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Discrepancies between service users' and care coordinators' views of need and service engagement.

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Abstract

Service engagement is paramount in ensuring effective services are delivered to help people with long-term mental health problems. Another important issue is the extent to which service users and professionals agree on recovery priorities so that these can be translated into needs to be met. Although the disagreement between service users and clinicians on opinions of need status (met or unmet) has been related to several clinical and functional outcomes the impact of discrepant views on service engagement has not been fully explored. This pilot study aimed to examine the association between differences in care coordinator and service user views of “Getting Better”, need status and service engagement. A total of 30 service users with a psychotic diagnosis and their care coordinators completed a What Getting Better Means Questionnaire and the Camberwell Assessment of Need Short Appraisal Scale to compare their recovery priorities and beliefs about need status. Service engagement as was measured by the Service Engagement Scale alongside the helping alliance (Helping Alliance Scale) and services users’ adjustment to psychosis (Recovery Style Questionnaire) were assessed. The result of this pilot investigation failed to support the main hypothesis that higher disagreement between staff and services users on recovery priorities and need status could lead to lower levels of service engagement. However a statistically significant correlation between staff-client agreement and the helping alliance was detected. In addition it was found that higher unmet needs and service engagement were correlated. Findings were understood in terms of health belief models. Clinical implications for the experimental results were explored.

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Dedicated to Beullah.

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Introduction

The public debates about mental health services have undergone several changes over the past two decades. A preliminary shift was the provision of mental health services from the hospitals to the community. With the move to care in the community it has long been recognized that people with severe and enduring mental health problems need to be effectively care managed and engagement with services is deemed to be important to support people with serious mental illness. Also around this time the purchaser/provider split in the 1990's, charging local authorities with the responsibility for providing healthcare, has led to a preoccupation with ascertaining the effectiveness of treatments in the NHS (Parry, 1996). The literature became littered with discussion of needs assessment. Another related more recent theme has been the increased attention paid to the expertise and experience of those very people who until recently were the passive recipients of care. The values of the user movement have influenced a new interest in the ideas of needs assessment made popular in the early 1990's and legislation now means services users have a 'voice' in most aspects of healthcare. The questions that connect these changes over the decade are: does service user engagement with services relate to getting what they want? Taking into account the 'voice' of the service user, what constitutes need? Thirdly, are there implications for service engagement if services and service user perceptions of needs and goals are at odds?

This introduction will be divided into two parts and literature that is relevant to the questions will be discussed and critically explored. Primarily it will present the person specific and service based factors that have been linked to service engagement. In the

second section of the introduction the concept of needs assessment will be discussed in detail. Different approaches to needs assessment methods used with people with long-term mental health problems will be presented and critiqued in order to establish the validity of the measure used in this study. Following this there will be an exploration of how the 'service user movement' has illuminated alternative conceptions of need to highlight the problems with past needs assessment tools. At this point the Camberwell Assessment of Need (Slade, Thornicroft, Loftus, Phelan & Wykes, 1999), a measure that makes some headway in the process of encompassing both service user and staff views, will be described. The focus will then move onto the research which demonstrates the implications of discrepancies between staff and client views of need. Finally, the conclusion will aim to emphasize the rationale for the present study and the research questions will be set out.

Service Engagement

Engagement has been described as the process whereby a practitioner approaches a potential service user and/or carer as the first stage in establishing a trusting relationship. It is an attempt to build a solid foundation for developing an ongoing constructive partnership (Bleach, 1994). It has been proposed that a certain degree of successful engagement is required to enable subsequent assessment, planning, implementing and monitoring of care. Without such engagement, these functions become at best biased towards the professional's view and at worst redundant if the client actively avoids contact. According to Kisthardt and Rapp (1989) engagement should be regarded as a separate function in and of itself. The research to date, alongside clinical experience, suggests that the concept of engagement is both complex and multifaceted. At the most

basic level, engagement is intuitively comprised of not only appointment keeping but also accepting interventions offered. Kinsthardt and Rapp (1989) suggest that the process of engagement should involve educating clients about the nature of support for their problems. Second, engagement should help client and practitioner to get to know and trust each other.

With the move to care in the community it has long been recognized that people with severe and enduring mental health problems require a mental health support system to enable them to function in the community. Since then, a large body of evidence has supported the efficacy of managed community care treatments (Marshall & Lockwood, 2001). Furthermore, engagement with mental health services is of particular concern to providers of community based models of service delivery because it has been shown that client non-engagement is a major barrier to effective treatment; non adherence with services may be a risk factor for relapse and increased hospitalization (Song, Biegel & Johnsen, 1998). It has been surmised that non-compliance is associated with forty-three percent of admissions to psychiatric hospitals (Kent & Yellowlees, 1994) and costs one hundred million pounds a year (Davis & Drummond, 1990). Additionally, there may be more of a political agenda. One of the concerns associated with patient non-engagement is the issue of forensic risk. That is the public fears that people with mental health problems are prematurely discharged from hospital, not adequately looked after in the community and go onto commit serious crimes. According to Tait, Birchwood and Trower (2002) service engagement could be used as an outcome measure in assessing the effectiveness of psychosocial interventions. Basically, an approach may be regarded as beneficial because the client accepts the help provided. Another example would be in

terms of community care model outcome trials. A measure of service engagement could help researchers ensure that clients' varying attendance or engagement do not confound outcome (e.g. relapse rate) when care models are evaluated and compared.

Despite the apparent importance of engagement, a review of care for individuals with long term mental health needs showed that engagement with mental health services is notoriously poor, with many clients failing to engage with treatment partnerships (Mueser, Bond, Drake & Resnick, 1998; Sainsbury Centre for Mental Health, 1998). The government has responded to this concern. The NHS Plan promised a large financial investment to fund assertive outreach teams specifically developed to address the priority of engaging patients with severe and enduring mental health problems. Moreover, one proposal of the highly contested new mental health act involves making the welfare benefits of psychiatric patients dependent upon their compliance (Thompson, 1996). The government's consideration of this controversial move may be construed as testimony to their commitment to tackling problems of service compliance.

In sum, engagement with services is crucial if clients are to benefit from community mental health care. To this end further research is necessary to elucidate the reasons for client disengagement with services. Despite this, the situation remains that little is known about the factors implicated in making teams more responsive to the needs of mental health service users (DoH, 2000). However, the literature does link service engagement to a handful of service and client factors. The next part of the introduction will discuss each element in turn alongside support from empirical research findings.

Aspects of the Service

To date the general focus on engagement with services has suggested that non-engagement may be the fault of the service users: clients do not engage with services rather than services not engaging with clients. However, McCabe, Heath, Burns and Priebe (2002) demonstrated how services may be implicated in the engagement process. They investigated how doctors engage with patients in routine consultations. The team analysed the conversations between thirty-two consultants and their patients with schizophrenia and schizoaffective disorder. They discovered that although doctors tended to ask about the frequency and severity of psychotic symptoms, patients' attempt to talk about their symptoms more generally was often impeded. Instead doctors avoided addressing questions posed by patients indicating reluctance to engage with their real concerns. Further to this, the research found that when a carer was present the psychiatrists frequently smiled or laughed in response to patients' talk of their symptoms. When patients were able to introduce topics of their concern it was often a source of communication problems. In short, the clients interviewed reported that psychiatrists' inability to engage empathically with psychotic material negatively affected engagement in consultations. The sensitive results of this research stimulated a great deal of comment from the medical world. One of the obvious problems with this study was that the sample contained consecutive 'attenders' of an outpatient clinic that arguably demonstrated good engagement. It may have been prudent to measure the engagement levels of the 'non-attenders' to ascertain whether the sample included in the study was biased. However this study added to the body of research which suggests that addressing patient concerns about their psychotic symptoms may encourage better

acceptance of services (Roter, Hall & Katz, 1987; Bertakis, Roter & Putnam 1991; Roter, Hall, Kern, Barker, Cole & Roca, 1995; Little, Everitt, Williamson, Warner, Moore, Gould et al. 2001).

Research by Watts & Priebe (2002) also showed that service disengagement was related to what psychiatric services do. Watts and Priebe (2002) gathered the perspective of twelve service users with severe mental health problems using a grounded theory approach. They assert that services often make false positive assessments of risk. They propose that clients are given coercive treatments such as medication enforced by sections of the mental health act unnecessarily. They note that between 1989 and 1993 the number of compulsory admissions increased by twenty-seven percent in the United Kingdom and that professionals tend to resort to over-restrictive styles to protect themselves from something going wrong (Harrison, 1997). In addition, it has been suggested that the experience of receiving a restrictive intervention such as a section may itself produce Post Traumatic Stress Disorder (Priebe, Broker, Gunkel, 1998). Further findings of the study were that a lack of agreement over “illness” models or consent could negatively influence relationships with psychiatric service providers.

The interviews suggested that the services’ preoccupation with risk and aversive custodial agendas harms the collaborative relationship. It was found that a services reliance on “proximal” intervention promoted disengagement. Proximal interventions were described as treatments, such as medication, which directly interfere with point of origin or in this case the body. On the other hand “distal” interventions such as housing and benefits are situated away from the point of origin (the body) and often focus on the

wider social environment. Clients described a pattern in which their non-compliance with proximal interventions was confounded by clinicians' non-compliance with distal interventions provoking clients' non-engagement (i.e. "You won't take your medication so we will not help you with your housing transfer)." A further factor associated with client non-engagement in the investigation was the services' negative reinforcement of willing engagement. The authors describe a situation in which service users who regain trust in the therapeutic relationship graduate to services that through resource deficits focus on the proximal interventions (e.g. medication) that led to their disengagement in the first place.

They also reported that many clients in their study had experienced a rejection of early help seeking behaviour or coercive interventions and they related this to their disengagement from services. The study claimed that coercive interventions were understood as an attack on the identities of the participants and all felt that their voices had not been heard. The authors noted that the difference between service users' and service providers' methods of reasoning partly explains the reasons why service providers ignore client aversive experiences as a factor in disengagement. Service users and service providers are believed to communicate in two different modes, which are thought to influence their therapeutic focus. The authors suggested that service providers use a *synchronic* reasoning style, concerned with events existing in a limited period of time, ignoring historical antecedents that may affect a person's disengagement. In contrast the participants' *diachronic* reasoning takes into account aspects such as language and culture that occur over a longer period of time. An example of diachronic

reasoning is taking into account a client's past experiences of mental health services and rejection in their private lives.

The major drawback of Watts & Priebe (2002) study was that the majority of the sample was Afro Caribbean and the qualitative approach limited the generalisability of the results. Although it has been found that a large number of those likely to disengage from services are Black (Sainsbury Centre, 1998) the number contained in this study are disproportional to the population and the generalisability of the results to other less urban areas is questionable. In the Watts and Priebe (2002) study 83% the service users came from Black and Asian backgrounds compared to 19% of the whole population (Sainsbury Centre, 1998). Furthermore, it is arguable that the qualitative nature of the pilot study compromises the applicability of the results to the long term mentally ill population. However this flaw of the research is likely to also be its strength: the research highlights the importance of incorporating the subjective views of various interested parties in the clinical decision making process.

Aspects of the Service Users Perception of the Service (Stigma)

Research has also suggested that engagement is concerned with the clients' experiences and perceptions of mental health services' behaviour. An important past review by the Sainsbury Centre (1998) endeavored to identify the issues regarded as important to people with long-term mental health problems in terms of non-engagement with psychiatric services, focusing on the perceptions of ethnic minority clients. Views about the particular problems of service users from black and ethnic minorities were sought by a variety of methods including half-day focus groups and semi-structured interviews.

The process also included a literature review and consultation with a number of experts. They proposed that problematic participation with services could be due to services being perceived as being culturally insensitive and dissatisfying (Sainsbury Centre, 1998). In addition this small scale exercise revealed that services were perceived as controlling at best and at worst dangerous. Some of the black service users reported that they feared that involvement with services would quite literally kill them. A fundamental problem with this review was that although it was one of the first sources to shed light on reasons for non-engagement, the qualitative nature of the research, focusing on service users from ethnic minority backgrounds makes the results less applicable to the general population.

The general conclusions from the Sainsbury Centre (1998) study proposed that non-attendance could follow from service users' negative appraisals of the quality of care received and social experiences of stigma. Stigma has been defined as when patient; "labeling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows them to unfold (Link and Phelan, 2001)". Similarly Onyett (1999) argued that one of the barriers to effective service-client relationships was the experience of the mental health services a being "socially devaluing and oppressive". Hagan (1990) stressed that clients' perception of services as stigmatizing and inaccessible, unwelcoming and culturally inappropriate were possible reasons for clients' non-engagement.

Aspects of the Service User

Finally elements concerning the individual with mental health problems, which have been linked to service engagement, will be addressed. Non-involvement with services has been linked to psychological factors such as poor memory and difficulties with structuring time (Hagan, 1990). The Sainsbury Centre (1998) report concluded that service disengagement was related to the individual user's personality characteristics. More relevantly, Kinsthardt and Rapp (1989) proposed that engagement should help the client to identify his or her own wants and needs. Hagan (1990) echoed this view and suggested that non-engagement with services may be associated with the extent to which a service user's perceived social and clinical needs are either met or unmet. The negotiating of goals has been hypothesized as being related to engagement but has yet to be empirically examined (Levy, 1998; Laslavia, Ruggeri, Azzi & Dall'Agnola, 2000; Watts & Priebe, 2002).

Recovery Style

A final major factor related to engagement, connected to aspects of the individual's personal style of coping with mental health problems, is recovery. Recovery style is the method of adjustment that a person with psychosis uses to cope with their illness. In 'sealing over' the individual deals with his illness by minimizing the significance of the symptoms and the impact of the psychosis. Conversely, individuals that are characterized by an "integrating" style tend to be curious about their symptoms and regard them as part of their life pattern and have a more flexible and variable attitude towards their illness. The distinct definitions were intended to represent two ends of a continuum (McGlashan, Levy, William & Carpenter, 1975).

The relationship between recovery style and psychopathology has received some support. McGlashan (1987) carried out a study in which two hundred and thirty-one patients with schizophrenia, schizoaffective, unipolar affective disorders, schizotypal and borderline personality disorders were followed-up. The results found that sealing over and integrating was strongly correlated to both functional outcome and psychopathology. However the various long-term trajectories of the different diagnostic categories may make the conclusion from this research difficult to interpret. For instance over a life course people with personality disorders may be more or less likely to suffer from depression and find work than a person with long-standing schizophrenia and in these cases connecting their engagement with adjustment processes become less clear.

The relationship between mental illness and coping style has been replicated in other research. Drayton et al. (1998) explored the relationship between recovery style, depression and childhood experiences with thirty-six participants. They showed that eighty-eight percent of the “sealers” were moderately to severely depressed. On the other hand, it was found that only fifty percent of the “integrators” were mildly depressed with none showing moderate or severe depressive symptoms. Furthermore, the results demonstrated that “sealers” tended to have vulnerable self-esteem, making more negative self-evaluation comments than the “integrators”. Finally, the authors reported that a history of insecure attachment and tendency to perceive their parents as being less caring in childhood predicted membership of the sealing over group. More recently, Birchwood et al (2000) hypothesised that those who were more likely to use a

“sealing over” strategy are probably more subject to the feelings of loss and shame and depression in relation to their illness and motivated by denial.

Tait, Birchwood and Trower (2003) took research a stage further and explored the effect of recovery style on both psychopathology and service engagement. They assessed fifty patients with a diagnosis of schizophrenia for service engagement, psychotic symptoms, insight and recovery style. In sum they discovered that those inclined to seal over at three months following an episode of psychosis were likely to disengage from services at six months. Of particular note in this study was the finding that there was no relationship between service engagement and either insight or psychotic symptoms. That is to say that the fact that someone came to services for help appeared to be independent of the realization that they had an illness. This sentiment of a person engaged with services with a sealing over coping style could be encapsulated by the phrase “I know I am ill with something it’s not schizophrenia but it was one of those things and I want to forget about it and move on.” (Tait, Birchwood & Trower, 2002). One problem with the study was that it is likely that what was observed was a snapshot in the lives of revolving door clients for whom sealing over was becoming an intrinsic part of their attitude to mental illness, leading to service disengagement. A second issue was that the participants came from urban inner city areas. It is conceivable that ethnicity and social disadvantage could influence adaptation to psychosis making these results less applicable to rural, less deprived mental health service users.

