empirical considerations. The theoretical involves the unobservable concept (the directly unmeasurable) that is, that which is represented by the response, and the empirical entails the observable response (the measurable) for example, the answer given to an interviewer in response to a given question. In the case of this thesis the response signified the presence or absence of need from both normative and self-report perspectives. However, as data in this thesis has shown, using two such sources produced different types of error in the assessment of need. This then raises the question of what is a measure or assessment of need valid for? The difficulty in attempting to answer this question centres both the definition of need used and the approach to the assessment of need used.

The definition of need.

The definition of need used in this thesis arose from three sources. Firstly, Wing's (1989) concept of social disablement. Secondly, consideration of the special problems of assessing the long-term mentally ill as outlined in Chapter 1 of this thesis. Thirdly, the idea of Kaplan et al., (1976) that it is easier to refer to departures from the norm than it is to specify the norm itself. In essence, need has been defined in terms of functioning.

The approach to assessing need.

The way need was assessed in this thesis was with the use of structured schedules. The reason for having need items written in standardised format was because they minimise confounds resulting from idiosyncratic response styles (Kidder and Judd, 1986). The theory is that a standardised format is likely to yield more reliable responses. The finding in this thesis was that neither client nor key-worker responses varied significantly over one week. However, when assessments were compared between key-workers and clients

agreement was poor. This situation gives rise to a number of controversies in the assessment of need. Such controversies are reflected in a number of standardised approaches that have attempted to measure need in mental health (e.g., Dellario et al., 1983; Brewin et al., 1987; Phelan et al., 1995; Marshall et al., 1995; Carter et al., 1996). In order to try and focus on the nature of the controversies surrounding need and the assessment of need in mental illness the most widely researched approach will be used. This is the MRC Needs for Care Assessment (Brewin et al., 1987).

In essence, four published studies show the MRC NFCAS to be reliable (Brewin et al., 1988; Lesage et al., 1991; Holloway, 1991; Van Haaster et al., 1994). However, problems and controversies have arisen in its use (e.g., Stansfield et al., 1998; Hogg and Marshall, 1992; Marshall, 1994; and Marshall et al., 1995). These can be summarised as follows. Firstly, reliability studies have not taken into account the effects of error arising from the standardised instruments used to collect data required for the identification of problems. Secondly, there are problems related to areas of 'employment skills' and 'household management' where it is unrealistic to expect severely disabled patients to exercise these skills themselves. The controversy centres on whether or not it is worthwhile for psychiatric patients who are fairly severely handicapped and need sheltered accommodation to for example, engage in skills training. Thirdly, problems have arisen in the assessment and measurement of need in other groups of mental health service users. For example, Stansfield et al., (1998) found that the MRC NFCAS was unsuitable for needs in very acutely ill patients whose mental status was rapidly changing. Fourthly, there is the potential for the identification of needs to differ from needs identified clinically (see the 'personification error' described in Chapter 2, page 45 of this thesis). The crux of the matter concerns the MRC NFCAS exclusion of patient and care-giver views. An omission Marshall (1994) argues, fails to comes close to the decision-making process that determines the more accurate character of need recognised by most clinicians.

In summary, what the key controversy seems to point to is the idea that 'need' cannot be objectified. Naturally, this creates a difficulty for the concept 'needs-assessment' and

listening to what it is people with a long-term mental illness have to say about their own needs. The problem hinges on the issue of 'self-rating' versus 'clinical or objective rating' – particularly, when there are differences between client-reported needs and key-worker or 'objective' assessments. The issue is whether one places more weight on assessments by key-workers or on the self-reports of people with a long-term mental illness. This is a complex issue, particularly as research in the area of needs-assessment in long-term mental illness is limited in terms of cultural validity, an exploration of different psychiatric populations, and the absence of an assessment of need instrument that provides a 'gold standard'. In this sense, establishing need accurately can only be limited given that by definition assessing need involves the making of value judgements, for example, in terms of what is meant by 'cooking' and 'cleaning'. The difficulty is that such items are particularly subjective and the reliability and validity of such items in an assessment of need might be uncertain. As Marshall (1994) cautions, assessor's of need must be clear about their conceptual foundations, preferred philosophy of care, and approach to measuring need before they start their assessment. This, as Marshall goes on to say, is because assessments are only as good as the quality of the information collected. In view of these points how can policy relate to practice in terms of listening to what it is people with a long-term mental illness have to say about their own needs?

Need in long-term mental illness: relating policy to practice.

In terms of the approach to assessing need developed in this thesis it might be argued that the output of both the key-worker and client schedules provides less information than the other approaches described. In this sense, the approach is clearly an over-simplification of a complex process. However, the main finding does have support from other studies in that clients and key-workers, in general, 'see' things differently. In view of this statement and data provided in this thesis, it seems that there are two main interpretations of what might dis-unify client and key-worker perceptions of client needs.

The first interpretation is that client responses are influenced by a given client's mental state. In this sense, there is concern that a person with a long-term mental illness might not

be able to recognise that they have a need due to poor insight. The second interpretation is that an assessment of need involves value judgements. In this sense, clients and key-workers seem to have different values with which they recognise different needs. The consequence is that one cannot assume agreement between key-workers and people with a long-term mental illness in a structured assessment of need. Clearly, in terms of relating policy to practice, this raises a number of issues in relation to defining need, assessing need, and listening to what it is the user has to say about their own needs. The chief issue concerns the situation that if differences exist between key-workers and clients is there a case for taking account of either one's perception alone? If so, should this be the key-worker or the client? This is an important question because on the one hand if there are minor or expected differences in relation to a particular need then there may be a case for only taking account of one person's perceptions. If, on the other hand, there are major and unexpected differences, then the viewpoints of both key-workers and clients should be considered. However, this may not always be possible. For example, being an active participant assumes that the quality of self-reported need by people with a long-term mental illness is not undermined by a lack of insight or some form of social response bias. This then leads on to the question of whether or not the identification of the need should be based on key-worker opinion alone? This brings into sharp relief the assumption that key-workers are in a 'good' position to act as proxies for people with a long-term mental illness. Such an assumption has clear potential for conflict. There are no easy answers to this situation other than to say that people with a long-term mental illness must be involved in identifying need and also in prioritising and responding to those needs. The key problem concerns the situation where key-workers and clients disagree on the presence or absence of need and the requirement for some sort of a 'balance' between the two perspectives. The notion of a balance is important because it cannot be assumed that information obtained from key-workers about a clients' needs is an indication of the clients' needs from the clients' perspective. This is because a clients' self-ratings of their needs and a key-workers' ratings of the client's needs may represent two different sources of information and as Marshall et al., (1995) argue client or key-worker assessments alone are not sufficient for planning and providing a needs-led service.

In summary, the various interpretations of self-report needs data presented have some important ramifications for the policy and practice of needs-assessment in long-term mental illness. From a normative perspective the first interpretation is perhaps more clearly dealt with and understood if levels of poor agreement are a function of a client's mental state. In this sense, there will be areas in which key-workers can, in agreed circumstances, over-rule clients in terms of identifying and meeting need. However, poor agreement as a function of different value judgements is more complex. Therefore, what conclusions can be drawn from the present study?

Conclusions.

There are a number of conclusions in relation to the present thesis. Firstly, by following the requirements outlined by Hall (1979) the assessment method devised to assess need in this thesis has been shown to have satisfactory characteristics. In this sense, analysis has gone some way toward establishing a method that has proved acceptable and appropriate to people with a long-term mental illness as well as key-workers. Secondly, the approach resulted in a methodology that conforms with policy guidance in terms of listening to what it is users have to say about their own needs. Thirdly, items reflect indices of need reliably over time for both clients and key-workers. However, low levels of inter key-worker:client reliability or agreement were found in relation to almost two-thirds of the need items. Fourthly, data seem to support the view that disagreement with key-workers is a function of poor client insight into need. Fifthly, several other factors may be related to the ability of people with a long-term mental illness to self-report need in a needs-assessment situation. These include, motivational processes as well as the possibility of a client social desirability bias either influencing self-reported measures of need by itself or in combination with levels of psychiatric symptomatology. The possibility of a key-worker bias has to be considered as well. The conclusion overall seems to be that the ability of people with a long-term mental illness to self-report need in a needs assessment situation is multi-factorial. Therefore, what sense can be made of the findings of this thesis?

Although the findings of this thesis are preliminary, and may be limited in their generality, the assessment procedure used does provide some valuable insights into the assessment of need in long-term mental illness. This is because what this thesis shows is that when the majority of people with a long-term-mental illness feel they have no need but someone close, for example, a key-worker, identifies that they have a need this raises the question of which one is the more reliable and valid? The perennial problem in answering this question relates to how need is defined, how need is assessed, and the resultant 'presence or absence of need'. In this sense, the self-report assessment of need schedule developed for the purpose of this thesis seems to be a consistent measure but could, in practice, be measuring something entirely different from that which was intended when compared to a key-worker measure of need. Set in this context, what this thesis shows is that the interpretation of results which take what it is the person with a long-term mental illness has to say about their own need and what it is a key-worker has to say about that client's need is problematical. This finding is consistent with findings obtained from other studies using, it must be stated different assessment of need tools (Dellario et al., 1983; Lynch and Kruzich, 1986; Lord, Schnarr and Hutchison, 1987; Marshall et al., 1995; Phelan et al., 1995; Slade et al., 1996 and 1998).

Clearly, there is no doubt that the concept and practice of needs-assessment is particularly challenging if it is going to influence user involvement and mental health gain. In this sense, policy makers, planners, purchasers, and providers should cautiously consider individualised information about 'need' especially details provided by people with a long-term mental illness who have poor insight and are in disagreement with their key-workers. The challenge, as Marshall (1994) points out, remains that of making an assessment of need feel both conceptually and practically 'right' in order that criteria for action can be agreed. Given this challenge can it be for example, that as insight increases a needs-assessment might be better advised? Or can it be that people with a long-term mental illness can overcome their poor ability to report their own needs compared to key-workers and can act on meeting their own needs if they are provided with situations where they can do so? In answer to the first question the clearest statement is that people with a long-term mental illness require a thorough assessment of their mental state and verification of their needs

with key-workers in a self-report assessment of need situation. However, this statement needs to be qualified on two counts. Firstly, results of the present study have implications for service development and research into approaches that might help people with a long-term mental illness identify, express and meet their own needs. What this suggests is that a level of 'optimal' self-reporting of need should be in place. This would involve different approaches to helping each person with a long-term mental illness gain insight into their own needs, and being able to overcome any potential bias related to self-esteem. However, this needs to placed in the context where there can be no doubt that some people with a long-term mental illness will need highly structured services necessitating the situation where such people have their needs assessed by others when and where appropriate. Secondly, it seems certain that schedules like the ones developed in this thesis and other studies can be used to measure change in need over time and that this can be useful for clinical practice and research. The benefit of a standardised assessment is that it allows researchers and/or clinicians to see which needs are present, which are not and which needs might be changing over time. In this sense, and from a normative or key-worker perspective, a standardised assessment of need has the potential to alert key-worker to areas of need that might require follow up and discussion with the client as a means of agreement in terms of need present and need absent.

Leading on from this and in answer to the second question, it might be speculated that people with a long-term mental illness can overcome their poor ability to report their own needs and act on meeting their own needs if they are provided with situations where they can do so. Evidence for this comes from three sources. Firstly, Bennett and Morris (1991) show that it is possible for people with a long-term mental illness to learn skills essential for successful functioning in the community. Secondly, long-term mental illness may qualify but does not prevent skill learning and may be less important than the range of residual disabilities and problems of social performance (Creer and Wing, 1974; Brown and Mumford, 1983; Cutler et al., 1983; Anthony et al., 1986; MacCarthy et al., 1988; MacCarthy, Lesage et al., 1989; Crosby and Barry, 1995). Thirdly, on occasions it has been found that people with a long-term mental illness have more accurate and up-to-date information than key-workers - particularly in community settings where key-workers have

less opportunity to observe patients' behaviour (MacCarthy et al., 1986). Clearly, such ideas require further research. Particularly, as the wider use of 'need' has come to necessitate the need to look beyond the confines of the 'medical model' based on mental health services, to the wider influences on mental health.

If the object of assessment is the task on which all else depends on then procedures should be valid i.e., a 'true' picture of the client's situation; reliable i.e., so that the results would be similar whosoever did the assessment; and efficient i.e., avoiding duplication. The idea is that this should be achieved through an assessment process that maximises the long-term mentally ill person's chance to voice their own needs; a clear specification of the form and content of an assessment of need; and close liaison with for example a key-worker. This might call into question the assessment procedure used in this thesis. It seems that there are a number of self-report assessment procedures or techniques available. Each, in all probability has its own unique strengths and limitations. This is against a background where whatever it is they can offer they need to establish a baseline against which change in a given individual's need status can be evaluated.

The self-report measure used in this thesis was in the form of a formal assessment procedure. The assumed advantage was that the schedule was easy to administer and score. The disadvantage was that responses might have been influenced by the client's mental state and motivation processes etc. In this sense, the formal assessment of need used in this thesis may be a useful indication of need in certain situations but may be inescapably limited in its application. The difficulty is that a formal 'scientific' approach should not be allowed to detract from what people with a long-term mental illness say about their need. The overall message concerning the type of self-report assessment of need used in this thesis has to be 'handle with care'. One challenge to an assessment of need that is formal and structured lies in the approach that provides clients with the opportunity to describe to their key-workers their everyday needs in their own words and at their own pace. In this sense, it is important not to sacrifice rapport for the sake of formal information or data gathering using the sort of approach developed for the purpose of this thesis. This might

mean that different approaches may be more appropriate. For example, it may be that asking simple open-ended questions that help avoid setting the client's agenda for them might work better. This might help where items or questions that do not have a simple 'Yes' or 'No' answer might be more readily explored in an assessment of need situation. An example, of what I mean by this is as follows. 'What do you feel are your main needs?' is an open-ended question that asks for a description from the client whereas 'Do you need help with your accommodation?' does not invite an expansive response. The idea is that an assessment of need done in this way has the potential to help the assessor and the assessee clarify the nature of the need. However, such an approach to an assessment of self-reported need requires testing for its reliability and validity.

Limitations of this thesis.

There are number of limitations with regard to this thesis.

Firstly, the present study was not developed to assist in the routine care and treatment of people with a long-term mental illness by encouraging systematic and regular needs-assessments that shape individualised care plans in mental health. This could be an important area for development in linking needs-assessment policy, theory and practice.

Secondly, the question of reliability did not taken into account the effects of error arising from the standardised instruments used to collect data required for the identification of needs from client and key-worker perspectives. This issue is addressed in the section 'Suggestions for future research'.

Thirdly, the reliability of responses of people with a long-term mental illness compared to those of key-workers may be a function of the type of assessment used in this thesis and other studies. In this sense, this study needs be supplemented by further fieldwork to fully explore the characteristics of not only the instrument used in this study but also those used in other studies as well as alternative way of assessing need.

Fourthly, the sampling procedure used in this thesis excluded those who might have been in more 'need' but either were not offered the chance or refused it. In this sense, the findings of the present study are based on a small non-representative sample. Therefore, it is important to use the schedule with clients who have needs which are less stable. Clearly, such a limitation is a key issue for how generalisable the findings of the present thesis might be to the overall population and/or other settings.

Fifthly, this study attempted to distinguish between 'Need present' and 'Need absent'. 'Need present' was rated when a key-worker or client judged that there was currently a

problem. A rating was made whether or not the need or problem area was receiving support. This may have given rise to confusion. For example, a 'need' in the area of 'Thoughts, feelings and behaviours' might have been rated 'Absent' in a symptom-free client on medication by both key-workers and clients. This might have been because the client was not experiencing symptoms and therefore registered no need. However, this has to be balanced against the finding that both key-workers and people with a long-term mental illness found the approach acceptable and understandable.

Suggestions for future research.

The method of self-report assessment of need by interview used in this thesis has an attraction for those carrying out a needs-assessment. Advantages of the approach are that it takes account of what it is the user has to say concerning their own need status over time, seems to provide a comprehensive coverage of needs with a common format, can be repeated as often as required, and does not take up much time. Thus, the relative number, importance and severity of different kinds of need can be compared with the reports of key-workers and other constructs. Disadvantages of the approach are that people with a long-term mental illness must be co-operative and must have sufficient insight into their own needs. However, and despite such criticisms such methods of assessment are frequently used in evaluation studies. As this thesis has demonstrated, and as other researchers have observed (e.g., McDowell and Newell, 1987; Peck and Shapiro, 1990), scales and self-rating scales have been found to have high correlations among themselves but may have low correlations between them; which indicates that the two types of scales are really measuring something different.

Clearly, there are potential problems with only having assessments of need from people who have long-term mental illness. What will have to be taken into account, from a methodological stance, is that it will be preferable to measure directly the behaviour of people with a long-term mental illness both in terms of symptoms and need from two different perspectives. Such an approach is of value for a number of reasons. Firstly, and in general, low levels of agreement in the present research suggest that the person with a long-term mental illness may not be the best source of need information. Secondly, in view of this knowledge data should be confirmed from other sources, for example, a mental health key-worker. Thirdly, when assessing the self-reported needs of people with a long-term mentally ill the researcher/assessor should consider the routine administration of some indicator of mental state. Such measures can be used to ascertain the likelihood of collecting valid data, and may also be useful as exploratory or predictive variables. Therefore, what this leads this thesis to conclude is that the self-rating scale used in the present study should not be regarded as a substitute for an assessment made for example, by

a key-worker, but as complementary. In this sense, if the self-rating assessment of need developed in this thesis is used with people who have a long-term mental illness then it should done so in combination with a key-worker. This is set against a picture where what emerges from related needs-assessment research is that an assessment of need is invariably oriented towards a normative perception rather than a self-report perception. Based on these points what suggestions for future research can be made?

Firstly, it is necessary to replicate the findings of the present study in order to determine which individuals with a long-term mental illness are best suited for an assessment of self-reported need. Because random sampling of the long-term mentally ill population was not possible in this study, and as Cook and Campbell (1979) and Kidder and Judd (1986) have noted, probability sampling is uncommon in field research, a case needs to be made where external validity might be enhanced by a number of further studies in order that findings might generalise. Bausell (1996) makes a useful recommendation in relation to this area of research. This author suggests that validity should be de-emphasised and that utility should be concentrated on a gradual build up of a number of studies over time. What this would mean for example, is that if the self-report assessment of need devised for this thesis proves useful its continued utility would be justified, if it does not prove useful its use would decline.

Secondly, a specific measure of cognitive processing is required. In this sense, it might be possible to examine more closely what aspects of cognitive deficit play a role in a self-report assessment of need situation. For example, Hemsley (1977, 1978) has used the idea that cognitive impairment leads to the adoption of particular information processing strategies to deal with 'information overload'. Such factors leading to the possible manifestation of institutionalised behaviour and symptoms like poverty of speech and social withdrawal. One hypothesis might be that such people might have greater difficulty self-reporting need in a needs-assessment situation. Furthermore, Wykes et al., (1992) found that some people who develop a long-term mental illness have high levels of cognitive disorganisation. Indeed, these authors found that settings which provide more

independence present more opportunities for choice and less predictability and thereby place a heavier demand on cognitive processing capabilities. If this could be found it would be possible to discriminate between poor and good responders to an assessment of self-reported need. However, such suggestions would need to rely on the further testing of the self-report assessment of need schedule and the measures proposed. For example, further evidence is needed in relation to whether or not self-reported need is stable over time and whether or not any difficulties related to mental state, cognitive functioning and social desirability factors, are stable over time.