Although anecdotally and intuitively it is assumed that there may be a link between insight and service user service engagement, this association is not borne out in the

literature. However insight has been associated with different factors in the various studies. For instance, Francis and Penn (2001) discovered that greater levels of insight were correlated with better social skills. In a later study, Williams and Collins (2002) explored the connection between insight, severity of symptoms, diagnosis, locus of control and engulfment (extent to which a person identifies with the patient role) amongst fifty-eight people with serious mental health problems. The researchers found an association between poor insight and both symptom severity and engulfment. Lang, Berghofer, Kager, Steiner et al. (2003) explored predictors of insight with four hundred and eighteen patients. The authors claimed that high insight corresponded with a number of important demographic and treatment related factors including young age, marital status (married/cohabiting), diagnosis of mood disorder, low level of physical problems, low illness severity, low age at first treatment and high treatment validation. In terms of criticism, only the last study mentioned included enough participants to be able to make firm conclusion about the correlational relationships. In addition, the cross-sectional nature of the studies means that their findings can be at best regarded as preliminary. Despite the shortcomings of the research, the studies outlined were of reasonable quality and managed to provide support for many variables related to insight but not service engagement.

The relationship between insight and service engagement is not borne out in the literature. On the other hand, the weight of the empirical evidence from cross-sectional studies suggests a firm link between psychopathology, recovery and service engagement. As a result it may be that although insight may not mediate the

relationship between engagement and recovery, severity of psychopathology may feature.

In summary of the first portion of the discussion, the need to attend to care in the community objectives and decrease client risk has highlighted the importance of service engagement as a research preoccupation. It has been proposed here that service engagement is a complex concept composed of issues regarding the individual's need and perceptions of the mental health organizations. Having said this, the quality of the research into service engagement is variable. There is quantitative research suggesting that service disengagement may be affected by the individual service users' personal coping style. The empirical research here is compromised by its reliance on measures that are not well established. There are many studies linking engagement to issues concerning services' inability to meet client need. However the majority of these use the opinion of experts (category three evidence) and qualitative methods, often consisting of samples that do not reflect the ethnic mix of the U.K. Despite the important revelations made by the qualitative studies mentioned, the main criticism levied at the research presented concerns the generalisability of the findings to the mentally ill population. This literature review highlights the need to study the issue that service disengagement is a consequence of staff and service users not agreeing need more closely.

Given that it has been established that there is evidence connecting service disengagement with service users' perceptions of needs being met, the second part of the introduction will focus on needs assessment. The next section will discuss and evaluate the results of studies illustrating the discrepancies between service users and staff

appraisals of need using quantitative methods. In order to do this, the concept of need will be defined and needs assessment measures will be reviewed and compared.

Needs Assessment and the Concept of Need

Different researchers, depending on various theoretical perspectives have produced different definitions of need. The concept of need has been used by psychological theorists to explain the basis of action. For instance, the American Humanist, Maslow (1970) proposed that humans are motivated by a series of innate needs which are required to be met in a particular order to achieve a meaningful and satisfactory life. Those needs lowest in the hierarchy are physiological (e.g. hunger, thirst etc.) and must be satisfied before the next layer of need involving safety (e.g. security and the avoidance of pain etc). At the higher levels are needs of intimacy, belonging, self-esteem and finally self-actualization. Bradshaw (1972) made the distinction between “normative”, “comparative”, “felt” and “expressed” need. Externally defined “normative need” is the service led type based on the judgment of professionals such as mental health clinicians. Needs are believed to be the result of clinical or social functioning of a particular individual falling below a level specified on the judgment of an expert on the basis of his own competence and that of a shared clinical community. For example a clinician may use a DSM-IV diagnosis of schizophrenia to decide that psychotic symptoms need intervention. He explained ‘comparative need’ as the position based on the comparison of status in relation to other individuals or reference groups. For instance the occupational functioning and needs of a person with a long term mental illness may be compared with people without mental illness. Bradshaw described “felt” need as

being only experienced whereas “expressed” need as being both experienced and communicated.

The definitions of need have been translated into types of clinical need assessment. Warheit, Vega and Buhl-Auth, (1983) concluded that there are at least five types of needs assessment to be found in the literature on mental illness with a normative, service led top down assessment of need predominating. Top down, service-led methods, popular in mental health services are those which use needs assessment to inform service resource allocation such as the numbers requiring mental health services (Carter, 1995). According to Warheit, Buhl and Bell (1978), Warheit et al. (1983) and Balacki (1988), the various conceptions of need lead to different information about what is needed by whom.

Several approaches to staff informed, normative needs assessments have been produced over the years (e.g., Hall & Baker 1983; Wykes, Sturt & Creer, 1985; Earl & Holmes, 1985; Perez, Mortimer & Russell, 1987; Tanzman, Wilson & Teo, 1992). These measures endeavour to evaluate the individual’s social, behavioural and accommodation needs. By focusing on observable behaviours, behavioural methods can be sensitive to individual differences. However such methods are less able to take into account the context in which behaviour takes place. According to Brewin, Wing, Mangen, Brugha and MacCarthy (1987) behavioural instruments fulfill the criteria for systematic assessment and research but lack the ability to provide a framework for recording the proper course of action that should be required when a problem presents. Brewin et al. (1987) developed a Needs Assessment System which covered twenty-one areas of

clinical and social functioning. This method claimed to be able to specify clients' problems in a systematic and standardized way that took into account which of the clients' issues were being addressed through treatment whilst identifying areas of over-or-under-provision. This group of assessment schedules assume that needs are alleviated by interventions. It defined need as present when a person's clinical functioning falls below a specified level due to a potentially redeemable cause (Brewin et al, 1987). That is to say that a need is identified only when the clinicians believe they know the cause and treatment for a problem. However, it is argued that it is often difficult to determine whether there is an intervention available that would be at least partly effective. Furthermore it is likely that such methods assess intervention effectiveness rather than service user need status (Slade, 1994).

A fundamental criticism of the more recent normative approaches is that although they are more patient orientated than previous methods, they implicitly make the judgment that the person has a "problem that has to be solved". Second, the situation remains that because the view recorded is that of the clinician only, none of the traditional approaches to needs assessment mentioned thus far allow an explicit statement of the service users expressed needs in terms of type, level and intensity. On a separate note, keyworker informed measures suffer from the problem that their estimations of need may be inflated. Research has found that interviews with residential staff revealed higher levels of problems than the day patients themselves (Brewin, Veltro, Wing, MacCarthy & Brugha, 1990). Liss (1993) emphasizes the important point that health care is but one need and it is not necessarily defined by the expert opinion of a clinician. He asserts that the fact that the primary purpose of needs assessment is the achievement of human

happiness, the individual should be the person who is able to define what is needed for that state. The normative, service led top down approach to needs assessment may not provide enough information about the ways an individual may vary in a single domain. On the other hand a bottom up, service user led method may be a more flexible and sensitive way of ascertaining the expressed needs of people with mental health problems rather than overall organization strategy (Baldwin, 1986).

The final definition of need to be presented here contrasts need with demand. Stevens and Gabbay (1991, cited in Carter, 1995) make the distinction between need as what people can benefit from in contrast to the need of what people ask for. From this point of view it would be a mistake to make the assumption that need can be ascertained from a professional's assessment. However up until recently the majority of needs assessments tools relied only on staff reports alone. Assessment of need from the expressed view of the person with a mental health problem is currently one of the most neglected areas of mental health research in the United Kingdom (Carter, 1995). However the developing strength of the service user movement will make the priorities of the people who use mental health services, or 'felt' need, hard to ignore.

Service User Involvement Challenging the Perceptions of Outcome and Need

Service user involvement has received more attention in recent years. A number of legislative changes in the last two decades have recommended that service-users are involved in the organization, the planning and the provision of community care services (Social Services Select Committee, 1990; National Service Framework Executive

Summary 1998). In particular the focus on service users has produced non clinical user involvements that include sitting on appointment panels (e.g. Long, Newnes and Mac Lachlan, 2000), participating in staff induction and training, defining services' values framework (Turner, Crowson, 1997), developing a staff-user academic forum and advising on life planning (Davis, 1999).

Inherent in this non-exhaustive list of service user involvement initiatives is that the users' perspective *is* important in providing mental health services. The emergence of the "Recovery Model" in the field of mental health has helped advance the ideals of service user involvement and facilitate its application to models of service provision. Within the service user led recovery model, recovery is seen as a process via which the individual adapts to their lives with their mental health problems. The personal journey of recovery is unique and the individual accepts living and growing beyond the limits of mental and social disability to find a new purpose and meaning in life (Anthony, 1993). As such the removal of psychiatric symptoms does not ensure a purposeful existence and the recurrence of symptoms is not believed to preclude it. Some authors argue that the crux of the user involvement movement is to change what services believe is a good outcome (Davies, Holden & Sutton, 2002). However, traditionally mental health service outcome research conducted by disciplines including both psychiatry and psychology over the years seems to have taken a narrow view of outcome. As a result it has been argued that services' perceptions of service user need priorities have not involved enough of a service user perspective (Perkins, 2001). The relationship between outcome and need is a subtle but important one that must be explained. One must know what one needs before they can have a satisfactory outcome and vice versa.

What can be guaranteed is that any assessment of need will include a reference to symptomatic alleviation (Perkins, 2001). Although symptom reduction is vitally important to many, implicit within this focus is the assumption that if symptoms are alleviated the life of an individual with schizophrenia will be improved. However a number of studies conducted by individuals at the forefront of the recovery movement have indicated that symptom reduction is neither necessary nor sufficient to improve the quality of life of the individual with long-term mental health problems. Instead the literature shows something different: symptom severity does not have an effect on employment status and those who do not experience marked improvement in their symptoms after intervention may still experience an increased sense of control or understanding of their illness. The discussion paper of Strauss (1994) asserts that focusing on disease concepts alone is not adequate for understanding mental illness and prognosis and environmental factors are important.

To demonstrate this point, Anthony et al. (1995) followed two hundred and seventy five clients from a psychosocial rehabilitation program and assessed their symptoms and work skills on four occasions after vocational training. The group found that both work skills and symptoms improved slightly at follow-up. In addition results did not find a negative correlation between symptoms and work skills suggesting that individuals' work abilities were not influenced by their symptomatology. One issue with this research was that the original symptom scores of the majority of the group, as measured by the British Psychiatric Rating Scale, was low suggesting that the findings may be applicable to a particular proportion of those receiving mental health services. A second

major drawback of this study was that salutary effects of employment on symptoms demonstrated was evident after more than a fifty percent level of drop out making conclusions of the analysis limited. Despite these problems the research showed that symptomatology should not be used as a proxy measure of a person's ability to work and 'recover' from mental illness. So it appears that the elements included in traditional needs assessments are often not necessary for helping individuals with chronic mental health problems lead purposeful lives. As a result although symptom alleviation enquiry must be included in any evaluation of need, other user defined needs must be elucidated and given equal prominence within needs assessment. Within evidence based practice it is crucial that the relevance of outcomes of successful intervention and therapeutic goals are explored from the perspective of the user as well as the professional (Meddings & Perkins, 2002).

If it is accepted that a proper needs assessment must involve service users and an understanding of what service users have to say then this leads to the question of whether canvassing their views can introduce problems. One problem is that service users' involvement in the needs assessment processes may lead to a greater demand on limited resources. However the research that has investigated this claim has found inconclusive results. Another concern is that a service user with psychosis may lack the insight to provide valid assessment and their responses may be distorted. McClelland, Atkinson, Clark and Lowell (1953) proposed that people generally have a personal stake in the evaluation of their own needs in terms of importance, motivation and fulfillment: a person may exaggerate need to gain support in one instance and then underestimate need to prevent a loss of self esteem. Service users may be poorly motivated to express

their need or have difficulty determining outcomes with regard to their general state of affairs (e.g. Lefcour, 1981; Wing & Morris, 1981; Brugha, Wing, Brewin, McCarthy & Mangen, 1988; Wing, 1990). Indeed Carter (2003) assumed that if people with mental illness could not recognize their mental illness then they probably would not be able to notice their mental health needs. He examined the relationship of insight to self reported needs with one hundred and sixty community mental health team service users and their care coordinators. It was found that service users with more insight rate higher levels of need whilst care coordinators rate need independently of their service users' insight levels. This raised the possibility that that self reported need for people without insight is inappropriate. However the correlational nature of the data analysis means that the results were not enough to assume causation. Slade (1994) cautions against this view that people without insight cannot assess their own need and points out that although a person without insight may not be able to evaluate their need for medication, they may be able to comment on other important needs such as accommodation. Conversely, several studies show that there is little evidence to support less weight being afforded to the service users' own account of their difficulties compared to staff (e.g. Dellario, Anthony and Roger, 1983; Lord, Schnarr, & Hutchison, 1987). MacCarthy, Benson and Brewin (1986) interviewed long-term psychiatric patients about their skills and motivations to perform activities of daily living alongside their current problems and coping strategies. They discovered that patients were able to respond consistently and reliably to the questions and argued that service planning should take into account the subjective priorities of patients. In addition, several authors have found that the systematic identification of need can be made both reliably and validly by people with mental illness in a test re-test situation (e.g. Hogg & Marshall, 1992; Phelan, Slade,

Thornicroft et al., 1995; Carter, Crosby, Geertshuis & Startup, 1996; Slade, Phelan, Thornicroft & Parkman, 1996).

Studies illustrating the problems with normative service led approaches (e.g. resource led) and service user led methods (e.g. lack of insight) tend to show evidence that both methods have shortcomings. The service user's view is likely to be filtered through a particular sociocultural context and may be influenced by their expectations and past experiences. For instance, Asian service users may recognize their physical needs more readily than their psychological. Similarly the staff's opinions will be tempered by the values of a British caring system and informed by professional training and a personal agenda. For example a medically trained care coordinator may notice and prioritize physical needs more readily than housing requirements. However it has been shown here that is little convincing evidence that service-users cannot reliably assess their own needs and as a result both service user and staff views should be made explicit within the assessment. Need is clearly socially negotiated and the definition of need for one person in one context may be different to another. The negotiation of need cannot be objective and should be the product of a negotiation between both staff and service users (Slade, 1994; Carter, 2003). This would suggest a requirement to compare the expressed needs of the individual service users with the evaluation of others involved in the mental health enterprise.

“What Getting Better Means” Study – The Expressed Needs of Service Users and Staff Perceptions of Need

Research has demonstrated that service users opinions are not only reliable but also add to our knowledge about what could be important to them. A recent exploratory descriptive study used this subjective element of the users’ unique experience of mental illness to expand a vision of needs assessment. A qualitative study of users’ perspectives of “getting better” revealed ten different notions of what recovery means to service users and staff (Meddings & Perkins, 2002). In summary the article showed that there were differences between the ideas of service users and staff about important outcomes. For instance, improvement for service-users included traditional notions of mental state improvement but also included greater empowerment and engagement in work and activities. The authors concluded that although traditional methods of needs assessment try to incorporate social and clinical aspects of functioning and take into account service concerns, they may currently fall short of encapsulating some of the more existential priorities which are often aspects not explicitly included in traditional needs assessments at the expense of others. They argued for a broader approach to intervention that is tailored to what is important to the individual. Despite making headway into exploring the views of service user needs there were methodological flaws in this investigation. Firstly, there were twice as many men in the sample than women and this difference is not representative of the long term mentally ill found in mental health services. Secondly, the fact that the rehabilitation service espoused a recovery model as their overarching philosophy of care could have meant that the study’s findings were

compromised as the staff would have been exposed to the approach. This qualitative research requires and merits replication in different settings.