Thirdly, future research might want to look at the relationship between key-workers and their clients in the needs-assessment process and examine the relationship. One disadvantage of the present study concerns the lack of an explicit measure of need from another professional who knows the client well. In this sense, ideally, at least two sets of key-worker need ratings would have been preferable so that the agreement between them could be assessed. However, as outlined in the methodology, resources did not allow for two key-worker ratings to be made. Nevertheless, this situation is partly informed by key-worker test-retest agreement data presented in Chapter 6 which provide some support for the stability and validity of key-worker ratings. What this would enable research to do is to examine the variable 'self-reported need' not only in terms of clients themselves but also in terms of whether or not the relationship between client and key-worker agreement of need is in fact itself influenced by that relationship. This might involve two members of key-workers each inter-rating a given clients' needs as well as mental state using standardised instruments separately and then examining how such scores relate to a clients' self-reported need and mental state. If one assumes that key-workers will have very good levels of agreement in relation to a clients' needs and mental state and that the same client differs with each key-workers' assessment then this might suggest that a clients' self-report is dissociated from that of the key-worker.

Fourthly, another possible line of research might be to include the examination of a given clients need status from the perspective of another client - a client who 'knows the other

client well'. What this would involve doing is looking for example, at whether or not people with a long-term mental illness who score low on measures of insight and are poor at identifying their own needs compared to key-workers could recognise need in others using the instrument developed in this study. In other words are clients in better agreement with the key-workers of other clients than they are with their own? If this were so, it might be speculated a) that different cognitive processes and/or value judgements enter into the identification of self-reported need compared to the identification of need in others; and b) that insight into the needs of others are independent to the identification of one's own needs.

Finally, the self-reporting of need technique used in the present study has been shown to be acceptable as a method for getting people with a long-term mental illness to report their own needs. Since there is a shortage of instruments suitable for use with such populations and as the present method has been tested on a sample of long-term psychiatric people, there is a need to compare its use with other devices which purport to measure the same construct, for example, the Cardinal Needs Schedule (Marshall et al.,1995) or the Camberwell Assessment of Need (Phelan et al.,1995). This is because further work is required which examines the reliability and validity of the self-reporting of need with different samples in different locations using different schedules.

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Appendix 1. Schedule for the Assessment of Client Expressed Need (V1).

Client's ID

Key-worker ID

Date of Assessment

DoB

Sex 1 = Female 2 = Male

Assessment Point: 1 2 3 4 5 6

Assessment Completed 1 = Yes 2 = No

If Assessment not completed code:-

1 = Client confused
2 = Client refused
3 = Client Mute
4 = Client broke-off interview
5 = Other, specify:

Total Time to Complete.....mins

Prior to assessing need the following should be said to the client:

"The idea is for me to ask you a few questions to try and find out a) what you feel your needs are, b) how important you feel your needs are and c) whether or not you feel your needs are being met. I would like you to think about your situation ***over the past month.*** *For example, if I ask you if you need help with your shopping and you say no, then that means that you go about it independently of any help or support. If you say yes, then perhaps you could tell me why it is you need help and so on. There are no right or wrong answers. Do you have any questions?"*

Key:

If Need present rate: 0 Absent 1 Present 2 Uncertain.

Importance rate: 1= Totally Unimportant 2 = Fairly Unimportant 3 = Uncertain 4 = Quite Important 5 = Very Important.

If Need present rate whether or not need is met: 1 = Totally unmet 2 = Mostly unmet 3 = Partly unmet 4 = Uncertain 5 = Part met 6 = Mostly met 7=Totally met

If met: rate who supports the need: 1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know.

If unmet: rate who should support need: 1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:.... 4 = Don't know

Need Item	Rating
Q1. *Do you need help with your shopping?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment. What help do you need? Why do you need help?	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q2. *Do you need help with cooking?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q3. *Do you need help cleaning where you live?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q4. *Do you need help bathing yourself?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment. What help do you need? Why do you need help?	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whome is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q5. *Do you need help washing yourself?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q6. *Do you need help dressing yourself?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q7. *Do you need help using the toilet?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whome is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q8. *Do you need help with getting up in the morning?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q9. *Do you need help from other people to manage your money?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q10. *Do you need help using a 'phone?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whome is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q11. *Do you need help with your post?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q12. *Do you need help with getting out and about?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q13. *Do you need help occupying yourself during the day?*	0 'Absent 1 'Present' 2 'Uncertain' 3 'Retired'
Comment. What help do you need? Why do you need help?	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met where are you occupied OR If unmet where would you like to be occupied? (Delete as appropriate)	1 = Drop in Centre 2 = Day Centre (Low pressure) 3 = Day Centre (Increased Activity) 4 = Sheltered Work (Low Pressure) 5 = Sheltered Work 6 = Open employment 7 = Other. Please specify
If met, whome is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q14. *Do you need help/support to move from the type of accommodation you are in at the moment?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
What type of accommodation would you like to live in*?	1 = Independent Living 2 = With family/supported lodgings - 3 = Independent group home 4 = Supported group home 5 = Rehabilitation unit 6 = Staffed Home (low staffing) 7 = Staffed Home (high staffing) 8 = Very Sheltered Nursing Home/Very Sheltered Residential Community Care Scheme 9 = Other. Specify. 10 = No preference.
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q15. *Do you need/want to live in another area?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment. What help do you need? Why do you need help?	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Where do you feel you belong?	1 = Closer to family 2 = In a large town (Urban) 3 = In a small town or village (rural) 4 = Closer to friends 5 = Closer to community services and facilities 6 = No preference 7 = Other
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whome is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q16. *Do you need help/support to feel safe where you are living at the moment?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q17. *Do you need help/support to feel accepted by your local community?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whome is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Q18. *Do you need help filling in your spare time?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment. What help do you need? Why do you need help?	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whome is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q19. *Do you have difficulties with your family with which you need help?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whome is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q20. *Do you need more contact with people?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q21. *Do you need a club/group/centre/befriending service where you can make friends?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Need Item	Rating
Q22. *Do you have difficulties with how you think, feel, and behave for which you need help?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor 2 = Mild 3 = Moderate 4 = Serious 5 = Very serious
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whome is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q23. *Do you ever feel that you need protection from yourself?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q24. *Do you need help with medication?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Q25. *Do you need someone who is skilled in talking to people about the way they might think, feel, and behave to talk with you?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	**Rating**
Q26. *Do you need help with motivating yourself?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q27. *Do you have difficulty contacting someone in the mental health services when you need to? e.g., a CPN, SW, support worker; you haven't got their phone number, or there is no-one available at night or W/E's.*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q28. *Do you need a care plan?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q29. *Do you need help from the mental health services e.g, CPN's, SW's, support workers to help you cope with life?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q30. *Do you need someone, possibly independent of the mental health services, to help you with informed choices and with making decisions in your life?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q31. *Do you have a physical disability with which you need help/support? * If No go to 33.*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q32. *Do you need help/support getting about in your home because of your physical difficulties?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q33. *Do you have any needs we have not talked about which you think are important?*	0 'Absent 1 'Present' 2 'Uncertain'
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that you get the help you need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q34. *Out of all of the needs we have talked about can you tell me which is your most important need to you?*	Domestic i.e., shopping, cooking, and cleaning. Personal care i.e., bathing, washing, dressing, toilet, getting up in the morning. Finances. Communication i.e., phone and post. Travel i.e., getting out and about. Employment/ocupation. Accomodation/living situation i.e., where you live, belonging etc. Leisure and recreation i.e., spare time. Social networks i.e., family, contact withothers. Mental health. Advocacy. Physical.

Appendix 2. Schedule for the Assessment of a Key-worker's Perception of Client Need (V1).

Key-worker ID

Client's ID

Date of Assessment

Assessment Point: 1 2 3 4 5 6

Total Time to Complete.....mins

Prior to assessing need the following should be said to the worker:-:

"The idea is for me to ask you a few questions to try and find out what you feel the needs are of the person you support; how important you feel those needs are for the person you support, and whether or not those needs are being met. I would like you to think about the person's situation over the last month. For example, if I ask you does the person you support need help with their shopping and you say "NO" then this means they can go about things independently of any help or support and in an 'ordinary' way. If you say "Yes", then perhaps you could tell me why it is you think help or support is needed. There are no right or wrong answers. Please remember it is important to think of the needs of the person you support in terms of the way you see the normal, independent everyday living of people at large".

Key:

If Need present rate: 0 Absent 1 Present 2 Uncertain.

Importance rate: 1= Totally Unimportant 2 = Fairly Unimportant 3 = Uncertain 4 = Quite Important 5 = Very Important.

If Need present rate whether or not need is met:1 = Totally unmet 2 = Mostly unmet 3 = Partly unmet 4 = Uncertain 5 = Part met 6 = Mostly met 7=Totally met

If met: rate who supports the need: 1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know.

If unmet: rate who should support need: 1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:.... 4 = Don't know

Need Item	Rating
Q1. *Does ... need help with their shopping?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment. What help do they need? Why Does ... need help?	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whom is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q2. *Does ... need help with cooking?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whom is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q3. *Do they need help cleaning where they live?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whom is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q4. *Does ... need help bathing?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, whom is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q5. *Does ... need help washing themselves?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q6. *Does ... need help dressing themselves?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q7. *Does ... need help using the toilet?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q8. *Does ... need help with getting up in the morning?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q9. *Does ... need help from other people to manage their money?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q10. *Does ... need help using a 'phone?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q11. *Does ... need help with their post?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q12. *Does ... need help with getting out and about?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q13. *Does ... need help occupying themselves during the day?*	0 'Absent 1 'Present' 2 'Uncertain' 3 'Retired'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met where are their occupied OR If unmet where would their like to be occupied? (Delete as appropriate)	1 = Drop in Centre 2 = Day Centre (Low pressure) 3 = Day Centre (Increased Activity) 4 = Sheltered Work (Low Pressure) 5 = Sheltered Work 6 = Open employment 7 = Other. Please specify
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q14. *Does ... need help/support to move from the type of accommodation they are in at the moment?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
What type of accommodation would they like to live in?	1 = Independent Living 2 = With family/supported lodgings - 3 = Independent group home 4 = Supported group home 5 = Rehabilitation unit 6 = Staffed Home (low staffing) 7 = Staffed Home (high staffing) 8 = Very Sheltered Nursing Home/Very Sheltered Residential Community Care Scheme 9 = Other. Specify. 10 = No preference.
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need Item	Rating
Q15. *Does ... need/want to live in another area?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Where Does ... feel they belong?	1 = Closer to family 2 = In a large town (Urban) 3 = In a small town or village (rural) 4 = Closer to friends 5 = Closer to community services and facilities 6 = No preference 7 = Other
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q16. *Does ... need help/support to feel safe where they are living at the moment?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating

Q17. *Does ... need help/support to feel accepted by their local community?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Q18. *Does ... need help filling in their spare time?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q19. *Do ... have difficulties with their family with which they need help?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q20. *Does ... need more contact with people?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q21. *Does ... need a club/group/centre/befriending service where they can make friends?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Need Item	Rating
Q22. *Does ... have difficulties with how they think, feel, and behave for which they need help?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor 2 = Mild 3 = Moderate 4 = Serious 5 = Very serious
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q23. *Does ... ever feel that they need protection from themselves?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q24. *Does ... need help with medication?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Q25. *Does ... need someone who is skilled in talking to people about the way they might think, feel, and behave to talk with them?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	**Rating**
Q26. *Does ... need help with motivating themselves?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q27. *Does ... have difficulty contacting someone in the mental health services when they need to? e.g., a CPN, SW, support worker.*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q28. *Does ... need a care plan?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q29. *Does ... need help from the mental health services e.g., CPN's, SW's, support workers to help them cope with life?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment.	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:.... 4 = Don't know
Q30. *Does ... need someone, possibly independent of the mental health services, to help them with informed choices and with making decisions in their life?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:.... 4 = Don't know

Need item	Rating
Q31. *Does ... have a physical disability with which they need help/support? * If No go to 33.*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q32. *Does ... need help/support getting about in their home because of their physical difficulties?*	0 'Absent 1 'Present' 2 'Uncertain'
Comment:	
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know

Need item	Rating
Q33. *Does ... have any needs we have not talked about which you think are important?*	0 'Absent 1 'Present' 2 'Uncertain'
Severity of need	1 = Minor problem 2 = Mild problem 3 = Moderate problem 4 = Serious problem 5 = Very serious problem
How important is it that they get the help they need?	Very Unimportant 1 2 3 4 5 Very Important
Is the need met or unmet?	Totally unmet 1 2 3 4 5 6 7 Totally met
If met, who is the need met by OR If unmet, who should the need? (Delete as appropriate)	1 = Informal Carer e.g., family member, friend, neighbour. 2 = Formal Carer i.e., Someone paid e.g., CPN, Support worker, Social Worker. 3 = Other. Specify:... 4 = Don't know
Q34. *Out of all of the needs we have talked about can you tell me which you think is their most important need to their ?*	Domestic i.e., shopping, cooking, and cleaning. Personal care i.e., bathing, washing, dressing, toilet, getting up in the morning. Finances. Communication i.e., phone and post. Travel i.e., getting out and about. Employment/occupation. Accommodation/living situation i.e., where their live, belonging etc. Leisure and recreation i.e., spare time. Social networks i.e., family, contact with others. Mental health. Advocacy. Physical.

Appendix 3. Schedule for the Assessment of Client Expressed Need (V2).

Client's ID

Key-worker ID

Date of Assessment

DoB

Sex 1 = Female 2 = Male

Assessment Point: First assessment or Second assessment

Assessment Completed 1 = Yes 2 = No

If Assessment not completed code:-
1 = Client confused 2 = Client refused 3 = Client Mute 4 = Client broke-off interview 5 = Other ...

Total Time to Complete.....mins

Prior to assessing need the following should be said to the client:

"The idea is for me to ask you a few questions to try and find out what you feel your needs are, how important you feel your needs are, and whether or not you feel your needs are being met. I would like you to think about your situation **over the past month.** For example, if I ask you if you need help with your shopping and you say 'No', then that means that you go about it independently of any help or support. If you say 'Yes', then perhaps you could tell me why it is you need help and so on. There are no right or wrong answers". Do you have any questions?

Key:

Rating need 'Present' or 'Absent'.

0 = No need present within the period rated. Normal functioning. No support or direct assistance needed by client or the client 'chooses' not to engage the skill.
1 = Mild need present. Client needed some support*/prompting during the period rated.
2 = Moderate need present. Client needed assistance** with functioning.
3 = Severe Need present. Client needed very intensive and direct assistance with functioning.
9 = Don't know/Uncertain. Rater is unsure as to whether or not client needed either support or assistance.

***Support** means encouragement or prompting to do things
****Assistance** means hands-on physical help or aiding

Rating need met or unmet

0 = Needs not met. No support or assistance received
1 = Needs partly met. Some support or assistance received, however client needs are mostly unmet.
2 = Needs mostly met. Client received support or assistance that mostly met the client's needs.
3 = Needs totally met. Client received an appropriate and effective level of support in relation to need.
9 = Don't know/Uncertain. Rater is uncertain as to whether or not the present level of support is meeting the need of a client.

Rating who 'meets the need' or if 'unmet' who should 'meet the need'.

1 = Informal Carer e.g., family member, friend, neighbour.
2 = Formal Carer i.e., Someone paid e.g., CPN, Social Worker, Community Support/ Worker.
3 = Other. Specify: ....
9 = Don't know

Circle the correct response for each item.

Need Item	Rating
Q1. *Do you need help with your shopping?*	No/Yes/ Don't know. *If Yes,* is it: Mild Moderate Severe?
Comment. *What help do you need? Why do you need help?*	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q2. *Do you need help with preparing a meal?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q3. *Do you need help cleaning where you live?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q4. *Do you need help with your self-care? For example, bathing, washing or dressing yourself?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need Item	Rating
Q5. *Do you need help with getting up in the morning?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q6. *Do you need help from other people to manage your money, budgeting from week-to-week for example?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q7. *Do you need help using a 'phone?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q8. *Do you need help with your post, filling in forms for example?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need Item	Rating
Q9. *Do you need help with getting out and about?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q10. *Do you need help occupying yourself during the day? For example, going to a day-centre, some sort of sheltered work or paid employment?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
If met where are you occupied OR If unmet where would you like to be occupied?	1 = Drop in Centre 2 = Day Centre (Low pressure) 3 = Day Centre (Increased Activity) 4 = Sheltered Work (Low Pressure) 5 = Sheltered Work 6 = Open employment 7 = Other. Please specify
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q11. *Do you need help filling in your spare time?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need Item	Rating
Q12. *Do you need help to move from where you are living at the moment?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Where do you want to move to?	Independent Living With family/supported lodgings Independent group home Supported group home Rehabilitation unit Staffed Home (low staffing) Staffed Home (high staffing) Very Sheltered Nursing Home/Residential Community Care Scheme Other. Specify. No preference.
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q13. *Do you need help to feel safe where you are living at the moment?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q14. *Do you need help to feel accepted by your local community? For example, getting on with other people – your neighbours, shop- keepers and so on?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need Item	Rating
Q15. *Do you have difficulties with your family with which you need help?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q16. *Do you need more contact with people? A club or a centre where you can make friends?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q17. *Do you have difficulties with how you think, feel, and behave for which you need help?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q18. *Do you need help with medication?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need item	Rating
Q19. *Do you need someone who is skilled in talking to people about the way they might think, feel, and behave to talk with you? For example, a counsellor or some form of talking therapy?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q20. *Do you need help with motivating yourself?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q21. *Do you have difficulty contacting someone in the mental health services when you need to? For example when problems come up at night or W/E's.*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q22. *Do you need help from the mental health services, your CPN's, SW's, support workers to help you cope with life? For example, helping you meet your needs with a car plan – something to help you plan a routine in your life from day-to-day.*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need item	Rating
Q23. *Do you need someone, possibly independent of the mental health services, to help you with informed choices and with making decisions in your life? For example, someone outside of the situation.*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q24. *Do you have any physical difficulties with which you need help/support?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment:	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q25. *Do you have any needs we have not talked about which you think are important?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q26. *From all the needs we have talked about can you tell me which you think is your most important need ?* 01 = Domestic i.e., shopping, cooking, and cleaning. 02 = Personal care i.e., bathing, dressing, getting up in the morning. 03 = Finances. 04 = Communication i.e., phone and post. 05 = Travel i.e., getting out and about. 06 = Employment/occupation. 07 = Accommodation/living situation i.e., where you live, belonging etc. 08 = Leisure and recreation i.e., spare time. 09 = Social networks i.e., family, contact with others. 10 = Mental health. 11 = Advocacy. 12 = Physical. 13 = Other	
Comment.	

Appendix 4. Schedule for the Assessment of a Key-Worker's Perception of a Client's Need (V2).

Client's ID

Key-worker ID

Date of Assessment

DoB

Sex 1 = Female 2 = Male

Assessment Point: First assessment or Second assessment

Total Time to Complete.....mins

Prior to assessing need the following should be said to the key-worker:

*"The idea is for me to ask you a few questions to try and find out what you feel the needs of the person you support are, and whether or not you feel their needs are being met. I would like you to think about the person's situation **over the past month.** For example if I ask you "Does the person you support need help with their shopping?" and you say "No" then this means that they can go about it independently of any help or support and in an ordinary way. If you say "Yes", then perhaps you could tell me why it is you feel help or support is needed. There are no right or wrong answers. Please remember it is important to think of the needs of the person you support in terms of the way you see the normal, independent everyday living of people at large over the past month. Do you have any questions?*

The respondent should be reminded that it is their perception of the client's need which is being rated and that the respondent should think about the client's most severe instance of need during the preceding month.