Previous quantitative research has mirrored the finding of this qualitative study and shown that opinions of professionals and services users often differ. A study carried out in a Massachusetts psychiatric unit found that staff regarded insight as a primary goal of intervention whereas patients placed insight at the bottom of their list of priorities (Dimsdale et al., 1979). Lynch & Kruzich (1986) found that there was a divergence between users and professional's perceptions of barriers to using mental health services. A separate evaluation of clinical case management compared the views of twenty-five service users with their case managers about their priorities of thirteen components of case management. The results showed that there was general agreement between the two groups regarding which components of case management had been delivered. Engagement, assessment and planning were seen as being important to both groups. However the study also found that service users rated psychoeducation more highly than case managers (Hemming & Yellowlees, 1997). A criticism of the study was that it was carried out in a remote mining town in Australia and this puts into question the generalisability of the findings to many parts of the U.K. For instance the isolated, rural service users included in the study may have enjoyed good family and social networks and as a result their priorities may be different from that of urban, ethnically diverse city dwellers.

As well as evidence that staff and service users hold differing opinions about successful outcome there are also reports that suggests that the various people involved in mental

health provision hold different ideas about the relevance of various indices of improvement (Bond, 1994). Whilst clinicians may explain successful intervention as symptom reduction, politicians are likely to afford pride of place to the reduction of the violent crime supposedly perpetrated by people with mental health problems and suicide rates. Although these are important clinical outcomes they may not be paramount to service users. Shepherd, Murray and Muijen (1995) used questionnaires, individual and group discussions to demonstrate differences between the views of clinicians, families and their patients regarding patient need and aspects of care. They discovered that although there was good consensus between the interested parties with families feeling that all aspects of care were important (i.e. symptom treatment, benefits, housing, everyday activity, practical aspects of care and relationships), service users placed more weight upon more practical aspects of care. On the other hand professionals prioritized treatment and symptom monitoring. However the areas of care that were prioritized were those that have been identified by research and clinical practice by clinicians as being significant and not generated by service users themselves. Moreover it was discovered that the families of service users prioritized gaining information about their relative's illness and receiving support to maintain them in their own roles as primary caregivers.

Given that there is evidence that service users and different stakeholders hold different, but valid opinions about the significance and definitions of outcomes then a standard method of assessing expressed needs of service users and carers would be useful. Needs assessment cannot simply be a process of listening to people with mental health problems or relying on carer views (Hansson, Vinding, Mackerprang et al. 2001; Carter, 2003). The next section will consider a well-established, needs assessment tool that has

been developed by clinicians, which tries to take into account the opinions of both service users and staff towards needs assessment.

The Camberwell Assessment of Need (Slade, Phelan, Thornicroft & Parkman, 1996)

Unlike previous models of need, The Camberwell Assessment of Need (CAN) uses a negotiation approach. The tool is comprised of a comprehensive range of both social and clinical health needs and permits the assessment of needs as perceived by both staff/carers and long-term mental health patients. The structured questionnaire is divided into twenty-two clinical and social areas. Both parties make ratings of the severity of problems on a scale of 0 to 2 with a rating of 2 and above constituting an unmet need. *A need is considered met when the service user or staff assesses that there is no problems in that area because help is being provided but a problem would exist without assistance. On the other hand a need is recorded as unmet when a service user or staff respondent reports a current problem in a particular domain regardless of whether help is provided.* If the assessment using the CAN does not produce any differences between the views of staff and service users then it is argued that either the staff or service user's viewpoint is seen as adequate. However if the differences between the two group's perceptions of need are statistically significantly different and do not correlate then both sets of perceptions are considered. The CAN is in accordance with governmental guidelines on assessing need, which states:

“...all users should be encouraged to participate to the limit of their capacity...Where it is impossible to reconcile different perceptions these differences should be acknowledged and recorded” (Department of Health Social Services Inspectorate, 1991).

Recently, there is an emerging literature comparing how clinician rated measures of individual service user needs differs from service users perceptions of their own difficulties. This part of the introduction will first present the studies, which compare the views of staff and service users' views of need using the CAN. It will proceed to discuss and critically evaluate the work that takes the situation a step further and relate the levels of need expressed to a variety of clinical and social variables.

Comparison of Service User and Staff Perceptions of Needs Using the CAN

An early investigation carried out by Middelboe, Mackeprang, Thalsgaard and Christiansen (1998) explored the profile of a community psychiatric service in Copenhagen. They interviewed forty-five residents with a diagnosis of schizophrenia living in a housing program using the Camberwell Assessment of Need and the Satisfaction with Life Domains Scale (Baker & Intagliata, 1982). They found that participants averaged a total of 8.33 met needs and 3.4 unmet needs in the twenty-two areas covered by the measure. The needs of residents were generally characterized by a high prevalence of unmet needs in the occupational/social sphere, probably indicative of the reason they were referred to the housing program. In particular it was reported that there was little agreement between residents and staff on the presence of need. Agreement between staff and residents were found only in the areas of psychological symptoms, physical health, alcohol and money. A discrepancy was discovered between staff and residents opinions on the importance of shopping and cooking. Further to this, as in the study by Shepherd et al. (1995) residents reported a much higher need for

information than staff. Staff views were partly in concordance with their clients and emphasized emotional support and help aimed at alleviating psychological distress and maintaining social support. However staff rated the prevalence of unmet needs within the spheres of psychological distress, psychotic symptoms, alcohol and drugs as about twice higher than the resident rated them. Interestingly the users' predominant unmet needs in the areas of psychological and social functioning were found to occur despite high satisfaction rates. Although this study appropriately used standardized assessments, the cross-sectional nature of this study and small sample size make it difficult to ascertain the relationship between life satisfaction and the other variables involved.

A second limitation of the study was the fact that it was carried out in Copenhagen and this aspect makes it difficult to extrapolate the conclusions to the United Kingdom. Research has demonstrated different patterns of need in various countries. For instance, McCrone, Leese, Thornicroft et al. (2001) compared the occurrence of need in patients with schizophrenia in Amsterdam, Copenhagen, London, Santander and Verona. They found that the differences between the sites were very low for overall needs. However it was shown that unmet need did vary between the countries with Copenhagen having relatively few and Amsterdam and London reporting more. The authors concluded that unmet needs are greater in urban areas like London and Amsterdam. In addition, they proposed that differences in the pattern could have partly been influenced by service provision.

An investigation carried out by Slade, Leese, Taylor and Thornicroft (1999) in the U.K assessed the impact of needs on the quality of life of a group of severely mentally ill

patients. One hundred and thirty-three patients meeting criteria for psychosis and staff completed the Camberwell Assessment of Need and the Lancashire Quality of Life Profile (Lehman, 1983). A relatively close agreement was found between staff and patient ratings of met needs. However a significant difference was apparent between staff and patients reports of unmet needs of patients. Most importantly higher unmet and met needs were associated with lower quality of life scores with higher levels of unmet needs carrying the stronger relationship. Another finding was that of all the sociodemographic variables, only age and diagnosis were associated with a higher quality of life. The authors proposed that a possible mediating factor could have been the presence of anxiety and depressive symptoms echoing the results of previous research (e.g. Levitt, Hogan & Bucosky, 1990; Lehman, 1983). This study discovered similar results as a previous study carried out by Slade, Phelan, Thornicroft and Parkman (1996) in which there was a difference found between staff and patient's ratings of need. An apparent strength of this study is that the sample, unlike the one described previously, was large and epidemiologically representative of the British population in terms of proportions of diagnoses. Although this study utilized more sophisticated statistical techniques to analyze the influence of the variables involved, as in the previous study the cross sectional nature of the research compromised the extent to which higher unmet need could be attributed to lower quality of life.

In 2000 Lasalvia, Ruggeri, Mazz and Dall'Agnola reported on the perception of needs in care staff and patients in a community based mental health service in South Verona. The study included patients with the full spectrum of diagnoses of mental disorder. The Italian version of the Camberwell Assessment of Need was administered to 247 staff and

patient pairs. The patient's level of disability and global functioning was assessed using the Disability Assessment Schedule (WHO, 1988) and the Global Assessment of Functioning Scale (APA, 1987) respectively. Psychopathology was assessed using the Brief Psychiatric Rating Scale (Ventura, Green, Shane & Liberman, 1993). The results showed that patients and staff identified roughly the same number of needs. As in the previous studies reported here, staff and patients most frequently mentioned needs in health and social arenas. Patients expressed needs most frequently in the domains of psychological distress, psychotic symptoms, physical health, company and intimate relationships. Staff identified a higher number of total needs in the areas of health, alcohol, safety to others and psychological distress. Conversely, as in the study carried out by Middelboe, Mackeprang, Thalsgaard and Christiansen (1998) and Slade, Phelan & Thornicroft (1998) patients described more unmet needs in the service domain such as information, telephone, transport and benefits. In general the findings suggested that staff report needs in the health sphere more frequently than patients. However whilst staff perceive such health needs as met, patients consider them as mostly unmet. The authors proposed that this discrepancy in opinion may have been due to differing opinions on the effectiveness of interventions provided. Most relevant to this study, they use these findings to suggest that the negotiation of goals on the basis of both the staff and patient judgments of need could result in better *uptake* of services offered. The results also showed that participants who were unemployed had a higher number of service contacts in the previous year, had more serious disability in social roles, and reported a higher number of needs. Furthermore the difference between needs rated by staff and patients was greater for those with poor global functioning. Although the study prided itself on the inclusion of patients with the full spectrum of mental disorders it

may be argued that different recovery and disability patterns of a heterogeneous sample could have differentially affected the results. People with serious mental health issues such as psychosis and personality disorders tend to constitute a broader group, less homogenous group with respect to need (Lasalvia et al., 2000). For instance people with such severe mental health problems have physical health issues that are not diagnosed and treated (Koran, Sox, Marton et al., 1989). A second criticism was that the results of correlations with employment, service contact and levels of disability were compromised by the sub-optimal level of subjects to variables ratio. Finally the number of people from ethnic minorities included in the sample was negligible making the findings of this study potentially less applicable to inner city U.K populations.

Hansson, Vinding, Mackerprang et al. (2001) presented a study that constituted part of a Nordic multicentre investigation. Countries included were Denmark, Copenhagen, Sweden, Norway, Finland and Ireland. Comparisons between keyworker and patient assessments were based on three hundred matched pairs. All participants had a diagnosis of schizophrenia as assessed by ICD-10. The authors reported a 55% participation rate. Assessment of need was measured using the Camberwell Assessment of Need and The Lancashire Quality of Life Profile (Lehman, 1983). The research explored the agreement between patients and their keyworkers in terms of presence of met need and unmet need. Again it was demonstrated that keyworkers identified slightly more overall needs than did their respective patients. It was shown that there was disagreements concerning in which domains the needs were identified and whether an unmet need existed in a specific area. However unlike the majority of previous studies (e.g. Middleboe et al., 1998; Slade et al., 1996) it was concluded that there was a moderate agreement in

seventeen out of the twenty-two life domains assessed. Furthermore, agreement on the level of unmet needs were lower with patients and keyworkers having a moderate to high level of agreement on only eleven out of the twenty-two domains of need. The discrepancy was greatest in the arena of information concerning treatment and condition, information about benefits and telephone. Additionally, they discovered that keyworkers associated more unmet needs with higher levels of psychopathology. On the other hand patients themselves related higher unmet need to worse overall quality of life. Both patients and keyworkers scores related higher unmet needs to poorer social networks. Positive aspects of this study included the clear and explicit reporting of inclusion and exclusion criteria and drop out rates, which allowed for a homogenous sample of patients from which clearer conclusions could be drawn. Having said this, the high dropout rate suggests that the sample from which the conclusions were drawn from could have been biased. For example, the service users included in the study could have been those who agreed to be tested, were better engaged with the service and therefore could have been more likely to agree with their care workers' views.

More recently Ochoa, Autonell, Penadas, Teba and Marquez (2003) conducted a study to examine the most common needs of a Spanish community sample. The team compared the views of staff and patients and focused on the correlates of unmet need. The research was comprised of two hundred and thirty outpatients with schizophrenia who were randomly drawn from a computerized register from a local mental health team. People with mental retardation and neurological disorder were not included in the study. Other inclusion criteria included at least one hospital outpatient appointment in the last six months. A number of different assessments were administered: The Positive

and Negative Syndrome Assessment – Spanish Version (Peralta & Cuesa, 1994); The Global Assessment of Functioning (APA, 1995); The Disability Assessment Scale (WHO, 1992); The Quality of Life Questionnaire (Baker & Intagliata, 1982) and the Camberwell Assessment of Need. They found that the mean number of needs identified by the group was similar to that reported in English and Nordic samples (i.e. Slade et al. 1998; Hansson, 2001). The mean needs expressed was higher than those found in the Italian study carried out by Lasalvia et al. (2000; described above). The most common needs mentioned apart from psychotic symptoms were food, house upkeep, daytime activities and company. These findings are consistent with the work of others (e.g. Rosales, 1999; Hansson et al., 2001; McCrone, 2001). In this study staff reported more needs than did patients. Furthermore, as with past studies, agreement between staff and patients was fair when assessing met need and low when unmet need was considered. It was detected that higher unmet need was weakly associated with more severe clinical symptoms and higher disability. In accordance with Slade et al. (1999) those patients with more unmet needs were found to have a worse quality of life. The positive aspects of the study included the tight inclusion criteria and the large sample size. However the focus on Spanish outpatients makes the generalization of the results to U.K. audiences limited. Secondly, the cross sectional nature of the research make statements of causation impossible.

Last year Slade, Leese, Ruggeri, Kuipers, Tansella and Thornicroft (2004) took the research in this area a stage further and carried out a longitudinal study investigating the relationship between patient rated unmet need and quality of life. The group measured the quality of life and needs of two hundred and sixty five mental health service users

using the Lancashire Quality of Life Profile and the CAN respectively. They revealed that higher baseline quality of life scores were associated temporally with fewer patient rated unmet needs. A regression analysis showed that meeting one patient need could result in an increase of 0.09 in Lancashire Quality of Life score. In a cross-sectional design, patient met need was also related to quality of life. The authors claimed that this was the first study to show that high levels of patient rated unmet needs causes low levels of quality of life. The strengths of this study included its use of routine outcome data, maximizing the relevance of the results to clinical work and the generalisability of the findings to other 'real world settings' and services. Although this study made progress in the area of research it only measured patient rated unmet need at baseline. As with previous studies mentioned the study took place in South Verona thereby limiting the applicability of the results to the British population.

To summarize, the studies described above appear to demonstrate a few consistent findings. These results have been made more convincing by their use of quantitative methodology and large research samples. The quality of research mentioned is also enhanced by the use of the CAN as one of the well established, psychometrically valid assessments of service user need (see Method section). The majority of the investigations demonstrate that keyworkers generally identify more overall needs than service users. Furthermore, there appears to be agreement between staff and service users in terms of met need and low agreement in regard to unmet need and mixed results concerning the common areas of agreement. However it is noteworthy that the results of the study, which demonstrated high staff/user inconsistency were compromised by its use of a small sample. The most common needs expressed by services users are need for

help with physical and emotional problems and information. Staff report needs in terms of physical health above everything else. Studies of generally high standards support the association between clinical outcomes and quality of life. Less consistently, higher need has been related to lower unemployment and global functioning and higher levels of service contact and disability.

The meaning of such findings must be set against the main criticisms of the studies. Firstly, the various diagnostic categories used in the different studies may differentially influence important variables leading to results that are difficult to interpret. Secondly, the majority of studies were carried out mainly in countries outside the U.K in a number of different settings (i.e. work projects, CMHT's, housing projects) and this may limit the extent to which the results can be generalized to British contexts and communities. Furthermore, in the majority of the studies, important methodological details have not been presented such as the exclusion and inclusion criteria (e.g. number of admissions and duration of helping relationships) and drop out rates. The lack of inclusion of such criteria may render the conclusions drawn by the reader less valid. Only one of the studies describes an appropriate sampling procedure. Inadequate information about sampling means that it is impossible to decipher whether those included and approached in the study could have been those who were most likely to agree with goals. The majority of the studies discussed included staff other than keyworkers as informant of need. It may be argued that staff other than care-coordinators may be in a position to influence aspects of the service users' lives. For instance a care worker at the service user's supported accommodation may know more about the service user's daily functioning than a care-coordinator who visits them once every month. In terms of

statistical analysis, it is unclear whether data from each of the staff was regarded as independent and whether this non-independence was accounted for in the data analysis in the studies. Finally the cross-sectional nature of most of the research means that statements about the causal influence of variables (e.g. unmet need on quality of life) cannot be made convincingly. So for example, according to Bollen (1998), the three criteria establishing a causal relationship are association, direction and isolation. The limitation due to the use of only association in the majority studies mentioned make it all the more important that the variables are tightly controlled and described.

All the studies mentioned utilized the CAN to assess service user need. Although the CAN makes headway in assessing the expressed needs of service users and relating discrepancies to outcome, most assessment measures have been devised by clinicians with few exceptions (Meddings & Perkins, 2002). According to Stallard and Chadwick (1991) there has been a lack of user involvement in designing questionnaires. This is despite the fact that it has long been recognized that the assessment of *individual need* is the most appropriate method of allocating mental health services. As a result, although the CAN recognizes both social and clinical aspects of need it does not include many aspects regarded as important by service users in qualitative investigation. Such unrepresented needs tend to be those at the higher end of the hierarchy of need (Maslow, 1970), concerned with affiliation and self-actualization. The present research aims to deal with this problem by including a service user influenced questionnaire to include other aspects of need in the study.

Summary

The introduction began by relating service disengagement to service users' negative perceptions of services in a number of mainly qualitative studies. Several aspects of psychiatric services that have been implicated in client disengagement were addressed alongside factors, which may cause clients to negatively appraise services. However the situation remains that further quantitative investigation is necessary to support the results. A focus on the mental health service users' negative perceptions of services led to a discussion of needs assessment. Reference to the existing research suggested that "The Camberwell Assessment of Need" could be reliably used to compare the discrepant views of staff and service users towards needs and the resultant clinical outcomes. Furthermore it was found that comparing views of staff and service users' towards needs revealed similar results to the qualitative studies and discrepant views were linked to a number of clinically relevant variables. This research aims to take the issue a stage further.

Recent debates in mental health services have focused on service users' wants and this introduction has shown that unmet need could be need related to engagement with services. Despite the fact the several authors have alluded to a relationship between wants, needs and service engagement there is no quantitative evidence documenting the link. Thus, the present study will use a quantitative methodology to ask whether service disengagement takes place when service users do not get what they want from services through care coordinators. The aims of the study are twofold: To evaluate whether staff and service users' views on the importance of a variety of indices of improvement differ

systematically in certain areas of recovery. Secondly, to ascertain whether discrepancies between staff and service users views of need and improvement affects service user engagement. In the process the research will examine whether recovery style acts as mediator between discrepant views and service engagement. These issues will be addressed by measuring service user need using the well validated CAN and assessed by questions which aim to understand further aspects of the service users' experience (What Getting Means Questionnaire). Differences in perceptions of needs will then be correlated with service engagement as measured by the Service Engagement Questionnaire.

Hypotheses

The research question will be explored by testing the following hypotheses:

- There will be a fair agreement between care coordinators' and service users' ratings of service user need status as measured by the CANSAS.
- Care coordinators will report more total needs than their service users as measured by the CANSAS.
- There will be a positive correlation between service user service engagement and recovery style.
- The greater number of unmet needs (as measure by the CANSAS) will be negatively correlated with levels of service user service engagement and recovery style.

- Greater differences between service user and care coordinator reports of unmet need will be associated with lower levels of service engagement.
- Greater agreement between the scores of service users and care coordinators on the CANSAS will be associated with the service users' higher level of engagement.
- Greater discrepancies between the scores of service users and care coordinators in the "What Getting Better Means" Questionnaire will be associated with the service users' lower levels of engagement with services.
- Service users will rate existential aspects (i.e. empowerment, self esteem and belonging) of improvement significantly higher than their care coordinators.
- Greater differences in ratings of existential aspects of improvement will be associated with lower service user service engagement.

Method

Overview

The present study was designed to investigate whether the views of service users' and their respective care co-coordinators' differ on what they believe "getting better" means and whether any discrepancies between their views negatively affect service user engagement. To do this, the research is divided into two parts: The first part of the study explores how service users and care coordinators define "getting better". This was done by posing a question about recovery to both parties.

The second part of the study addresses the research questions by testing the hypotheses set out at the end of the introduction. The number of total needs and unmet needs as reported by service users on the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS; Slade, Thornicroft, Loftus, Phelan & Wykes, 1999) will be compared with the total number of needs and unmet needs identified by the care co-coordinators using the same measure. Total unmet needs will be correlated with degree of engagement as measured by the Service Engagement Questionnaire (Tait, Birchwood & Trower, 2002). The agreement between service users' and care coordinators' views of need as measured by the CANSAS will be correlated with service engagement. Following this, the discrepancy between service users' and care co-coordinators' scores on the "What Getting Better Means" Questionnaire will be correlated with the service users scores on both the Service Engagement Questionnaire and the Recovery Questionnaire (Drayton & Birchwood, 1998). Finally the service users and care

coordinators' ratings of existential aspects of getting better (i.e. empowerment, self esteem and belonging) will be compared.

Participants

Ethical approval was obtained from East London and the City Research Ethics Committee (see Appendix 1). The participants were drawn from one of the East London and the City Mental Health NHS Trust community mental health teams. The community mental health team meetings were attended and all care coordinators with a current caseload agreed to take part in the research. Eligible participants were identified in a meeting with care coordinators. All of the care coordinators' respective service users who had a diagnosis of a psychotic disorder and at least a six-month care relationship were included. Service users who had been in a care-coordinating relationship for more than five years were not included in the study. It was a requirement that all participants spoke English. Those who had a diagnosis of organic brain damage or a primary diagnosis of drug misuse were excluded from the study. Diagnosis was primarily identified by care coordinators and verified through the doctor's diagnosis.

Measures

The "What Getting Better Means" Questionnaire (Meddings & Perkins, 2002)

The questions used in the measure were lifted directly from a piece of qualitative research that aimed to explore the nature of what getting better meant to service users of mental health services (Meddings & Perkins, 2002). The qualitative study interviewed

thirty participants and asked about desirable outcomes of treatment. A content analysis of the transcripts revealed a total of ten themes. These themes were re-categorized by a blind rater and a high level of agreement was found (87%). The main categories were as follows:

1. Improved mental state.
2. Improved general well-being.
3. Improved relationships.
4. Empowerment, confidence and self worth.
5. Greater engagement in work and activities.
6. Going out more.
7. More able to cope with day-to-day life.
8. Improved access to help and support.
9. Improved material well-being.
10. Improved physical health.

The ten research categories were further divided into thirty-three sub themes that were turned into thirty-four questions for the present questionnaire. Questions were presented on a 10-point Likert scale categorizing responses from “Important” to “Not important”. Two versions of the questionnaire were developed, one for service users (Appendix 2) and one for care coordinators (Appendix 3) with the only difference being in the wording of the instructions inviting care coordinators to think about the meaning of ‘getting better’ in terms of their respective service users.

The Camberwell Assessment of Need Short Appraisal Schedule (Slade, Thornicroft, Loftus, Phelan & Wykes, 1999)

The Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) is a tool that assesses the needs of people with enduring mental health problems for both clinical and research use (Appendix 4). Both a service user and staff interview are carried out in order to tap into the service users' subjective perceptions of need as well as the staff members' perspectives. The CANSAS comprises the first question from each of the twenty-two domains of the Camberwell Assessment of Need (CAN) without assessing aspects of service use. The CANSAS addresses problems that pertain to the last month in 22 domains of life presenting a snapshot of the current situation: accommodation, food, looking after the home, self-care, daytime activities, physical health, psychotic symptoms, information about condition and treatment, psychological distress, safety to self and others, alcohol, drugs, company, intimate relationships, sexual expression, childcare, basic education, telephone transport, money and social benefits. The clinical version has three sections of which this study will use two. The first section assesses whether a problem is currently present using a three point scale, where serious problem=2, no problem/moderate problem due to help being given=1 and no problem=0. A rating of 2 is considered to represent an unmet need whilst a rating of 1 constitutes a met need. A met need is considered present if the service user or staff member believes that there is no problem in a specific area because help is provided by services or other means. Unmet need is recorded when the interviewee judges that there is a problem present in a domain regardless of whether any help is being provided.

Most of the evidence supporting the psychometric properties of the CANSAS is derived from investigations into the CAN. The English version of the CAN has been found to have satisfactory psychometric properties. Several studies have documented adequate inter-rater and test reliability (e.g. Phelan, Slade, Thornicroft et al. 1995; Hansson, Bjorkman & Svenson, 1995; Andresen, Caputi, Oades & Lindsay, 2000; Arvidsson, 2003). For instance, McCrone, Leese, Thornicroft, Schene et al. (2000) found that test-retest reliability pooled over several sites was 0.85 for total needs, 0.69 for met needs and 0.78 for unmet needs. Pooled estimates for inter-rater reliability were 0.94, 0.85 and 0.79 for total met and unmet needs respectively. Furthermore Issakidis & Teeson (1999) compared the Health of a Nation Scales (Wing, Beevor, Curtis et al. 1998 - HONOS) and the CAN and revealed that disability as measured by the HONOS and unmet need as assessed by the CAN were correlated ($r=0.68$).

Research supporting the psychometric properties of the CANSAS is fewer in number. Slade, Beck, Bindman et al. (1999) compared the routine use of the HONOS and the CANSAS. The authors showed that there was a good correlation between the two measures on the presence of need ($r=0.65$, $p<0.001$) and unmet need ($r=0.62$, $p<0.001$). Seven factors were identified within the twenty-two CANSAS domains. For some domains there was a high correlation between the HONOS and the CANSAS on the presence of need (e.g. Safety to Self and Others – $r=0.70$, $p<0.05$ and Activities of Daily Living $r=0.59$, $p=0.05$). There was less correspondence in areas such as Living Conditions ($r=0.13$, $p<0.02$). Although the study provides some level of concurrent validity, the limited associations between the measures were explained by the fact that

the scales contained separate domains that did not correspond with each other. Andresen, Caputi & Oades (2000) evaluated the inter-rater reliability of the CANSAS under routine conditions, including raters from different occupational backgrounds. They compared the ratings of observers with the ratings of both patients and staff. It was found that agreement of individual areas of need was high (0.85) and met need moderate (0.68).

The Recovery Style Questionnaire (Drayton & Birchwood, 1998)

The Recovery Style Questionnaire (RSQ) is a self-report measure designed to assess a service users' recovery style (Appendix 5). The "Integration" category is defined as the acknowledgement of and curiosity about the significance of psychosis by the service users and their active attempts to cope with illness. Conversely the 'Sealing Over' recovery style is characterized by cognitive and behavioural avoidance of the experience of psychosis. This measure aimed to provide a shorter alternative to the lengthy Recovery Style Interview developed by McGlashan, Wadeson, Carpenter et al. (1977). The RSQ is comprised of thirty-nine forced choice questions. The thirteen subscales have three statements reflecting the categories designed by McGlashan et al. (1977). The subscales are as follows:

1. Curiosity – Assesses whether the person is curious about their psychotic experience and wants to understand the psychosis.
2. Education – Investigates the extent to which the individual regards their psychosis as a source of information about themselves.
3. Optimism – Measures whether the person can see their psychosis in a positive light.

4. Impact – Identifies the change that the experience of psychosis has had on the person's life.
5. Fear – Measures the individual's negative feelings towards their psychosis.
6. Liking – Questions whether the person has enjoyed any of their psychotic experiences.
7. Continuity - Assesses the individual's awareness of the relationship between their thoughts and feelings during their psychosis and prior emotional conflict.
8. Ownership – Evaluates the extent to which the person regards the psychosis as alien to himself or herself.
9. Responsibility – Assesses how much the individual owns their thoughts and behaviour during the psychotic experience.
10. Help seeking – Identifies whether the person seeks the help of others to manage their psychosis.
11. Blame - Evaluates whether the individual attributes the illness to problems coping with life.
12. Cause – Asks if the person believes that they have suffered a medical illness.
13. Satisfaction – Question if the individual believes their psychosis has influenced their satisfaction with life.

Examples of questions include: “There was a gradual build up to me becoming ill” and “I am curious about my illness”. Higher scores on the measure suggest that the individual adopts a ‘sealing over’ recovery style. Four categories of recovery style can be differentiated: Integration, mixed picture in which sealing over predominates, mixed picture in which integration predominates and sealing over.

Investigations into the RSQ suggest that it has good psychometric properties. Drayton, Birchwood & Trower (1998) compared the RSQ with the lengthy Recovery Interview measure and found it to be a reliable and valid measure of McGlashan's concept of recovery style. Test-retest reliability was found to be 0.81 suggesting that the measure was stable and it achieved an internal reliability score of 0.73. The 0.91 correlation between the RSQ and the well-validated Recovery Interview suggests a strong relationship between the measures indicating that they are tapping into the same construct. Furthermore the RSQ takes only 10 minutes to administer in comparison with the 30 minutes taken for the Recovery Interview.

The Helping Alliance Scale (Priebe & Gruyters, 1993)

The Helping Alliance Scale (Appendices 6 and 7) aims to measure the quality of the therapeutic relationship between a service user and their therapist. Amongst other things, the helping alliance scale reflects the degree to which the client views the therapist as helpful and positive. The scale comes in two separate forms, to be completed by the service user (Appendix 6) and the therapist (Appendix 7). Both are made up of five questions on a ten point visual analogue scale and two forced choice questions. All questions focus on the participant's perceptions of the quality of the relationship including aspects of understanding and involvement in treatment.

The strength of the Helping Alliance Scale lies in the fact that keyworkers/care coordinators have been used in the place of therapist in many of the past studies that

have demonstrated the measure's psychometric properties. The simplistic nature of the questionnaire aims to avoid excluding any service users who are less able or unwilling to answer more extensive questionnaires.

In terms of psychometric properties, Priebe and Gruyters (1993) used the Helping Alliance Scale to assess the quality of the helping alliance between patients and care coordinators and evaluated its predictive value. They found that aspects of Helping Alliance Scale were associated with fewer partial hospitalizations ($r=-0.40$, $p<0.001$). The full score from the Helping Alliance Scale was also correlated with higher employment ($r=-0.29$, $p<0.05$) demonstrating some level of predictive validity.

The Psychiatric Assessment Scale (Krawiecka, Goldberg & Vaughan, 1977)

Also referred to as the “Manchester Scale” the Psychiatric Assessment Scale (PAS – Appendix 8) is a five point Likert type scale, which aims to screen the mental state of individuals with psychosis. The measure takes the form of a structured interview in which the clinician asks the service user questions about depression, anxiety, delusions and hallucinations. Observations are made of incoherence and irrelevance of speech, poverty of speech, flattened incongruous affect and psychomotor retardation. Each area is rated on a scale of zero to four with higher scores representing more severe psychopathology. A three-point scale is used to assess the side effects of medication.

The psychometric properties of the scale have been widely investigated. Krawiecka, Goldberg and Vaughan (1977) reported a substantial agreement (between 0.62 and 0.82)

between psychiatrist raters demonstrating acceptable inter-rater reliability. A comparison of the PAS with the well established Brief Psychiatric Rating Scale (BPRS - Ventura, Green, Shane & Liberman, 1993) suggested that the PAS showed higher inter-rater reliability in more areas. For instance, when raters took measurements at two time points, correlations on the PAS averaged 0.83 whereas the BPRS averaged 0.57 (Manchanda, Saupe & Hirsch, 1986). The authors concluded that the PAS could be used as an alternative to the BPRS. Jackson, Henry, Burgess, Philip, Minas and Joshua (1990) showed that the PAS has good concurrent validity. Jackson and his co-workers demonstrated a change in scores in a group of people with schizophrenia at discharge and a positive correlation between with their counterpart items on the Schedules for the Assessment of Positive Symptoms (Andreasen, 1984) and Negative Symptoms (Andreasen, 1983).

The Service Engagement Questionnaire (Tait, Birchwood & Trower, 2002)

The Service Engagement Questionnaire (SES) aims to measure the service users' engagement with Community Mental Health Services (Appendix 9). The sixteen items are completed by the staff with reference to the service users. It consists of four subscales:

1. Availability – Assesses the availability of the service user to attend arranged appointments.
2. Collaboration – The service user's active collaboration with managing the illness.
3. Help seeking – Whether the person seeks necessary help.