Key:

Rating need 'Present' or 'Absent'.

0 = No need present within the period rated. Normal functioning. No support or direct assistance needed by client as perceived by the carer or the client "chooses" not to engage the skill.
1 = Mild need present. Client needed some support*/prompting during the period rated as perceived by the carer.
2 = Moderate need. Client needed assistance* with functioning as perceived by the carer.
3 = Severe Need. Client needed very intensive and direct assistance with functioning as perceived by the carer.
9 = Don't know/Uncertain. Carer is unsure as to whether or not client needed either support or assistance.

***Support** means encouragement or prompting to do things
****Assistance** means hands-on physical help or aiding

Rating need met or unmet

0 = Needs not met. No support or assistance received as perceived by the carer.
1 = Needs partly met. Some support or assistance received, however client needs are mostly unmet as perceived by the carer.
2 = Needs mostly met. Client received support or assistance which mostly met the client's needs as perceived by the carer.
3 = Needs totally met. Client received an appropriate and effective level of support in relation to need as perceived by the carer.
9 = Don't know/Uncertain. Carer is uncertain as to whether or not the present level of support is meeting the need of a client as perceived by the carer.

Rating who 'meets the need' or if 'unmet' who should 'meet the need'.

1 = Informal Carer e.g., family member, friend, neighbour.
2 = Formal Carer i.e., Someone paid e.g., CPN, Social Worker, Community Support/ Worker.
3 = Other. Specify: ....
9 = Don't know

Circle the correct response for each item.

Need Item	Rating
Q1. *Does ... need help with their shopping?*	No/Yes/ Don't know. *If Yes,* is it: Mild Moderate Severe?
Comment. *What help do they need? Why do ... they need help?*	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q2. *Does ... need help with preparing a meal?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q3. *Does ... need help cleaning where they live?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q4. *Does ... need help with their self-care? For example, bathing, washing or dressing themselves?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need Item	Rating
Q5. *Does ... need help with getting up in the morning?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q6. *Does ... need help from other people to manage their money, budgeting from week-to-week for example?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q7. *Does ... need help using a 'phone?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q8. *Does ... need help with their post, filling in forms for example?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need Item	Rating
Q9. *Does ... need help with getting out and about?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q10. *Does ... need help occupying themselves during the day? For example, going to a day-centre, some sort of sheltered work or paid employment?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
If met where are you occupied OR If unmet where would you like to be occupied?	1 = Drop in Centre 2 = Day Centre (Low pressure) 3 = Day Centre (Increased Activity) 4 = Sheltered Work (Low Pressure) 5 = Sheltered Work 6 = Open employment 7 = Other. Please specify
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q11. *Does ... need help filling in their spare time?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need Item	Rating
Q12. *Does ... need help to move from where they are living at the moment?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Where do you think they want to move to?	Independent Living With family/supported lodgings Independent group home Supported group home Rehabilitation unit Staffed Home (low staffing) Staffed Home (high staffing) Very Sheltered Nursing Home/Residential Community Care Scheme Other. Specify. No preference.
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q13. *Does ... need help to feel safe where they are living at the moment?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q14. *Does ... need help to feel accepted by their local community? For example, getting on with other people – their neighbours, shop- keepers and so on?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need Item	Rating
Q15. *Does ... have difficulties with their family with which they need help?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q16. *Does ... need more contact with people? A club or a centre where they can make friends?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q17. *Does ... have difficulties with how they think, feel, and behave for which they need help?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q18. *Does ... need help with medication?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need item	Rating
Q19. *Does ... need someone who is skilled in talking to people about the way they might think, feel, and behave to talk with them? For example, a counsellor or some form of talking therapy?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q20. *Does ... need help with motivating themselves?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q21. *Does ... have difficulty contacting someone in the mental health services when they need to? For example when problems come up at night or W/E's.*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q22. *Does ... need help from the mental health services, to help them cope with life? For example, helping them meet their needs with a car plan – something to help them plan a routine in their life from day-to-day.*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Need item	Rating
Q23. *Does ... need someone, possibly independent of the mental health services, to help them with informed choices and with making decisions in their life? For example, someone outside of the situation.*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment.	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q24. *Does ... have any physical difficulties with which they need help/support?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment:	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know
Q23. *Does... have any needs we have not talked about which you think are important?*	No/Yes/Don't know. *If Yes,* is it: Mild Moderate Severe.
Comment:	
Is the need met or unmet?	Not met/Met/ Don't know. *If met,* is the need Partly, Mostly or Totally met?
If met, who meets the need OR If unmet, who should meet the need?	Met/Unmet: Informal/Formal Carer/Other. Don't know

Out of all of the needs we have talked about can you tell me which need <u>you perceive</u> as being ... 's most important need ?

01 Domestic i.e., shopping, cooking, and cleaning.
02 Personal care i.e., bathing, dressing, getting up in the morning.
03 Finances.
04 Communication i.e., phone and post.
05 Travel i.e., getting out and about.
06 Employment/occupation.
07 Accommodation/living situation i.e., where the client lives, belonging etc.
08 Leisure and recreation i.e., spare time.
09 Social networks i.e., family, contact with others.
10 Mental health.
11 Advocacy.
12 Physical.
13 Other

Appendix 5. Psychiatric Interview.

General instructions: All questions in italics must be asked. Questions in parentheses are provided as additional probes and may be omitted. For those symptoms elicited, the frequency-intensity should be determined, e.g.., if interviewee admits to experiencing hallucinations, it should be determined how often the experience occurs and the extent to which this interferes with his/her behaviour. The time frame to be used is the **past week**.

1. *Can you tell me what day it is today?*

2. *Do you know what today's date is?*
   (What month it is?) (What year it is?)

3. *How old are you?*

4. *What was the date of your birth?*
   (What year were you born?) (What month were you born?)

5. *Where were you born?*

6. *How long have you been in hospital?*

7. *Can you remember why you had to come to hospital?*
   (What was it that brought you to hospital?) (Has the doctor said what the problem is/was?)

8. *How do you feel about living here?*

9. *How do you get on with the other people living here?*
   (Do you have any friends here?)

10. *How do you get on with the staff, e.g.., nurses, doctors?*

11. *In general, how is your physical health?*

12. *Have you been physically ill during the past week?*
If yes, enquire as to;

a) condition (What was wrong?);
b) how serious (Did the doctor see you about it?) (What did the doctor say was wrong?) (Did you receive any medication or treatment for it?)
c) duration (How long were you ill?) (How are you feeling now?)

13. *Have you had headaches, or other aches or pains, during the past week?*
(How often?)
(Could you describe these to me?)

14. *Do you worry about your physical health?*

15. *Do you tend to worry about things in general?*
(Do you worry about a lot of things? e.g.., money, friends)
(Are you a worrier?)

16. *During the past week have you been worried about anything in particular?*
(Does this occupy your mind most of the time?)
(Can you control your worry?)
(Are you able to thing of other things or does this occupy your mind most of the time?)

17. *Do you often feel on edge or keyed up?*
(Do you generally suffer with your nerves?)

18. *Have you had any difficulty in relaxing during the past week?*

19. *Have you been very anxious or frightened recently?*
(Did your heart beat fast?)
Has this happened during the past week?
(How often, i.e., most of the time or only once or twice?)

20. *Are there any particular things or certain situation in which you tend to get anxious or frightened?*
(Has this happened during the past week?)

21. *What has your appetite been like during the past week?*
(Have you enjoyed your food?)
(Have you had a good appetite during the past week?)

22. *Have you had any trouble getting off to sleep during the past week?*

23. *Have you been reasonably happy during the past week?*

24. *Have you been very depressed or unhappy during the past week?*
(Have you cried at all?)
(When did you last really enjoy doing anything?)
(Are you able to turn your attention to more pleasant things?)

25. *Do you seem to be lacking energy or slowed down in your movements recently?*
(Have you been feeling tired-out recently?)

26. *Have you felt particularly cheerful and on top of the world or full of energy or exciting ideas recently?*
(Do you need less sleep than usual?)
(Do you find yourself extremely active but not getting tired?)

27. *Have you been very much more bad tempered than usual recently?*
(Do you keep it to yourself, or shout, or even hit people?)
(Have you been involved in any arguments or fights?)

28. *How do you get on with people in general?*
(Do you have any difficulty in getting-on with people when you go on outings from the hospital/home?)

29. *Have you felt like staying away from other people?*
(Can you say why you feel this way)

30. *Do you ever have the feeling that other people are looking at you in a critical way or are talking about you?*
(When you walk into a room do you ever feel like other people are looking at you critically or talking about you?)

31. *Do you believe there is anyone out to get you or trying to harm you in any way?*

32. *Do you believe anyone else is responsible for any troubles you may have?*

33. *Do you feel you have done anything very wrong for which you deserve punishment?*
(Have you been thinking of past problems?)
(Do you tend to blame yourself for things that have happened?)

34. *Do you have the feeling something terrible is going to happen?*
(What? How often?)

35. *What has your concentration been like recently?*
(Do you find it difficult to follow what's going on when watching T.V.?)
(Do you find it difficult to follow what people are saying when they are speaking to you?)
(Do you find it difficult to concentrate on things?)

36. *Can you think quite clearly or is there any interference with your thoughts?*
(Are you in full control of your thoughts)
(Is there anything like hypnotism or telepathy going on?)

37. *Have you suffered any lapses of memory recently?*
(Do you find you forget things recently?)

38. *Have you done anything unusual or had anything happened during the past week that had been out-of-the ordinary?*
(Have any odd or strange things occurred during the past week?)
(Has anything during the past week that has seemed a bit odd or unusual?)