4. Treatment adherence – Evaluates the individual's attitude towards taking medication.

Two experts in the field of psychosis, Max Birchwood and Peter Trower, developed the items in response to a review of the literature and from discussion. Service users are rated on a four point Likert-type scale. Higher scores were intended to reflect greater levels of problematic engagement.

According to Tait, Birchwood and Tower (2002) preliminary psychometric results are promising. They state that the test-retest reliability of the SES is in the good to excellent range (between 0.80 and 0.97). Furthermore the internal consistency of the test was found to be adequate. Criterion validity was found to be satisfactory. They asked an assertive outreach team to identify the ten poorest and ten best engagers in terms of availability, collaboration, help seeking and treatment adherence. As predicted they discovered that the less engaged clients had higher scores on the SES than did those staff judged to be better engaged with their service. It was concluded that the SES distinguished between groups of clients based on their levels of engagement with services.

Procedure

The community mental health team's meetings were attended and all care coordinators with a current caseload agreed to take part in the research. Eligible service user participants were identified in a meeting with care coordinators. All of the care

coordinators' respective service users who had a diagnosis of a psychotic disorder and a minimum six-month (maximum five year) care relationship were included.

Service users were sent a letter inviting them to take part in the study (Appendix 10). Those who agreed to take part in the study were administered the questionnaires either at their homes or in the community mental health team base, in the presence of the researcher to provide any assistance required. Participants were reminded that they were free to withdraw from the study at any time and if they became distressed after the interview they could contact a trained clinical psychologist. After reading the Participant Information Sheet (Appendix 10) and signing a consent form (Appendix 13), service users completed the "What Getting Better Means" open-ended question (Appendix 12). Participants were then invited to fill in the following questionnaires in the order: The "What Getting Better Means" Questionnaire; The Helping Alliance Scale (Priebe & Gruyters, 1993); Camberwell Assessment of Need Short Appraisal Schedule (Slade, Thornicroft, Loftus, Phelan & Wykes, 1999); The Recovery Style Questionnaire (Drayton & Birchwood, 1998). The service users were then interviewed to assess symptomatology using the Psychiatric Assessment Scale (Krawiecka, Goldberg & Vaughan, 1977). At the end participants were given a £5 reimbursement.

Meetings with care coordinators took place following the assessment of their respective service users. These appointments took place as soon as was possible following meeting with the service user and were on average four weeks after the meeting with the service user. After completing the Staff Participant Information Form (Appendix 11) and signing a consent form, care-coordinators were asked to complete four questionnaires

with reference to their respective service users' in the following order: The "What Getting Better Means" open ended question (Appendix 14) and questionnaire; The Service Engagement Questionnaire (Tait, Birchwood & Trower, 2002); Camberwell Assessment of Need Short Appraisal Schedule (Slade, Thornicroft, Loftus, Phelan & Wykes, 1999) and the Helping Alliance Scale (Priebe & Gruyters, 1993).

Planned Analyses

Statistical Analysis

All of the quantitative data were analysed using the statistical software package SPSS for Windows version 11.5. All bivariate correlations were performed using a Spearman's rank correlation test since these data were considered non-parametric. Agreement between care coordinator and service users' views of need status was analysed by means of a Kappa statistic. A coefficient of up to 0.20 was considered slight agreement, between 0.21 and 0.40 as a fair agreement and between 0.41 and 0.60 as a moderate agreement and more than 0.80 as almost perfect agreement. Regression analyses were used to assess the influence of important variables on service engagement after transformation procedures had been performed. Non-parametric, Wilcoxon tests were used to investigate the difference between the care coordinator and service user views of the subsets of the "What Getting Better Means Questionnaire". T-tests were performed to compare participants' ratings of need. Where multiple tests were conducted Bonferroni-adjusted significance levels were reported.

Open Ended Question Procedure and Analysis

All service user and care coordinator participants were asked to write down their responses to the open-ended question:

- What does “getting better” mean to you (Appendix 12)?

The question was adapted slightly for the care coordinators so they considered ‘getting better’ as relevant to their service user:

- What does “getting better” mean in terms of your service user (Appendix 14)?

The question was intended to elicit the desirable outcomes of treatment provided by the service and meant to be open enough to generate a detailed personal account.

The open-ended question was asked for two reasons: Firstly, the question intended to provide a check on the authenticity of the participants’ responses to the answers on the “What Getting Better Means” Questionnaire. That is to say that the participants’ responses to the “What Getting Better Means” Questionnaire were only considered if they scored highly in those areas that they mentioned in the open ended question. The process of judging the acceptability of the questionnaire involved dividing the responses to the open-ended question into meaningful chunks. For instance the open ended question response; “(getting better means) having more friends” would be classified as corresponding to the “What Getting Better Means” Questionnaire question eleven (less lonely/more friends). The score for the corresponding question would be ascertained and responses from the “What Getting Better Means” Questionnaire regarded as reliable only if all the phrases from the open ended question achieved a score of six and over.

Secondly the responses from the open-ended question were to be used to illustrate and support the quantitative findings. As such it was expected that excerpts from the open ended question would be presented in the results and discussion to “bring the results alive” (Yardley & Furnham 1999).

Results

The total sample consisted of thirty-nine people. This included thirty service users and their nine care coordinators. The characteristics of the participants in the study are shown in the tables 1 and 2. Of the ninety-five service user participants deemed as meeting the inclusion criteria thirty (32%) were contactable and agreed to take part in the study. As can be seen in table 1 there was a preponderance of men in the service user sample. The predominant diagnostic subgroup was paranoid schizophrenia. Many of the participants lived in a supported accommodation or group home (60%). The remaining forty percent of the service users resided in an independent living situation. The majority of the service user participants had left school without qualifications (40%). Thirty-three percent of the service users left school with qualifications and a minority (6.9%) completed a university degree. Similarly, sixty-six percent of the service users were unemployed. A small proportion of the service user sample worked voluntarily (16.7%), part-time (3.3%) or full-time (13.3%). Inspection of the demographic data not included in the table revealed that service user participants not born in the U.K had been resident for an average of thirty-seven years. Only one woman in the sample had children under the age of sixteen. Of the thirty service users who took part in the study sixty three percent reported suffering from physical ailments. The average amount of time that the service users had spent in a care relationship with their respective care coordinators was forty one months.

Table 1- Demographic characteristics of the service user participants.

	Total Number	Percentage %	Mean
Men	25	83	
Women	5	17	
Age			42.1 \pm 12.3
Years since 1 st admission			12.7 \pm 9.7
Total number of hospital admissions			2.8 \pm 2.3
Paranoid schizophrenia	22	73.3	
Bipolar	3	10	
Psychotic other	5	16.7	
White	18	60	
Black (Afro Caribbean)	4	13.3	
Asian	4	13.3	
Other ethnic group	4	13.3	
Single	27	52.9	
Married	0	0	
Divorced	3	10	
Unemployed	20	66.7	
Part-time work	1	3.3	
Full-time work	4	13.3	
Voluntary work	5	16.7	
Left school with qualifications	10	33.3	
Left school without qualifications	12	40	
Further training	5	16.7	
Degree Level	2	6.9	
Supported accommodation	18	60	
Independent accommodation	12	40	

All of the nine care coordinators provided information about more than one participant.

The mean number of service users reported on by care coordinators was 2.7. The staff group consisted of five community psychiatric nurses, three social workers and a clinical psychologist. Forty-four percent of the staff sample was from a White British or English background. Thirty-three percent of the care coordinators defined themselves as Asian (Bangladeshi). Twenty-two percent described themselves as Black Caribbean. The

average amount of time spent in the United Kingdom for care coordinators not born in the country was 31.2 years. The mean number of years that staff had worked in the mental health profession since qualification was 16.1 years.

Table 2 - Demographic characteristics of the care coordinator participants.

	Total Number	Percentage %	Mean
Men	5	55.5	
Women	4	44.4	
Age			44.1 \pm 8.9
White	4	44.4	
Black (Afro Caribbean)	2	22.2	
Asian	3	33.3	
Other ethnic group	1	11.1	
Single	2	22.2	
Married	6	66.6	
Divorced	1	11.1	

Staff and Service User Priorities

Hypothesis 1 – Service users will report existential aspects (i.e. empowerment, self esteem and belonging) of improvement significantly higher than their care coordinators.

An item analysis revealed that both the staff and service user versions of the What Getting Better Means Questionnaires achieved high overall item correlation scores suggesting the measures had good item reliability. The staff questionnaire obtained a total score of 0.97 and the service users' version received a score of 0.94.

As can be seen from means scores in Table 3, service users' rate existential aspects of getting better (i.e. empowerment, self-esteem and belonging aspects not included in the CANS) more highly than their care coordinators. For instance, as one service user explained, "getting better means"; "...I am able to apply myself step by step and

appreciate how much better I have become.” The mean ‘existential aspects’ score obtained by service users was 33.5 (S.D 7.8). The average ‘existential aspects’ score of care coordinators was 30.1 (S.D 8.9). The difference between the two groups’ ratings of existential aspects was statistically significant, $z=-2.156$, $p<0.05$. The difference did not reflect an overall trend for service users to rate all aspects higher. This was evidenced by the fact that no statistical differences found between the mean ratings made by care coordinators and service users on mental state aspect ($z=-0.589$, $p=0.558$). Quotes from the care coordinator and service user participants support the finding that they both prioritise mental state issues. A care coordinator said ‘getting better’ was; “..to remain mentally stable”. One service user echoed these same sentiments using his own language and for him recovery was; “..feeling well in myself....not getting my schizophrenia.”

Assessment of Need

Hypothesis 2 - There will be a fair agreement between care coordinators’ and service users’ ratings of service user need status as measured by the CANSAS.

Comparison of service user and care coordinator ratings of need was conducted by correlating each pairs’ individual scores on each of the subsets (0=no problem, 1=met need, 2=unmet need) with that of the other. In terms of levels of agreement, the overall Cohen’s Kappa, 0.21 showed a fair agreement. Service users received an average CANSAS need score of 0.5 (S.D 0.8). Their care coordinators scored an average CANSAS need score of 0.8 (S.D 1.5).

Hypothesis 3 - Care coordinators will report more total needs than their service users as measured by the CANSAS.

Tables 3 and 4 show the mean scores obtained by the participants on the various questionnaires (i.e. What Getting Better Means Questionnaire, Camberwell Assessment of Need Short Appraisal Schedule, Helping Alliance Scale, Recovery Style Questionnaire, Service Engagement Questionnaire and the Psychiatric Assessment Scale). As measured by the CANSAS, service users report an average of 4.1 (S.D 2.3) met needs and care coordinators reported an average of 5.3 (S.D 2.4) met needs. Analysis revealed that there was a statistically significant difference between the number of met needs as reported by care coordinators and service users, $t(29) = -2.2$, $p < 0.05$. The average unmet needs reported by service users and care coordinators were 3.1 (S.D 2.4) and 3 (S.D 2.8) respectively. There was no statistically significant difference between these scores, $t(29) = 0.11$, $p = 0.91$. The mean number of total needs recorded by service users was 7 (S.D 3.5) and care coordinators reported an average of 8.3 total needs (S.D 2.9). Again data analysis showed that there was no significant difference between the reported total needs from the two groups ($t(29) = -1.8$, $p = 0.07$). In addition it was found that there was a negative correlation between staff age and number of unmet needs reported ($r(29) = -0.42$, $p = 0.008$). The average age of the staff was 58 (S.D 8.8).

Table 3 - Mean scores from the What Getting Better Means Questionnaire

	Service User (n=30) +S.D	Care Coordinator (n=9)+S.D)	z	p
What Getting Better Means Difference	87.7 \pm 44.1	-	-	-
What Getting Better Means (Existential Aspects) Difference	6.9 \pm 7.4	-	-	-
What Getting Better Means Subsets				
Mental State	37.3 \pm 10.5	35.6 \pm 12.4	-0.6	0.56
Well-Being	34.5 \pm 7.1	28.9 \pm 8.5	-2.9	0.00
Relationships	37.6 \pm 11.1	34.4 \pm 11.1	-1.4	0.15
Existential Aspects	33.5 \pm 7.8	30.1 \pm 8.9	-2.2	0.03*
Work	46.8 \pm 11.1	43.7 \pm 13.3	-1.6	0.97
Going Out	31.6 \pm 8.4	28.0 \pm 9.3	-2.4	0.01
Everyday Activities	34.4 \pm 6.9	27.3 \pm 9.8	-3.2	0.00
Support from Others	24.5 \pm 4.9	19.4 \pm 6.8	-3.1	0.00
Material Well-Being	32.9 \pm 6.8	25.4 \pm 10.4	-3.1	0.00
Physical Health	8.7 \pm 2.2	7.2 \pm 3.6	-2.5	0.01

* Bonferroni-adjusted

Table 4 – Mean scores from the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS), Helping Alliance Scale, Recovery Style Questionnaire, Service Engagement Scale (SES) and the Psychiatric Assessment Scale (PAS).

	Service User (n=30) (+S.D)	Care Coordinator (n=9) (+S.D)	t	p
Met needs (CANSAS)	4.1 \pm 2.3	5.3 \pm 2.4	-2.2	0.03*
Unmet needs (CANSAS)	3.1 \pm 2.4	3.0 \pm 2.8	0.1	0.91
Total needs (CANSAS)	7.0 \pm 3.5	8.3 \pm 2.9	-1.8	0.07
Helping Alliance	39.3 \pm 11.7	36.8 \pm 8.0		
Recovery Questionnaire	60.2 \pm 5.8	-		
Service Engagement Scale	11.7 \pm 7.0	-		
PAS	3.3 \pm 2.9	-		

*Bonferroni-adjusted

Need Status and Engagement

Hypothesis 4 - The greater number of unmet needs (as measure by the CANSAS) will be negatively correlated with levels of service user service engagement.

Table 5 shows the relationships found between the various measures of outcome and need as measured by the CANSAS. The average unmet needs reported by care coordinators were 3 (S.D 2.8). The mean Service Engagement Scale (SES) score reported by care coordinators was 11.7 (S.D 7.0). The mean number of unmet needs reported by the service users was 3.1 (S.D 2.4). The average helping alliance score of care coordinators was 36.8 (S.D 8.0). The average number of months that the pair had been in a care relationships for was 41 months (S.D 15.2). A multiple regression was performed. Out of all the variables only care coordinator reported helping alliance and care coordinator unmet need were found to be significant predictors of service user engagement ($\text{Engagement} = 4.56 + -0.4 \text{ Helping Alliance} + -0.28 \text{ Unmet Need}$). R Square was 0.24 suggesting that 24% of the variance was accounted for and this was significant ($F(2, 27) = 4.3, p < 0.05$). In other words the number of months that a service user and care coordinator had been in a relationship, and client reported unmet needs were not found to be correlated with service engagement.

Table 5 – Correlation between needs status and outcome measures.

	Engagement	Mental State	Service User Helping Alliance	Care Coordinator Helping Alliance	Recovery
Service User Met Need	0.18	0.25	-0.04	-0.08	0.23
Service User Unmet Need	-0.05	0.65**	-0.14	0.11	-0.23
Service User Total Need	0.08	0.62**	-0.07	0.09	0.04
Care Coordinator Met Need	-0.25	0.31	-0.40*	0.28	0.09
Care Coordinator Unmet Need	0.43*	0.14	0.023	-0.43*	0.15
Care Coordinator Total Need	0.26	0.52**	-0.34	-0.11	0.21

* $p < 0.05$

** $p < 0.005$

A hierarchical multiple regression was performed to analyse whether staff unmet needs and the helping alliance were both significant predictors of service engagement. The data were entered in two separate blocks – one including the helping alliance and service engagement and the other with care coordinator rated unmet need. R Square for the model including only helping alliance was 0.12 therefore 12 % of the variance was accounted in this model. However the second model including the unmet needs revealed an R Squared value of 0.24 suggesting that 25% of the variance is accounted for by this model and this was significant ($F(2,27)=4.3, p<0.05$).

Table 6 - Results of Hierarchical Regression

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	Constant	4.556	.627		7.262	.000
	Staff Helping Alliance	-.344	.179	-.341	-1.918	.065
2	Constant	5.508	.747		7.373	.000
	Staff Helping Alliance	-.414	.173	-.410	-2.396	.024
	Staff Unmet Need	-.275	.132	-.358	-2.093	.046

Dependent Variable: Engagement

Aside from the research hypothesis, several other significant results were apparent from the data analysis. Table 5 shows that there was no evidence to support a correlation between service user rated unmet need and service engagement ($r(29) = -0.05$, $p = 0.8$). Secondly there was a statistically significant strong association between mental state (mean Psychiatric Assessment Scale score 3.3; S.D 2.9) and service user reported unmet needs ($r(29) = 0.65$, $p < 0.005$) and total needs ($r(29) = 0.62$, $p < 0.005$). However there was no statistically significant correlation between care coordinator rated unmet need and mental state ($r(29) = 0.14$, $p = 0.47$). The correlation between care coordinator rated total need and mental state was also found to be statistically significant, $r(29) = 0.52$, $p < 0.005$).

Service Engagement and Discrepant Views of Need

Differences in views between care coordinators and their service users was operationalised by difference scores on each of the subsets of the What Getting Better Means Questionnaire as well as a difference score from each of the questions. Secondly,

agreement was represented by the correlations between the service user and care coordinator scores on the CANSAS. Finally discrepancies were shown via the difference between both parties reported number of unmet needs as measured by the CANSAS.

The average total difference between the service users' and care coordinators' views on the "What Getting Better Means Questionnaire" was 87.7 (S.D 44.4). The average total difference between the service user and care coordinator scores on the existential aspects (empowerment control, stigma and self value) was 6.9 (S.D 7.4). The responses from the open ended questions on the "What Getting Better Means Questionnaire" matched the scores rated above six on the questionnaire in all but one case. This suggested that the information contained in the questionnaires were generally reliable.

Hypothesis 5 - Greater discrepancies between the scores of service users and care coordinators on the "What Getting Better Means" Questionnaire will be associated with the service users' lower levels of engagement with services.

The research data did not support the study's main hypothesis that greater discrepancies between service user and care coordinator views on "What getting better means" would be related to service user service engagement ($r(29)=0.07, p=0.72$). The mean service users' score on the What Getting Better Means Questionnaire was 87.7 (S.D 44.4). The average Service Engagement Scale (SES) score was 11.7 (S.D 7.0).

Hypothesis 6 - Higher differences in ratings of existential aspects of improvement will be associated in lower service user service engagement.

No statistically significant association emerged between service user service engagement and the difference between care coordinator and service users views on existential aspects of getting better ($r(29)=-0.18, p=0.72$). The mean SES and 'Existential Aspects Difference' scores obtained were 11.7 (S.D. 7.0) and 6.9 (S.D. 7.4) respectively.

Hypothesis 7 - Greater agreement between the scores of service users and care coordinators on the CANSAS will be associated with the service users' higher level of engagement.

There was no statistically significant negative correlation between the service users' and care coordinators' need status scores and service engagement, ($r(29) = -0.19, p=0.32$). Service users received an average CANSAS correlation score of 0.41 (S.D 0.2). Their care coordinators reported a service engagement score of 11.7 (S.D 7.0). That is to say that there was no evidence to provide support for the prediction that greater agreement between service users and their care coordinators on need status was related to better levels of service engagement.

Hypothesis 8 - Greater differences between service user and care coordinator reports of the number of unmet need will be correlated with service engagement.

The data did not support a statistically significant positive correlation between the difference between service users unmet need CANSAS scores and their care coordinator's CANSAS unmet need scores (mean score, 2.3; S.D 2.2) and service

engagement (11.7; S.D 7.0). In other words higher disagreement between service users and care coordinators regarding the number of need was not related to service engagement ($r(29) = -0.08, p = 0.7$).

The data supported a few hypotheses concerning the effect of discrepant views on various other outcomes apart from service engagement (i.e. mental state, helping alliance and recovery style). For instance, the data supported a correlation between higher levels of agreement between service users and care coordinators and higher levels care coordinator reported helping alliance ($r(29) = -0.37, p < 0.05$). The mean CANSAS correlation score obtained was 0.4 (S.D 0.2). The average staff rated helping alliance score was 3.2 (S.D 1.2). Similarly there was a fair to moderate correlations between care coordinator rated helping alliance and the What Getting Better Means total discrepancy scores ($r(29) = -0.46, p < 0.05$). The mean score CANSAS agreement and What Getting Better Means total discrepancy scores obtained by service users was 87.7 (S.D 44.1). However service user rated helping alliance was not significantly correlated with staff-client discrepancies. As illustrated in Figures 1 and 2 the data revealed that the service user helping alliance variable was more positively skewed than the care coordinator rated helping alliance.

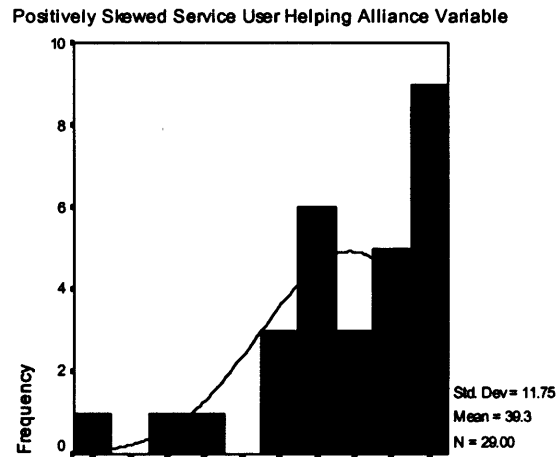


Figure 1 – A graph showing the positively skewed distribution of the service user helping alliance variable.

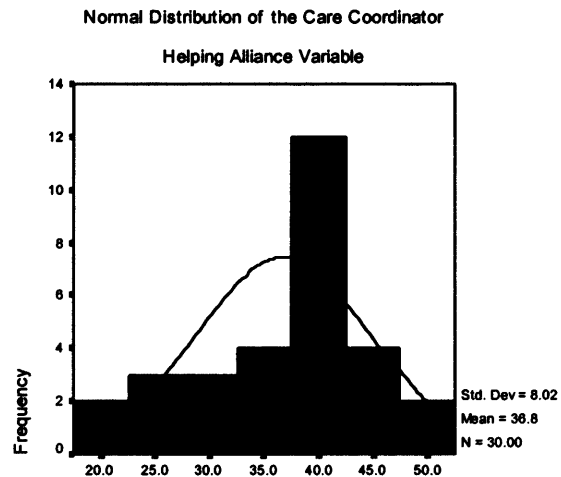


Figure 2 – The normal distribution of the care coordinator rated helping alliance variable.

Another interesting result was the positive correlation between ratings of service user mental state and discrepancies between the service user and their care coordinator ratings of mental state issues was evident ($r(29) = 0.64, p < 0.05$). Service users obtained an average mental state score of 3.3 (S.D 2.9). The mean mental state issues discrepancy score was 12.5 (S.D 7.4). Higher levels of agreement between service user and care coordinator views of the importance of mental state was associated with better mental state in the service user.

Table 6 – Correlations between the levels of agreement and outcomes measures

	Engagement	Mental State	Service User Helping Alliance	Care Coordinator Helping Alliance	Recovery
CANSAS Agreement	-0.10	0.27	0.17	-0.37*	0.33
CANSAS Met Needs Difference	-0.28	-0.04	0.025	0.089	-0.12
CANSAS Unmet Needs Difference	-0.08	0.12	-0.04	-0.04	-0.12
CANSAS Total Needs Difference	0.05	-0.08	0.26	-0.15	-0.15
What Getting Better Means Difference	0.07	-0.29	-0.16	-0.46*	0.11
Mental State Difference	0.16	-0.64*	0.13	-0.31	-0.15
Well-Being Difference	0.15	-0.41*	0.08	-0.29	-0.30
Relationships Difference	-0.24	-0.08	-0.10	-0.22	0.30
Existential Aspects Difference	-0.23	-0.40*	-0.07	-0.21	0.07
Work Difference	-0.08	-0.04	-0.01	-0.23	0.13
Going Out Difference	0.17	-0.23	-0.13	0.01	0.12
Activities of Daily Living Difference	0.19	-0.08	-0.03	-0.30	-0.06
Support from Others Difference	0.04	-0.37*	0.45*	-0.42*	-0.10
Material Well-Being Difference	0.06	-0.17	0.31	-0.23	0.07
Physical Health Difference	0.16	-0.20	-0.10	-0.31	-0.06

*= $p < 0.05$

Hypothesis 9 - There will be a positive correlation between service user service engagement and recovery style.

The effect of recovery style on service user engagement was tested using a bivariate correlation analysis. The data did not support any statistically significant relationship between service engagement (mean SES score, 11.7; S.D 7.0) and recovery style (mean Recovery Questionnaire score 60.2; S.D 5.8), ($r(27) = 0.06$, $p = 0.75$). Recovery was not found to be related to any type of need or outcome (e.g. mental state and helping alliance).

Discussion

Engagement with services is paramount in ensuring effective community treatment and support. It has been proposed that individual needs assessment and service user perspectives about care are an important part of a responsive, community based mental health service (Shepherd, Murray & Muijen, 1995). One of the methodological issues that this has raised is whether the opinion should be from the service user or staff member. Only a handful of studies have investigated the agreement between staff and service users' reports of need and even fewer have related discrepancies to any clinical and social outcome. This pilot study mainly aimed to explore the priorities of service users and their care coordinators and to examine if discrepancies between their views influenced the service user's engagement with services. This discussion will set out and explain the main research findings and compare them with previous research. The methodological problems with the present research will be offered amongst discussion of ideas for future related areas of research. The conclusions will then be evaluated for possible clinical and theoretical implications in an effort to place results in a clinical context.

Summary of Results

Service User-Care Coordinator Agreement and Positive Outcome (Service Engagement and Helping Alliance)

The research results did not support all of the study hypotheses. There was no support for a significant correlation between the difference between service users and their care coordinators reports of "What Getting Better Means" and service engagement. Similarly

there was no evidence for an association between service user and care coordinator agreement of need status (i.e. no problem, unmet need or met need), differences in number of unmet needs and higher levels of service user service engagement. However, a statistically significant relationship between care coordinator rated helping alliance and CANSAS staff client agreement of need was observed. All findings were in the context of a fair service user-care coordinator agreement of need status.

Needs Status

The study found that significantly higher levels of care coordinator reported unmet need is correlated with lower levels of service user engagement without special reference to the helping alliance. The amount of time service users and care coordinators had been in a care relationship and service user rated unmet need were not related to service engagement. There was evidence presented for a statistically significant difference between service user and care coordinator reports of met needs as measured by the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS - Slade, Thornicroft, Loftus, Phelan & Wykes, 1999) with staff rating more met needs than their service users.

Service User and Care Coordinator Priorities

In terms of service user priorities there was a statistically significant difference between service users' and their care coordinators ratings of existential (empowerment, self-esteem and belonging) aspects of improvement. However the findings did not provide any support for the hypothesis that higher differences in ratings between service user and

care coordinator on the existential aspects of the What Getting Better Means Questionnaire would be significantly correlated with lower service engagement.

Comparisons with Past Research

Unmet Needs and Service Engagement

The present findings must be set against previous research. In line with the study's prediction, there was a statically significant negative correlation between unmet needs and service engagement. Although this result has not been supported in the research literature directly, associations have been found between unmet needs and other important clinical factors. For instance, higher patient rated unmet needs has been related to lower quality of life in a cross-sectional study (Hansson et al. 2001; Slade, Leese, Taylor & Thornicroft, 1999) and a prospective, longitudinal study (Slade, Leese, Ruggeri, Kuipers et al. 2004). Some studies claim that unmet needs are associated with psychopathology (e.g. Hansson, Vinding, Mackerprang et al, 2001; Slade, 2004).

Helping Alliance and Service Engagement

The research supporting the finding relating the helping alliance to service user service engagement is qualitative in nature. Watts and Priebe's (2002) phenomenological account of service users' experience of community treatment postulated that one of the critical ingredients for engagement with mental health teams was the quality of therapeutic relationships between client and keyworker. Staff-client relationships that are experienced as impersonal, paternalistic and uncaring were shown to result in negative interactions with services. Although the helping alliance has not been firmly related to service user service engagement, there is some support for this contention in

the literature. For instance, Watts & Priebe (2002) showed that service user' perceptions of a positive helping alliance and engagement were influenced by their perceptions of the staff's acceptance of their own world views. Despite the similarities between the investigation mentioned and the present one it must be taken into account that unlike the present study Watts and Priebe used a qualitative methodology, employing fewer participants. Furthermore the authors make inferences about the helping alliance by paraphrasing and interpreting the narratives of the participants rather than measuring the concept with a psychometrically valid measure as was done in the present research. On a related theme, Holzinger, Loffler, Muller, Priebe et al. (2002) discovered a relationship between the helping alliance and service user compliance with medication. They studied the subjective illness theories of seventy-seven people with schizophrenia and its relationship to service engagement. Against their original hypothesis it was concluded that the helping alliance, rather than the subjective illness theory, was predicative of service user adherence to recommended medication. Although this study was comparable to the present research in the sense they both utilised correlational methods, the similarity in findings must be set against the fact that a similar but not identical form of adherence was being investigated (i.e. medication compliance rather than service compliance).

Indirectly, the finding relating the helping alliance to service engagement replicates a well-documented research conclusion. Over the past twenty years several researchers have postulated that the therapeutic or helping alliance is a vital aspect of the therapeutic process (e.g. Hovarth & Symonds, 1991 & Safran & Muran, 1995). It has become increasingly common for researchers from a variety of theoretical orientations to

conclude that the alliance has a strong relationship to therapeutic outcome (Horvath & Symonds, 1991). Some authors have advised that the quality of the helping alliance is more important than the type of treatment in predicting positive therapeutic outcomes (e.g. Safran & Muran, 1995).

Service Users Higher Rating of Existential Aspects (i.e. empowerment, self-esteem and belonging).

The finding that service users rate existential aspects of improvement more importantly than their care coordinators builds on the previous qualitative research (i.e. Meddings and Perkins, 2002). According to Meddings and Perkins' (2002) study exploring whether there was a disparity between service users and psychiatric rehabilitation staff, service users mentioned self-esteem issues more often than staff. It may be remarkable however that the present study assessed existential issues (empowerment, self esteem and belonging) together and did not separate out the differences in opinion regarding self esteem separately. In accordance with the previously cited qualitative research, this investigation did not detect any differences in how important service users and care coordinators believed that mental state issues were to improvement. On the other hand, the data presented concerning staff and service users agreeing on the importance of mental state issues refutes the qualitative account of service users' view of service engagement (Watts and Priebe, 2002). Unlike the present research their study concluded that the perspective of service users and staff differed with staff focusing more on interventions directly affecting the body (e.g. medication) as opposed to the wider social environment (e.g. benefits). In doing so, Watts and Priebe (2002) suggested that mental state issues are not as important to staff as they are to service users. In opposition to

Watts & Priebe (2002) the present investigation found that staff and clients agreed on how important mental state issues were to recovery. However the difference in findings presented here and the Watts and Priebe (2002) study may be explained by the fact that Watts and Priebe (2002) canvassed views of fewer participants and included individuals from an assertive outreach team. For instance it may be argued that clients from an assertive outreach team constitute a group of people who by definition have different needs that could make it more likely that they would see mental state issues as less important (i.e. problems with service engagement and treatment compliance). Having said this, the agreement between staff and clients on mental state issues reported here are also not consonant with the quantitative study by Shepherd, Murray and Muijen (1995), which assessed people with schizophrenia in the community and discovered that professionals placed greater emphasis on treatment and symptom monitoring (mental state issues). The reason for this difference in findings presented here and the Shepherd, Murray and Muijen (1995) study could be that they managed to recruit a much larger number of participants (417 participants) than that recruited for the present research providing more statistical power to detect differences. Furthermore the fact that the study employed doctors as health professionals could explain their greater increased focus on mental state aspects of recovery.