39. *Do you have any special powers or abilities?*

40. *Is there a special purpose or mission to your life?*

41. *Do you ever seem to hear noises or voices when there is no one about, and nothing else to explain it?*

42. *Do you ever see things or have visions which other people don't?*

43. *Is there anything unusual about the way things feel, taste, or smell?*

44. *Do you thing there is anything the matter with you?*
(What do you think the cause is?)
(What do you think it is?)

45. *Is there anything else which has occurred during the past week which you would like to tell me about?*

Appendix 3b. Brief Psychiatric Rating Scale (Overall and Gorham, 1961)

DIRECTIONS: The ratings for items 1-12 are based on the patient's answers to the interviewer's questions. The time frame for these items is the past week. Items 13-21 are based on the patient's behaviour during the interview and the time frame covered is the interview period only. When the anchor point definitions contain an 'or' the patient is assigned the highest rating that applies, e.g., if a patient has hallucinations persistently throughout the day (a rating of 7) but the hallucinations only interfere with functioning to a limited extent (a rating of 5), a rating of 7 is given.

RATINGS BASED ON VERBAL REPORT

1. **SOMATIC CONCERN** - Degree of concern over present bodily health. Rate the degree to which physical health is perceived as a problem by the patient, whether complaints have realistic basis or not.

0		Not present
1-2	Mild	Occasional complaint or expression of concern.
3-4	Moderate	Frequent expressions of concern or exaggerations of existing ills. Some preoccupation. Not delusional.
5-6	Severe	Preoccupied with physical complaints or somatic delusions.
9		Not assessed

2. **ANXIETY** - Worry, fear, or over-concern for present or future. Rate solely on the basis of verbal report of patient's own subjective experiences. Do not infer anxiety from physical signs.

0		Not present
1		Very mild. Reports feeling worried more than usual or some discomfort due to worry.
2	Mild	Worried frequently but can turn attention to other things.
3	Moderate	Worried most of the time and cannot turn attention to other things easily but no impairment in functioning *or* occasional anxiety with autonomic accompaniment but no impairment in functioning.
4	Moderately severe	Frequent periods of anxiety with autonomic accompaniment *or* some areas of functioning are disrupted by anxiety or constant worry.
5	Severe	Anxiety with autonomic accompaniment of the time *or* many areas of functioning are disrupted by anxiety or constant worry.

6	Extremely severe	Constantly anxious with autonomic accompaniment *or* most areas of functioning are disrupted by anxiety or constant worry.
9	Not assessed	

3. **DEPRESSION** - Include mood-sadness, unhappiness, anhedonia; and cognitions-preoccupation with depressing topics (Can't switch attention to T.V., conversations), hopelessness, loss of self-esteem (dissatisfied or disgusted with self). **Do not** include vegetative symptoms, e.g., motor retardation, early waking, loss of appetite, etc.

0	Not present	
1	Very mild	Reports feeling sad/unhappy/depressed more than usual.
2	Mild	Same as 2, but can't snap out of it easily.
3	Moderate	Frequent periods of feeling very sad, unhappy, moderately depressed, but able to function with extra effort.
4	Moderately severe	Frequent periods of deep depression *or* some areas of functioning are disrupted by depression.
5	Severe	Deeply depressed most of the time *or* many areas of functioning are disrupted by depression.
6	Extremely severe	Constantly deeply depressed *or* most areas of functioning are disrupted by delusional thinking.
9	Not assessed	

4. **Guilt** - Over concern or remorse for past behaviour. Rate on the basis of the patient's subjective experiences of guilt as evidenced by verbal report with appropriate affect; do not infer guilt feelings from depression, anxiety, or neurotic defences.

0	Not present	
1-2	Mild	Worries about having failed someone or at something. Wishes to have done things differently.
3-4	Moderate	Preoccupied about having done wrong or injured others by doing or failing to do something.
5-6	Severe	Delusional guilt *or* obviously unreasonable self-reproach.
9	Not assessed	

5. **HOSTILITY** - Animosity, contempt, belligerence, threats, arguments, tantrums, property destruction, fights, and any other expression of hostile attitudes or actions. Rate solely on the basis of the verbal report of feelings and actions of the patient toward others. Do not include isolated appropriate anger. (Rate attitude toward interviewer under "Uncooperativeness".)

0	Not present	
1	Very mild	Irritable, grumpy.
2	Mild	Argumentative, sarcastic, *or* feels angry.
3	Moderate	Overtly angry on several occasions *or* yelled at others.
4	Moderately severe	Has threatened, slammed about or thrown things.
5	Severe	Has assaulted others but with no harm likely, e.g., slapped, pushed *or* destroyed property (Knocked over furniture, broken windows).
6	Extremely severe	Has attached others with definite possibility of harming them or with actual harm, e.g., assault with hammer or weapon.
9	Not assessed	

6. **SUSPICIOUSNESS** - Belief (delusional or otherwise) that others have now, or have had in the past, malicious or discriminatory intent toward the patient. Include persecution by supernatural or other non human agencies (e.g., the devil). On the basis of verbal report, rate only those suspicions which are currently held whether they concern past or present circumstances.

0		Not present
1-2	Mild	Seems on guard. Unresponsive to 'personal' questions. Describes incidents where other persons have harmed or wanted to harm him/ her that sound plausible. Patient feels as if others are laughing at or criticising him/her or public.
3-4	Moderate	Says other persons are talking about him/her maliciously *or* says others intend to harm him/her. Beyond likelihood of plausibility but not delusional.
5-6	Severe	Delusional. Speaks of Mafia plots, MI5, or other poisoning food.
9	Not assessed.	

7. **UNUSUAL THOUGHT CONTENT** - Unusual, odd, strange, or bizarre thought content. Rate here the degree of unusualness of the degree of disorganisation of speech. Delusions are patently absurd, clearly false, or bizarre ideas verbally expressed. Include thought insertion, withdrawal, and broadcasting. Include grandiose, somatic, and persecutory delusions even if rated elsewhere.

0		Not present
1	Very mild	Ideas of reference (people star/laugh at him/her). Ideas of persecution (people mistreat him/her). Unusual beliefs in psychic powers, spirits, UFO's. Not strongly held. Some doubt.
2	Mild	Same as 2 with full conviction by not delusional.
3	Moderate	Delusion present but not strongly held-functioning not disrupted; *or* encapsulated delusion with full conviction-functioning not disrupted.
4	Moderately severe	Full delusion(s) present with some preoccupation *or* some areas of functioning disrupted by delusional thinking.
5	Severe	Full delusion(s) present with much preoccupation *or* many areas of functioning disrupted by delusional thinking.
6	Extremely severe	Full delusion(s) present with almost total preoccupation or most areas of functioning disrupted by delusional thinking.
9	Not assessed.	

8. **GRANDIOSITY** - Exaggerated self-opinion, conviction of unusual ability or powers or identity as someone rich or famous. Rate only on the basis of patients statements about himself or self-in-relation-to-others, not on the basis of his/her demeanour in the interview.

0	Not present	
1	Very mild	Feels great and denies obvious problems.
2	Mild	Exaggerated self-opinion beyond abilities and training.
3	Moderate	Inappropriate boastfulness, claims to be 'brilliant', understands how everything works.
4	Moderately severe	Claims to be great musician who will soon make recordings or will soon make patentable inventions-but not delusional.
5	Severe	Delusional-claims to have special powers like ESP, to have millions of pounds, made movies, invented new machines, worked at jobs when it is known that he/she was never employed on these capacities.

6 Extremely severe — Delusional-claims to have been appointed by God to run the world, controls the future of the world, is Jesus Christ, Prime Minister, etc.

9 Not assessed.

9. **HALLUCINATIONS** - Reports of perceptual experiences in the absence of external stimuli. Rate only those experiences which are reported to have occurred within the last week and which are described as distinctly different from the thought and imagery processes of normal people.

0 Not present

1 Very mild — While resting or going to sleep, sees visions, hears voices, sounds or whispers in absence of external stimulation but, not impairment in functioning.

2 Mild — While in a clear state of consciousness, hears non-verbal auditory hallucinations (e.g., sounds or whispers) or sees illusions (e.g., faces in shadows) on no more than two occasions and with no impairment in functioning.

3 Moderate — Occasional verbal, visual, olfactory, tactile, or gustatory hallucinations (1-3 times) but no impairment in functioning *or* frequent non-verbal hallucinations/visual illusions.

4 Moderately — Daily *or* some areas of functioning are disrupted by hallucinations.

5 Severe — Several times a day *or* many areas of functioning are disrupted by hallucinations.

6 Extremely severe — Persistent throughout the day *or* most areas of functioning are disrupted by hallucinations.

9 Not assessed.

10. **ELEVATED MOOD** - A pervasive, sustained, and exaggerated feeling of well-being, cheerfulness, euphoria (implying a pathological mood), optimism that is out of proportion to the circumstances. Do not infer elation from increased activity or from grandiose statements alone.

0 Not present

1 Very mild — Seems to be unusually happy, cheerful without much reason.

2 Mild — Some unaccountable feelings of well-being.

3 Moderate — Reports excessive or unrealistic feelings of well-being, cheerfulness, confidence, or optimism *inappropriate to*

circumstances, some of the time. May frequently joke, smile, be giddy, or overly enthusiastic *or* few instances of marked elevated mood with euphoria.

4 Moderately severe — Reports excessive or unrealistic feelings of well-being, confidence, or optimism *inappropriate to circumstances* much of the time. May describe feeling "on top of the world," "like everything is falling in place," or "better than ever before." *or* several instances of marked elevated mood with euphoria.

5 Severe — Mood definitely elevated almost constantly throughout interview and inappropriate to content, *or* many instances of marked elevated mood with euphoria.