Care Coordinators' Higher Ratings of Met Need

The surprising finding that staff ratings of met need was higher than service users' is echoed in previous research. For instance, Arvidsson (2001) assessed the needs of four hundred and eighty five patients with schizophrenia and found that staff rated more met needs. This research did not detect any statistically significant differences between

service user and staff reports of and unmet and total needs. The lack of detected differences between service user and care coordinator total need reports evident here goes against several separate pieces of research (e.g. Thornicroft and Parkman, 1996; Slade, Leese, Taylor & Thornicroft, 1999; Lasalvia, Ruggeri, Mazz and Dall'Agnola, 2000; Hansson, Vinding, Mackerprang et al. 2001; Hancock, Reynolds, Woods, Thornicroft et al., 2003; Ochoa, Autonell, Penadas, Teba and Marquez, 2003; and Tobias, 2004), all discussed in more detail in the Introduction. However the differences between these studies compared to the present investigation could have affected the results. For example, the majority of the aforementioned research contained larger numbers of participants and were carried out in countries apart from the U.K (e.g. Norway, Sweden and Italy). Other potentially important variations between the studies are the difference in selection procedures employed. For instance, unlike the present study Lasalvia, Ruggeri et al. (2000) selected only those who had a diagnosis for more than one year and a minimum of one service contact. Similarly, Ochoa et al. (2003) recruited a sample that was randomly selected from a computer whereas the present study included all those meeting the criteria.

Service User-Care Coordinator Fair Agreement of Need Status

Next, the research result that there was fair agreement between service users and care coordinators on the presence of need was replicated in the investigation of Middleboe, Mackerprang, Thalsgaard and Christiansen (1998) and later Ruggeri, Mazz and Dall'Agnola (2000). However, fair agreement evident here is not consonant with the conclusions made by Hansson, Vinding, Mackerprang et al (2001). Instead the authors reported a moderate agreement between keyworkers and their respective clients in the

majority of areas of need. Again the difference in findings may have been due to the larger number of participants used in the study in comparison to the present investigation.

Recovery and Service Engagement

On a different theme, the absence of data to support a significant correlation between service user service engagement and recovery style does not conform to all of the previously published research. The majority of studies exploring the individual's adjustment to their psychosis link recovery style to engagement (e.g. Tait, Birchwood & Trower, 2003 Birchwood & Trower, 2004). Part of the reason for the discrepancy in results between this research and the study of Tait, Birchwood & Trower (2003) could be that their study included acute inpatients with psychosis rather than those who were living in the community. A second difference was that their study used a longitudinal prospective design and recovery style at three months was related to engagement at six months rather than immediately. In addition, this investigation does not provide any evidence for the prediction that recovery style is linked to psychopathology (as measured by the Psychiatric Assessment Scale) as others have in the past (e.g. Drayton, Birchwood & Trower, 1998; Birchwood, Iqbal & Chadwick et al.; 2000; Birchwood & Trower, 2003). However it is noteworthy that all these studies used alternate, more extensive methods of measuring psychopathology (Structured Clinical Interview for the Positive and Negative Syndrome Scale - Kay, Fiszbein & Opler, 1986) and the limited appraisal of psychotic symptoms in the present study may have compromised its ability to detect associations.

The Meaning of Findings

Higher Unmet Need and Service Engagement

The next step will involve making sense of the findings of the present investigation in order of their relevance to the research question. The indication of a positive relationship between staff rated unmet needs and service engagement is challenging to interpret because the term unmet need is ambiguous. For instance the finding could mean that service users reduce engagement because their needs cannot be met by current treatment options. Alternately they decrease involvement because their needs are treated but remain a problem. Another possibility could be that service users engage less with services because they do not take up treatment options. In any case, as the perception of unmet needs were from the staff, all these interpretations imply that somehow the staff group have a better or more accurate perception of the service users' unmet need. The acceptance of this position would involve accepting the argument that it may be that correlation between an outcome (e.g. unmet need and service engagement) takes place only in areas in which the informant knows more about. For example staff unmet needs are more likely to be associated in areas such as psychopathology because they are more likely to be able to judge it accurately due their ability to compare levels with a reference group of other people with mental state issues. Conversely quality of life may be better evaluated by the person who experiences the satisfaction in the various domains that contribute to the construct (e.g. Liss, 1993). Indeed this has been borne out the literature. For example, Slade et al. (1999), Hansson et al. (2001) and Slade et al. (2001) only found a link between patient-rated unmet need and subjective quality of life.

A further finding reported by Hansson et al. (2001) was that psychopathology tended to be related to keyworker reports of unmet need.

A further plausible interpretation is that unmet need increases because clients do not engage and needs *cannot* be met by services because service users do not attend appointments. The interpretation assumes that lower service engagement causes unmet needs rather than unmet needs leading to lower service engagement. Although the cross-sectional design of this study precludes any firm conclusion to this question, there were some data here which could shed light on the situation. On inspection of the data, one of the domains of need that could be plausibly related to lower service engagement was mental state. A post hoc analysis comparing the relationship between mental state and service engagement resulted in a non-significant result. This lack of association might suggest that poor mental state does not lead to disengagement from services and provides more supports for the hypothesis that higher unmet needs lead to lower levels of service user service engagement.

Helping Alliance and Service Engagement

The study's findings that staff reported helping alliance was related to service user service engagement is surprising. Despite the fact that a measure of the helping alliance was included in the study to assess the confounding effects of engagement, the results demonstrated that helping alliance has its own independent effects. Consequently, the relationship between helping alliance and engagement may be regarded as significant in that it implies non-specific aspects of the relationship between service user and care coordinator could result in the positive outcome of better service engagement. However

it must be noted that the positive effect of the therapeutic relationship on engagement was apparent only when the helping alliance was appraised by the care coordinators and not the service users. Unlike in the previous case, it cannot be argued that the difference is shown in the care coordinator reports because they have more relative knowledge of the variable (helping alliance). Instead another argument can be made for the difference: Observation of the distribution of the service user and care coordinator helping alliance variables provided evidence for a slight positively skewed distribution in the case of the service user data only. Transformations of the data were performed to deal with this issue. One explanation for this pattern is that the service users' appraisals of their relationships with their care coordinators were more likely to be influenced by a social desirability bias. Finding support for this speculation is beyond the remit of this study. Future research could deal with the potential affect of a service user's social desirability bias on the helping alliance variable by including an appropriate measure and ascertaining its effect on the results.

In short, the positive association between the helping alliance and engagement alongside higher unmet needs and lower engagement could suggest that care coordinators perceive the helping alliance as negative and non-specific aspects of the negative helping alliance lead to more needs becoming unmet and lower service engagement. So in effect the care coordinator's perception that the service users is not getting what they want somehow influences service user engagement behaviour through their perception of the helping alliance. Given the difficulty in ascertaining causality, another explanation is equally valid: care coordinator perception of higher unmet needs could result in a negative helping alliance that leads to a poorer service engagement.

Service User-Care Coordinator Agreement

This section will briefly discuss the fair association between staff and service users rating of the presence of need. The result could reflect a difference between care coordinators and their service users views on which elements of care are being addressed and which aspects are important to receive intervention. However the research findings explained here propose that lower levels of agreement between service users and staff do not necessarily lead to the main negative outcomes investigated (service engagement).

Service User-Care Coordinator Agreement and the Helping Alliance

Despite the low agreement between staff and clients regarding need status, there was a significant association between the staff rated helping alliance and the CANSAS and What Getting Better Means Questionnaire. This result is arguably one of the most clinically relevant findings of this research. It is noteworthy however that although the two measures of agreement (CANSAS and What Getting Better Means Questionnaire) were used to answer the same empirical question they measure subtly different aspects. The “What Getting Better Means Questionnaire” endeavours to capture the variations between client and professionals views of the client’s improvement whereas the CANSAS assesses the client and professional’s agreement on whether a need has been met not whether it is important. Having clarified this issue the finding suggests that better staff client agreement could influence a more positive helping alliance. Obviously, given the cross sectional design of the study the opposite is equally plausible and when service users and care coordinators have a better helping alliance they are more likely to agree on whether a need is met or not and what are the most important aspects of need.

Service Users Higher Rating of Existential Aspects (i.e. empowerment, self-esteem and belonging).

The conclusion that service users and their respective care coordinators do not agree on the importance of existential aspects of improvement could be taken at face value. This position is strengthened by the fact that the effect was differential and not all the other aspects of improvement were rated differently by the staff-client pairings. The reason for this difference may be that staff regard as important only those elements that they feel they have the power or interventions to change. For instance, they may not know how to increase their service user's level of empowerment but they may feel confident intervening in their medication and ability to work. This proposition is supported in this research in the result that there were no differences between staff and client evaluations of work and medication issues. Further research could answer this question by using the full version of the CANSAS (i.e. The Camberwell Assessment of Need - Slade, Thornicroft, Loftus, Phelan & Wykes, 1999) to ascertain which services are being used to meet service user needs and observing whether the organisations have established methods of treatment.

Care Coordinators' Higher Ratings of Met Need

The surprising result that staff reported only more *met* needs than service users is unlike most other research and needs to be examined. These results are contrary to Slade et al. (1999) who argued that a plausible explanation for correlations between staff assessment of unmet needs, met needs and total needs is that staff unmet need is influenced by the levels of met need. They maintain that staff may have an internal estimate of patient's level of need so their ratings of unmet need influence how many met needs are present.

More met needs fall more in line with the proposition made by Hansson et al. (2001) who claim that staff ratings may be less reliable due the fact that they may have less knowledge of the patient's circumstances. They believe that staff may be more likely to rate needs as met because they are reluctant to rate them unmet unless they have firm evidence of this being the case. According to Slade et al. (1996) this tendency could be related to staff perceptions of their own professional competence. Post hoc analysis of the data from this investigation gives some measure of support for this contention revealing a negative correlation between unmet needs and staff age. In other words, more experienced staff are more likely to rate needs as unmet.

There was a lack of empirical support for some of the research predications. Unfortunately data did not provide any support for the main experimental hypotheses concerning higher discrepancies between service users and care coordinators' views on improvement being correlated with lower service user service engagement. Besides this, there was no evidence for an association between the two groups when agreement was measured by the CANSAS and the difference between service user and care coordinator perceptions of the number of unmet needs. In the same vein, there was an absence of a statistically significant correlation between recovery style and service engagement.

Study Limitations

The absence of support for these hypotheses may be for two reasons: either because no such associations exist or due to flaws in the research design and shortcomings of the particular measures used to operationalise the variables. In any case it is important that

the validity of the research findings be considered in light of problems with the research design. The sample issues and specific challenges presented by the experimental measures will be considered. The study's limitations will be presented alongside ideas for dealing with them in future research.

Sample

One of the most obvious shortcomings of this research concerns the low number of participants that were successfully recruited. Despite the fact that some important statistically significant findings received support from the data, this aspect of the study compromised the statistical power and the chances of finding significant results. As a result, the findings from the regression analyses performed should be judged with caution in light of the low participants to variable ratio. Low sample size, high staff turnover in mental health teams and temporary residents are indicative of the reality of real life research in an inner city area.

Moving on, it is noteworthy that this research was undertaken within a deprived inner city area of London's End that contains a disproportionately high number of people from Bangladeshi communities. Moreover the sample did not contain service users from many of the other ethnic groups commonly found in London. For instance the 2001 Census shows that portions of people from ethnic backgrounds apart from those contained in this study are thirty-one percent. Taking this argument one step further, the ethnic variation contained in this study is quite different from that reported from England as a whole. Whereas the present study was forty seven percent White, thirteen

percent Asian and thirteen percent black the 2001 Census indicates that England is comprised of eight seven percent White, one percent Asian and two percent Black. Consequently, it is questionable to what extent the results from this study can be applied to the whole of the long term mentally ill population in the U.K. This observation is important as it is possible that people from diverse communities hold contrasting views of need and recovery from the British population. For instance studies have shown that narratives about the causes of mental illness differed amongst cultures (Kleinman, 1980; McCabe & Priebe, 2004) and this may have an effect on compliance (MacCarthy, 1988). It was added that even people with a different ethnic origin born in the U.K could differ in terms of acculturation and draw on multiple cultural and linguistic resources when constructing illness accounts. The relatively low numbers of participants contained in this study prevented any analysis of the potential effect of cultural background on constructs of mental health need and improvement. Nonetheless, despite such criticisms, it is proposed that proportions of people from the various ethnic backgrounds recruited for the present study are broadly similar to that of the majority of urban areas of England (Commission of Racial Equality, 2001). Furthermore, given that deprivation and mental illness often go hand in hand it arguable that the findings are still useful.

Measures

Some of the constraints of this research concern the relative limitations of the measures and scales used in the study. One reason for the non-significant results could have been because of the measures used. For instance, the questions used in the What Getting Better Means Questionnaire contained words which some service users may not have been able to understand (e.g. empowerment and functioning). This position is given

credence by the observation that the majority of service users left school without qualifications. Although this measure was included to reflect the demographics of the group it is arguable that it may provide a limited estimation of the participants' levels of understanding. If service users answered questions without comprehending the definition of a term this could have affected the results in an unexpected manner. This issue could have been dealt with by comparing the results of those with various levels of education. However the low participant numbers precluded any analysis of between group differences. In the same vein, the Recovery Questionnaire consisted of thirty nine forced choice questions. It is possible that many of the service users may have suffered from cognitive impairments or thought disorders that would have made such distinctions between categories problematic by definition of their status as long term mentally ill. It is a well known research finding that many people with severe mental illness have cognitive difficulties and struggle to deal with abstract information (e.g. Frith, 1979). In fact the number of questions involved in the study could have presented an intolerably high cognitive load. Anecdotally, several service users reported that they found answering the questions from the Recovery Scale difficult. One service user refused to answer the questionnaire on such grounds. It may be argued that statements such as "My illness is alien to me" and "My illness is part of me" could be construed as vague and its answer not definitive. The arguably challenging forced choice questions in the Recovery Scale may have been better dealt with by a likert type or visual analogue scale as in the case of the Helping Alliance Scale. Future research could deal with this problem by including a measure of cognitive ability within the battery of questionnaires administered to the participants. Having said this, the data did not reveal any evidence of acquiescence within any of the questionnaires.

As discussed in the previous section (Meaning of Findings), one of the shortcomings of the CANSAS is that the concept of unmet need is ambiguous. For instance, the CANSAS does not allow for the differentiation between a need that is unmet irrespective of the help given (e.g. intractable psychotic symptoms) a need that is unmet because a service users refuses treatment and a need that is unmet because it has not been noticed by care providers. However answering this question could involve obtaining further information from the client about the type of services they take up as is required in the fuller version of the CANSAS the Camberwell Assessment of Need (Slade, Thornicroft, Loftus, Phelan & Wykes, 1999). As a result resolving this ambiguity is beyond the scope of this research. This categorisation issue compromises any significant conclusions involving unmet need.

Problems were also associated with the What Getting Better Means Questionnaire. Unlike the CANSAS the What Getting Better Means Questionnaire had not been assessed for its psychometric properties before it was used here. As a result, aspects of its reliability and validity are uncertain and the findings presented here must be considered with caution. In the same vein, the Recovery Questionnaire receives little support for its psychometric properties in comparison to some of the measures used in this study. It may be argued that further evaluation into the reliability and validity of the Recovery Questionnaire is necessary for it to be used with confidence.

Furthermore there is evidence that that a person's recovery style is an attribute which can change (Birchwood & Tower, 2003). This is at odds with the assertion that recovery

is a stable trait characteristic (McGlashan, 1987). The consequence of this particular issue for the present research is that it is possible that an effect of recovery on service engagement was not found because of the study's design. The lapse in time between administering questionnaires to service users and their care coordinators introduced the possibility that a service users' engagement may have been assessed after their recovery status had changed. This problem could have been dealt with by reducing the time that both parties were administered questionnaires to an absolute minimum.