6 Extremely severe — Seems almost intoxicated, laughing, joke, giggling, constantly euphoric, feeling invulnerable, all inappropriate to immediate circumstances.

9 Not assessed.

11. **DISORIENTATION** - Does not comprehend situations or communications. Confusion regarding person, place, or time.

0 Not present

1-2 Mild — Occasionally seems muddled, bewildered, or mildly confused.

3-4 Moderate — Seems confused regarding person, place, or time. Has difficulty remembering facts e.g., where born-or recognising people. Mildly disorientated as to time or place.

5-6 Severe — Grossly disoriented as to person, place, or time.

9 Not assessed.

12. **CONCEPTUAL DISORGANISATION** - Degree to which speech is confused, disconnected or disorganised. Rate on the basis of integration of the verbal products of the patient; do not rate on the basis of the patient's subjective impression of his/her own level of functioning.

0 Not present

1 Very mild — Peculiar use of words, rambling but speech is comprehensible.

2 Mild — Speech is a bit hard to understand or make sense of due to tangentiality, circumstantiality, or sudden topic shifts.

3 Moderate — Speech difficult to understand due to tangentiality, circumstantiality, or topic shifts on may occasions *or* 1-2 instances of severe impairment, e.g., incoherence, derailment, neologisms, blocking.

4	Moderately severe	Speech difficult to understand due to circumstantiality, tangentiality, or topic shifts most of the time *or* 3-5 instances of severe impairment.
5	Severe	Speech is incomprehensible due to severe impairments most of the time.
6	Extremely severe	Speech is incomprehensible throughout interview.
9	Not assessed.	

13. **INCOMPREHENSIBILITY OF SPEECH** - Degree to which speech is difficult to understand due to unintelligible, inarticulate vocalisations. Rate only the degree to which communication is difficult due to muttering, mumbling, indistinctness, mouthing, whispering, etc. Do not rate on basis of content, coherence, or logicality.

0	Not present	
1-2	Mild	1-2 instances of mumbling, muttering, etc., but most of speech understandable *or* so softly spoken as to require some repetition.
3	Moderate	Same as above but about 25% of replies must be repeated in order to understand.
4	Moderately severe	More than half of responses must be repeated.
5	Severe	Interview completed with considerable difficulty. Most replies have to be repeated.
6	Extremely severe	Interview not possible due to incomprehensibility of replies.
9	Not assessed.	

RATINGS BASED ON BEHAVIOUR AT INTERVIEW

14. **MOTOR HYPERACTIVITY** - Increase in energy level evidenced in more frequent movement and/or rapid speech.

0	Not present	
1	Very mild	Some restlessness, difficulty sitting still, lively facial expressions, or somewhat talkative.
2	Mild	Occasionally very restless, definite increase in motor activity, lively gestures, 1-3 brief instances of pressured speech.
3	Moderate	Very restless, fidgety, excessive facial expressions, or non-productive and repetitious motor movements. Much pressured speech up to one-third of interview.
4	Moderately	Frequently restless, fidgety. Many instances of excessive non-productive and repetitious motor movements. On the move most of the move most of the time. Frequent pressured speech, difficult to interrupt. Rises on 1-2 occasions to pace.
5	Severe	Excessive motor activity, restlessness, fidgety, loud tapping, noisy, etc., throughout most of the interview. Constant pressured speech with only few pauses. Speech can only be interrupted with much effort. Rises on 3-4 occasions to pace.
6	Extremely severe	Constant excessive motor activity throughout entire interview, e.g., constant pacing, constant pressured speech with no pauses, interviewee an only be interrupted briefly and only small amounts of relevant information can be obtained.
9	Not assessed.	

15. **MOTOR RETARDATION** - Reduction in energy level evidenced in slowed movements and speech, reduced body tone, decreased number of spontaneous body movements. Rate on the basis of observed behaviour of the patient only; do not rate on the basis of patient's subjective impression of own energy level. Rate regardless of medication effects.

0	Not present	
1-2	Mild	Noticeably slowed or reduced movements or speech compared to most people.
3	Moderate	Large reduction or slowness in movements or speech.
4	Moderately severe	Seldom moves or speaks spontaneously *or* very mechanical stiff movements.

5	Severe	Does not move or speak unless prodded or urged.
6	Extremely severe	Frozen, catatonic.
9	Not assessed.	

16. **BLUNTED AFFECT** - Reduced emotional tone, apparent lack of normal feeling or involvement. This rating should focus on overall severity of symptoms, especially unresponsiveness, eye contact, facial expression, and vocal inflections **as assessed by the Scale for the Assessment of Negative Symptoms.**

0	Not present	
1-2	Mild	Some loss of normal emotional responsiveness.
3	Moderate	Emotional expression very diminished, e.g., doesn't laugh, smile or react with emotion to distressing topics except on 2 or 3 occasions during interview.
4	Moderately severe	Emotional expression extremely diminished, e.g., doesn't laugh, smile, or react with emotions to distressing topics except for a maximum of 1 time during interview.
5	Severe	Mechanical in speech, gestures, and expression.
6	Extremely severe	Frozen expression and flat speech. Shows no feeling.
9	Not assessed.	

17. **TENSION** - Physical and motor manifestations of tension, "nervousness" , and agitation. Tension should be rates solely on the basis of physical signs and motor behaviour and not on the basis of subjective experiences of tension reported by the patient (rate self-report on the time anxiety).

0	Not present	
1-2	Mild	Seems tense. Tense, nervous mannerisms some of the time.
3-4	Moderate	Seems anxious. Fearful expression, trembling, restless.
5-6	Severe	Continually agitated, pacing, hand wringing.
9	Not assessed.	

18. **MANNERISMS AND POSTURING** - Unusual and bizarre motor behaviour; the type of motor behaviour which causes certain patients to stand out in a crowd of normal people. Rate only abnormality of movements; do not rate simple heightened motor activity here.

0	Not present	
1-2	Mild	Eccentric or odd movements or activity that ordinary persons would have difficulty explaining, e.g., grimacing, picking.
3-4	Moderate	Mannerisms or posturing maintained for 5 seconds or more that would make the patient stand out in a crowd as weird or mad.
5-6	Severe	Posturing, intense rocking, foetal positioning, strange rituals that dominate patient's attention and behaviour.
9	Not assessed	

19. **UNCOOPERATIVENESS** - Evidences of resistance, unfriendliness, resentment, and lack of readiness to cooperate with the interviewer. Rate only on the basis of the patient's attitude and responses to the interview and the interview situation; do not rate on the basis of reported resentment or Uncooperativeness outside the interview situation.

0	Not present	
1-2	Mild	Gripes or tries to avoid complying but goes ahead without argument.
3-4	Moderate	Verbally resists, or negativistic but eventually complies. Some information withheld.
5-6	Severe	Refuses to cooperate.
9	Not assessed.	

20. **EMOTIONAL WITHDRAWAL** - Deficiency in relating to the interviewer and the interview situation. Rate only degree to which the patient gives the impression of failing to be in emotional contact with other people in the interview situation.

0	Not present	
1-2	Mild	Tends to show emotional involvement with interviewer but responds when approached.
3-4	Moderate	Emotional contact not present most of the interview. Responds only with minimal affect.
5-6	Severe	Actively avoids emotional participation. Unresponsive or yes/no answers. May leave when spoken to or just not respond at all.

9 Not assessed.

21. **DISTRACTIBILITY** - Degree to which observed sequences of speech and actions are interrupted by minimal external stimuli. Include distractibility due to intrusions of visual or auditory hallucinations. Interviewee's attention may be draw to noise in adjoining room, books on a shelf, interviewer's clothing, etc. Do not include preoccupation due to delusions or other thoughts.

0	Not present	
1	Very mild	Generally can focus on interviewer's questions with only 1 distraction or inappropriate shift of attention of brief duration due to minimal external stimuli.
2	Mild	Same as above but occurs 2 times.
3	Moderate	Responsive to irrelevant stimuli in the room or in the environment much of the time.
4	Moderately severe	Same as above, but now interferes with comprehensibility of speech.
5	Severe	Extremely difficult to conduct interview or pursue a subject due to preoccupation with unimportant and irrelevant stimuli or almost totally incomprehensible because attention shifts rapidly between various irrelevant external stimuli and interviewer's questions.
6	Extremely severe	Impossible to conduct interview due to preoccupation with unimportant and irrelevant external stimuli.
9	Not assessed.	

BRIEF PSYCHIATRIC RATING SCALE SCORING SHEET

PATIENTS ID NO. _____ D.O.B. _____ SEX (M or F) _____

DATE OF INTERVIEW _____ PLACE OF INTERVIEW

_____

INTERVIEW NOT DONE/COMPLETED

1) Interview completed
2) Patient refused
3) Patient too confused
4) Patient mute
5) Patient broke off interview
   Reasons: _____

Somatic Concern	0	1	2	3	4	5	6	9
Anxiety	0	1	2	3	4	5	6	9
Depression	0	1	2	3	4	5	6	9
Guilt	0	1	2	3	4	5	6	9
Hostility	0	1	2	3	4	5	6	9
Suspiciousness	0	1	2	3	4	5	6	9
Unusual thought content	0	1	2	3	4	5	6	9
Grandiosity	0	1	2	3	4	5	6	9
Hallucinations	0	1	2	3	4	5	6	9
Elevated mood	0	1	2	3	4	5	6	9
Disorientation	0	1	2	3	4	5	6	9
Conceptual Disorganisation	0	1	2	3	4	5	6	9
Incomprehensible speech	0	1	2	3	4	5	6	9
Motor hyperactivity	0	1	2	3	4	5	6	9
Motor retardation	0	1	2	3	4	5	6	9
Blunted affect	0	1	2	3	4	5	6	9
Tension	0	1	2	3	4	5	6	9
Mannerisms and posturing	0	1	2	3	4	5	6	9
Uncooperativeness	0	1	2	3	4	5	6	9
Emotional withdrawal	0	1	2	3	4	5	6	9
Distractibility	0	1	2	3	4	5	6	9

Appendix 6. Guide Lines for Use of the Krawiecka Scale

In making these ratings the rater is expected to use his/her clinical judgement to make overall assessments about the patients in each particular area. Ratings should be based on both the patient's demeanour and behaviour during the interview and the history over the previous week given by the patient.

General rules for the Five-Point Scale

Rating "0" Absent:	The item is for all practical purposes absent.
Rating "1" Mild:	Although there is some evidence for the item in question, it is not considered pathological.
Rating "2" Moderate:	The item is present in a degree just sufficient to be regarded as pathological.
Rating "3" Marked}	–> See individual definition
Rating "4" Severe}	

Depression

This does not only include the actual behaviour observed at interview - dejected pose, sad appearance, despondent manner - but should be a clinical rating which expresses the overall assessment of depression, and the contribution that this abnormality of affect is making in the abnormal mental state being rated. Where there is a discrepancy between depression observed at interview and depressed mood reported as having been experienced in the past week, the rating made should be the greater of the two.

Rating "0" Absent:	Normal manner and behaviour at interview. No depressive phenomena elicited.
Rating "1" Mild:	Although there may be some evidence of depression - occasional gloominess, lack of verve, etc. - the rater does not consider that it is pathological, or takes it to be an habitual trait not amounting to clinically significant depression.
Rating "2" Moderate:	The patient is thought to be clinically depressed but to a mild degree. *or* Occasional depressed feelings which either cause significant distress or are looked upon by the patient as a significant departure from his usual self, in the past week.
Rating "3" Marked:	The patient is thought to be clinically depressed, in marked degree. *or* Frequent depressed feeling as described in "2" in the past week, or occasional extreme distress caused by depression.
Rating "4" Severe:	The patient is thought to be clinically depressed in extreme degree. Major depressive phenomena should be present; strongly held suicidal ideas, uncontrollable weeping, etc. *or* Depression has caused extreme distress frequently in the past week.

Anxious

In addition to direct evidence of anxiety observed by the rater at interview, this rating should express the rater's view of the contribution which morbid anxiety is making to the mental state under consideration. (There may be some physiological signs of sympathetic over-activity, moist palms, mild tremor, blotchy patches on the skin, etc.) Where anxiety is of such a degree that there is associated motor agitation, this will be rated on this key as not less than "3". Where there is a discrepancy between anxiety as observed at interview and anxiety expressed in the previous week the rating made should be the greater of the two.

Rating "0" Absent:	Normal mood at interview.
Rating "1" Mild:	Such tenseness as the patient displays is thought either to be an habitual trait not amounting to pathological proportions or is thought to be a reasonable response to the interview situation.
Rating "2" Moderate:	The patient is thought to display a mild degree of clinically significant anxiety or tension. *or* Anxiety sufficient to cause significant distress has occurred occasionally in the past week.
Rating "3" Marked:	The patient is thought to display a marked degree of clinically significant anxiety or tension. He may be apprehensive about the interview and need reassurance, but there are only minor disruptions of the interview due to anxiety. There may be associated motor agitation of mild degree. *or* Anxiety sufficient to cause significant distress has occurred frequently in the past week, or anxiety has caused extreme distress for the individual concerned occasionally in the past week.
Rating "4" Severe:	The patient is thought to display an extreme degree of clinically significant anxiety or tension. He may be unable to relax, or there may be major disruptions of the interview due to anxiety. There may be associated motor agitation of marked degree, or a fearful pre-occupation with impending events. *or* Anxiety has caused extreme distress frequently in the past week.

Coherently Expressed Delusions

Rating "0" Absent:	No abnormality detected at interview.
Rating "1" Mild:	Eccentric beliefs and trivial misinterpretations: that bad weather is caused by nuclear tests; superstitions, religious sects, etc.
Rating "2" Moderate:	Over valued ideas and ideas of reference, or undoubted misinterpretations. Special meanings.
Rating "3" Marked:	Undoubted delusions or delusional perception are described as having occurred in the past month, but the patient denies that he still holds the beliefs at present, *or* Delusional ideas are expressed but they are not strongly held or incorrigible.
Rating "4" Severe:	Undoubted delusions are present and are still held by the patient.

Hallucinations

The rater must decide whether hallucinations have occurred in the past week; if so whether they are true - or pseudo-hallucinations, and how frequently they have occurred.

Rating "0" Absent:	No evidence of hallucinations.
Rating "1" Mild:	The hallucinatory experiences reported to the rater are definitely morbid, hypnogogic hallucinations, eidetic images and illusions.
Rating "2" Moderate:	Pseudo-hallucinations of hearing and vision; hallucinations associated with insight - e.g., those following bereavement.
Rating "3" Marked:	True hallucinations have been present in the past week but have occurred infrequently.
Rating "4" Severe:	True hallucinations have occurred frequently in the past week.

Incoherence and Irrelevance of Speech

Rating "0" Absent:	No evidence of thought disorder
Rating "1" Mild:	Although replies are sometimes odd the abnormalities fall short of those required for thought disorder: it is always possible to understand the connection between ideas.
Rating "2" Moderate:	Occasional evidence of thought disorder elicited, but patient is otherwise coherent.
Rating "3" Marked:	Frequent evidence of thought disorder but meaningful communication is possible. *or* Several episodes of incoherent speech occur.
Rating "4" Severe:	Replies difficult to follow owing to lack of directing associations. Speech frequently incoherent, without a discernible thread of meaning.

Poverty of Speech, Mute

Rating "0" Absent:	Speech is normal in quantity and form.
Rating "1" Mild:	Patient only speaks when spoken to; tends to give brief replies.
Rating "2" Moderate:	Occasional difficulties or silences but most of interview proceeds smoothly: *or* Conversation impeded by vagueness, hesitancy or brevity of replies.
Rating "3" Marked:	Monosyllabic replies; often long pauses or failure to answer at all. *or* Reasonable amount of speech, but answers slow and hesitant, lacking in content, or repetitions and wandering that meaningful conversation was almost impossible.
Rating "4" Severe:	Mute throughout interview, or speaks only two or three words. *or* Constantly murmuring under breath.

Flattened, Incongruous Affect

Flatness refers to an impairment in the range of available emotional responses; the patient is unable to convey the impact of events while relating his history, and cannot convey warmth or affection while speaking about those near to him. If rating in relation to flat-blunted affect, consider ratings on the Scale for the Assessment of Negative Symptoms.

Rating "0" Absent:	Normal mood at interview.
Rating "1" Mild:	The patient may be laconic, taciturn or unresponsive in discussion emotionally charged topics, but the rater considers that this is an habitual trait rather than a sign of illness.
Rating "2" Moderate:	Clinically significant impairment of emotional response of mild degree. Definite lack of emotional tone discussing important topics; or occasional but undoubted incongruous emotional responses during the interview.
Rating "3" Marked:	Clinically significant impairment of emotional responses of marked degree. No warmth or affection shown. Cannot convey impact of events when giving history, no concern expressed about future; *or* Frequent incongruous responses of mild degree or occasional gross incongruity.
Rating "4" Severe:	Clinically significant impairment of emotional response of extreme degree; no emotional response whatever elicited *or* gross frequent incongruity; fatuous, supercilious, giggling, etc., in such a way as to disturb interview.

Psychomotor Retardation

Rating "0" Absent:	Normal manner and speech during interview. Questions answered fairly promptly; air of spontaneity and changes of expression.
Rating "1" Mild:	Although there may be evidence of slowness or poor spontaneity the rater considers that this is either an habitual trait or that it does not amount to clearly pathological proportions.
Rating "2" Moderate:	The rater detects slowness, or lack of spontaneity at interview and attributes this to psychiatric illness; it is just clinically detectable. Delays in answering questions would merit this rating providing that the rater considers that it is part of a morbid mental state rather than an habitual trait of the patient.
Rating "3" Marked:	Psychomotor retardation attributable to psychiatric illness is easily detectable at interview and is thought to make a material contribution to the abnormalities of the patient's present mental state.
Rating "4" Severe:	Psychomotor retardation is present in extreme degree.

Scoring Sheet for Krawiecka Rating Scale

Patients ID No. _____ DOB _____ Sex (M or F)

Date of Interview _____ Place of Interview _____

INTERVIEW NOT DONE/COMPLETED

1) Interview completed
2) Patient refused
3) Patient too confused
4) Patient mute
5) Patient broke off interview
   Reasons: _____

Name of Rating	**Rating**					
Rating made by replies to questions:						
Depressed	0	1	2	3	4	9
Anxious	0	1	2	3	4	9
Coherently expressed delusions	0	1	2	3	4	9
Hallucinations	0	1	2	3	4	9
Ratings made by observation						
Incoherence of speech	0	1	2	3	4	9
Poverty of speech, mute	0	1	2	3	4	9
Flattened incongruous affect	0	1	2	3	4	9
Psychomotor retardation	0	1	2	3	4	9

Appendix 7. Scoring Key for Self-reported Insight (Birchwood et al., (1994).

Please read the following statements carefully and then tick the box which best applies to you:

		Agree	Disagree	Unsure
1.	Some of my symptoms are made by my mind.	2	0	1
2.	I am mentally well.	0	2	1
3.	I do not need medication .	0	2	1
4.	My seeing someone from the CMHT is necessary.	2	0	1
5.	The doctor is right in prescribing medication for me .	2	0	1
6.	I do not need to be seen by a doctor or psychiatrist .	0	2	1
7.	If someone said I have a nervous or mental illness then they would be right.	2	0	1
8.	None of the usual things I experience are due to an illness.	0	2	1

Items (Total = 12)		
1, 8	=	relabel (total 4)
2, 7	=	awareness of illness (total 4)
3, 4, 5, 6	=	need for treatment (total 4) items to be added and divided by 2