An important issue to consider when assessing the conclusions of the research is the extent to which the measure of service engagement adequately represents the construct of engagement. Despite demonstrating adequate psychometric properties it is arguable that the various elements comprised of the scale reflect a narrow view of service engagement. For instance the Service Engagement Questionnaire is divided into four separate subscales (i.e. Availability, Collaboration, Help Seeking and Treatment Adherence). Of the four scales only treatment adherence deals with any form of intervention and the intervention it focuses on is medication. This definition ignores other important activities that may contribute to a person's improvement. Besides treatment monitoring, these could include other preoccupations of community mental health teams such as accommodation, social support and vocational support (Watts & Priebe, 2002). As a result, the emphasis that the Service Engagement Scale has on adherence to biological intervention appears restrictive. Furthermore, where services deliver inappropriate and insensitive provision, service user non engagement may be regarded as an understandable response. Watts & Priebe (20002) illustrate the case of Mr B. who acknowledged his previous forensic history but would have preferred to live

with the voices given the consequences of his medication on his social and sexual life. The engagement measure would have scored him lowly though he may have been engaging with services to some extent and attending a number of social venues to enhance his quality of life. Much of the literature shows that there is a tendency to see compliance with professional and prescriptions as the only rational choice thus non-compliance is a problem to be fixed (Perkins & Repper, 1999). So arguably, another definition apart from that offered in the Introduction widely adopted in services may be; “the extent to which a person’s behaviour..coincides with medical health advice (Hayne, Taylor & Sackett, 1979).” However disengagement in the case explained above could be regarded a rational choice. Rather than being a problem of the client to be remedied the issue of engagement transforms into a rational, empowered choice made by them. In short, the decision not to take up mental health services could be an understandable decision made by service users and high engagement may not necessarily be positive and low engagement negative. Future work could involve more exploration into the construct of engagement from the perspective of service users.

Summary of Research Interpretation

At this point in the Discussion, there are three important findings to bear in mind. Firstly, there is little evidence to support the main research prediction that individual factors (e.g. recovery style and service users’ attitudes to recovery and whether their needs are met) influence service engagement. However there is evidence that staff-client agreement of need status and recovery improve the helping alliance. Thirdly, the interpretation of the data linking unmet need to service engagement is twofold: Higher unmet need and low engagement could mean service users perceive services and support

as lacking and then reduce engagement. Alternately care coordinators may perceive a negative helping alliance and higher unmet needs and this could result in lower service engagement. These relationships are difficult to disentangle and beyond the scope of this research. However the discovery that higher care coordinator rated unmet needs leads to worse service user engagement alongside the helping alliance's association with better staff-client agreement about need status at the very least suggests that the attitudes of others involved in the enterprise of mental health may have more of an impact on service user engagement and positive outcomes. As a result the implications of all interpretations will be presented.

Theoretical and Clinical Implications: Health Belief Models and Motivational Interviewing

Health behaviour theories offer useful paradigms in which service adherence behaviour and the present research findings can be better conceptualised. For example, the Health Belief Model (Becker, 1974; Rosenstock, 1974) describes how cognitive aspects through value expectancies are related to health behaviour. He purports that when faced with illness people behave in a rational way to diminish personal threat and enhance perceived benefits (including illness behaviour). People perform specific illness reduction behaviour if they believe that they will adequately address their symptoms whilst not causing them undue side effects. It has been further proposed that obstacles to compliance related to these value expectancies could come from the service users' perception of the treatment regime as coercive and demanding and they do not adhere to treatments they do not understand or believe will benefit. In such cases reactance or the patient's tendency to behave in opposition to the intent of a threat (Brehm, 1966) may

take place and result in disengagement. Research has shown that this reactance may be one of the reasons why people do not comply with prolonged treatment regimes that may be perceived as threatening (e.g. Fogarty, 1997).

In terms of the first interpretation, if it is accepted that higher unmet was associated with lower service engagement due to service users not accepting treatment offered for whatever reason this is an instance of service users making a value expectancy judgement about how much treatments and service involvement help as mentioned in the model. Techniques that aim to promote compliance by modifying value expectancies have been developed. For instance motivational interviewing helps the individual assess the costs and benefits of continuing a behaviour (e.g. not complying with a treatment regime). The collaborative psychosocial strategy aims to address some of the barriers to constructing normative value judgments in a non-coercive manner. This approach has been found to yield effective results when applied to medication adherence and coupled with cognitive behavioural therapy (e.g. Kemp, Hayward, Applewaite et al. 1996; Healey, Knapp, Astin, Beecham et al. 1998). Most relevantly motivational interviewing has been applied to service engagement (e.g. Baker & Hambridge, 2002). Humphress, Igel, Lamont et al. (2002) examined the impact of a motivational interviewing inspired strategy on a group of forty-five clients of a community mental health team. Although the results of this study were compromised by the fact that the motivational interviewing strategy was operationalised by a letter, it provided preliminary evidence that interventions for promoting service engagement running along the lines of motivational interviewing techniques could be useful.

If the higher unmet need leading to lower service engagement apparent here is due to the type of unmet need caused by users not accepting treatment they do not value and understand then providing psychoeducation as part of a package of motivational interviewing could help improve their involvement with services. According to Perkins (1995) this intervention should afford realistic rather than paternalistic advice on medication and should include information about the multi-causal nature of mental illness and relapse prevention. In this way a compliance therapy approach to service engagement would dovetail two themes of the research findings: increasing empowerment and promoting engagement.

However, one well-documented problem with the health belief theories mentioned so far are their reliance on intrapersonal activity or psychological process within the individual. On the other hand, the Theory of Reasoned Action (Fishbein & Ajzen, 1975; Becker & Rosenstock, 1976) claims that the attitudes and beliefs of *significant others* also determine a patient's health behaviour. As a result the present findings correlating unmet needs and helping alliance with engagement is in accordance with the health belief model. Furthermore it supports the second interpretation that service engagement involves at the very least the care coordinator's perception of their helping relationship rather than involving only the attitude of the service user.

In brief, the discrepancies between service user and care coordinator views on improvement negatively affecting service engagement may not be wholly untrue but merely simplistic and unlikely to be detected with the poor levels of power present in this research. It is conceivable that although differences in views may be important other

factors have more relative influence. Some of these factors, mentioned in the Introduction may concern elements of the service (e.g. stigmatisation, inaccessibility and a diachronic focus) and the service user (e.g. cognitive problems, personality/attachment status and ethnicity) but others could involve the rest of the social network (i.e. staff). Health Belief Models frequently attempt to bridge the gap between reported attitudes and behaviour and highlight some of the other factors concerned with the person that may more fully explain service engagement. From the idea that some of the findings may be broadly related to elements of health belief models we will now turn to a discussion of how the findings can be used to improve service user service engagement.

Research Findings Summary

Although the main hypothesis relating differences in attitudes toward improvement to service engagement were not supported, there was evidence to suggest that staff-service user agreement leads to the positive outcome in terms of the helping alliance. Second it was found that clients and staff place emphasis on different aspects of care. Moreover it has been shown that service users' lower engagement may take place because they do not receive enough effective services. Alternately a negative helping alliance with the client leads the client to engage less because their clinical social and therapeutic relationship needs are not met. Either way, put together these findings paint a picture of service users potentially disengaging because they are not getting what they need from services through care coordinators. At this point it is important that the general the conclusions of this research are evaluated for their research and clinical implications.

Further Research

Although this study dealt with the association between service user and care coordinators perceptions of need on the CANSAS altogether, the heterogeneity of the needs contained in the questionnaire necessitates that analysis should have been carried out on each individual area of need and engagement. Amalgamating the assessments had the limitation that it gives equal weight to areas that could differentially affect engagement. Separate analysis of each domain could potentially reveal that a particular domain of need is more likely to influence service engagement. Future work could involve evaluating the individual areas of met and unmet need in order to investigate whether meeting some needs disproportionately affect engagement, the helping alliance and other important outcomes (e.g. mental state and empowerment). Possible evidence for the speculation that agreement in a particular domain could lead to positive outcomes in the same area come from experimental result that the mental state discrepancy scores from "What Getting Better Questionnaire" corresponded with measure of psychopathology. Future research would investigate the probability that discrepancies are more likely to be related to specific outcomes. Studies could also explore which particular areas of unmet need are related to lower service engagement and ascertain whether these domains are the same as those which staff and service users prioritise differently.

A potential area for exploration concerns the relationship between professional background and recovery priorities. However, the relatively small sample of care coordinators in this sample made it impossible for many associations to be convincingly

supported. For instance it is likely that those from a medical background afford pride of place to health concerns whilst those from social backgrounds may special relationship concerns. This aspect receives support from Shepherd, Murray and Muijen (1995) who found differences in priorities, even within the same profession. He showed that consultants gave less emphasis to monitoring and support than junior doctors. More relevantly, professional background and therapeutic emphasis may differentially affect service engagement. This factor remains an important issue given that discipline specific practice is still a contentious subject within community mental health teams (Shepherd, Murray and Muijen 1995). According to Bachrach (1993), case management must be defined according its functions rather than according to the disciplines of its practitioners. Furthermore the relative difference may be important to multidisciplinary care. It would be beneficial if future empirical exploration could employ larger numbers of participants to investigate whether differences between the level of importance that multidisciplinary professionals give to various aspects of recovery reveal information regarding 'therapeutic optimism' that may present issues for service user care.

Clinical Implications

Firstly, the link between the staff-client agreement about needs status and recovery priorities and the helping alliance has potential implications for the way services provide help. It suggests that better staff client agreement could influence a better helping alliance which is a positive outcome in its own right. As a result it may be that care coordinators need to place more weight on ensuring agreement of need is obtained. On the other hand, the helping alliance's association with service engagement could mean that empirical investigation should explore the other ways in which the helping alliance

could be improved to enhance services' ability to meet needs. For instance, Fehrenbach and O'Leary (1982) claim that 'attributional biases' can influence the development of a helping relationship. In other words the therapist's tendency to explain the client's difficulties with personality aspects rather than external factors impacts on the helping alliance.

In addition, attempts should be made to involve staff in promoting service user engagement by putting more effort into ascertaining and meeting more of the needs of service users rather than just relying on the categories included in the present assessment tools. Although some of the needs may be specific (e.g. empowerment) others may be less specific and involve reevaluating the importance of what they already provide (therapeutic alliance). Broadening and changing the emphasis of the concept of recovery may also involve allowing service users to be given the right to stipulate which parts of the service to engage with and use. This may entail staff not becoming overtly embroiled in risk agendas. The proposed attitude of clinicians towards the importance of compliance and need to control due to risk issues could negate an alternative option and goal for the engagement intervention: Partial engagement. The research finding that service user and staff rate existential aspects of recovery differently suggests that staff have limited priorities for recovery. The responses given to the open-ended question presented in this research also adds weight to the claim that staff have different risk oriented agendas to clients. For instance, when asked; "What getting better means to you?" one service user hinted at a recovery rather than cure intention by stating; "Mental illness is a chemical and you have to accept it and keep going." Another said "getting better" meant, "...I can get on with my life." Conversely, none of the staff mentioned any

aspects that have not been covered by traditional needs assessment tools. At the moment, it has been claimed that care coordinators tend to rank medication adherence as the most important therapeutic goal (Corrigan, Rao & Lam, 1999).

Although there is an obvious need for risk assessment and service users agree on its priority, the climate of blame present in mental health services may mean that clinicians are reluctant to risk changing their focus if they are at odds with service users - injectable medication to more acceptable and controllable oral medication or the acupuncture requested by the client. It is likely that mental health services' potential preoccupation of risk rather than broadening views to less tangible aspects recovery is borne out of a tendency to cure and get rid of symptoms whether these are neurochemical imbalances, faulty cognitions or dysfunctional family relationships. It has been purported however that cure-based approaches are of little value when working with people who by definition have persisting problems. Rather this approach has been said to lead to both demoralisation and hopelessness in both client and staff if services fail at doing something they cannot achieve at the time (Perkins, 2003). In a nutshell, if our aim as clinicians is to help people to "function at an optimum level" (Bennett, 1978) we should not constrain that level in term of our own expectations.

The implication of low agreement between staff and service users' views of need taken at face value suggests that neither views are interchangeable and both should form part of a comprehensive needs assessment. What can be said is that depending on the area it may be more useful for staff to report their views. For instance, staff views may be more pragmatically useful in terms of affecting engagement whereas service users' reports

could have more impact on areas they are more likely to know about such as quality of life issues. The research shows that the needs assessment measure is useful in predicting important outcomes and as such should serve as the basis for continued evaluation to ensure aid is given appropriately and improvement in mental health services.

Discussion Summary

In the final analysis, the preliminary data has provided limited support for the contention that service user choice to receive help from services could be related to them getting what they require. As a result this discussion has considered several avenues for future research. The notion of need appears to be a more complex concept than is currently reflected in present needs assessment measures. The study's conclusion alongside reference to health belief literature suggests that service engagement contains not only aspects of the personal (attitude to needs being met and coping style), but also interpersonal and social (e.g. staff perceptions of unmet need and the helping alliance). As a consequence encouraging client involvement with services may involve helping staff acknowledge their understanding of their influence in encouraging service engagement in specific ways (i.e. broadening the concept of need and making efforts to meet these) and less specific (i.e. understanding and support). On a positive note the finding concerning staff and clients making similar ratings of indices of improvement suggests that there are some agreements on care priorities. This research can be offered as a pilot study, which suggests that the care coordinator beliefs and attitudes could influence positive outcomes and service user involvement with services.

What perhaps is most striking about this research are its revelations about the nature of service engagement. At best promoting service engagement may involve service providers trying to deliver as many effective services as possible. At worst the problem for services is an acceptance that lack of uptake of provision is a rational choice which can be dealt with by inviting services to examine their own expectations of what service users need are before they can be met.

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East London and The City Local Research Ethics Committee

Aneurin Bevan House, 81 Commercial Road, London E1 1RD

Miss Deodata Monero
11 Macbeth House
Arden Estate
London N1 5JG

22nd March 2004

Our ref:

Dear Miss Monero

Re: P2/04/020 – A comparison of care co-ordinators' and service users' views on need and getting better

Thank you for your letter of 26th February 2004 addressing the points of the Committee's earlier letter. I am happy to tell you that I am now able to approve this study on Chairman's action to be noted at future meeting of the Committee. However, there are a few provisos as follows:

- a) Please revise Section 9.8 so it reflect on English Speakers.
- b) Please address section 3, has it applies to all 2 group subjects.
- c) Confirmation of Indemnity is required.

Please note the following conditions to the approval:

1. The Committee's approval is for the length of time specified in your application. If you expect your project to take longer to complete (i.e. collection of data), a letter from the principal investigator to the Chairman will be required to further extend the research. This will help the Committee to maintain comprehensive records.
2. Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee or Chairman's approval.
3. The Committee should be notified immediately of any serious adverse events or if the study is terminated prematurely.

4. You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, such as extra work for laboratories.
5. You must ensure that, where appropriate, nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.
6. The Committee should be sent one copy of any publication arising from your study, or a summary if there is to be no publication.

I should be grateful if you would inform all concerned with the study of the above decision.

Your application has been approved on the understanding that you comply with Good Clinical Practice and that all raw data is retained and available for inspection for 15 years.

Please quote the above study number in any future related correspondence.

Yours sincerely

 **DORA OPOKU**
Chair
East London and The City Research Ethics Committee

What Getting Better Means Questionnaire (Service Users)

Staff Code:

Service User Code:

Date:

For the statements which follow below circle how important the different definitions of "getting better" are to you on a scale of 0 to 10.

1. Improved mental state

Not Important 1 2 3 4 5 6 7 8 9 10 Important

2. A reduction in symptoms

Not Important 1 2 3 4 5 6 7 8 9 10 Important

3. A reduction in medication side effects

Not Important 1 2 3 4 5 6 7 8 9 10 Important

4. A reduction in danger to self and others

Not Important 1 2 3 4 5 6 7 8 9 10 Important

5. Improved understanding/insight of my illness

Not Important 1 2 3 4 5 6 7 8 9 10 Important

6. Improved general well-being

Not Important 1 2 3 4 5 6 7 8 9 10 Important

7. More relaxed/less anxious

Not Important 1 2 3 4 5 6 7 8 9 10 Important

8. Happier, more contented

Not Important 1 2 3 4 5 6 7 8 9 10 Important

9. Improved memory and concentration

Not Important 1 2 3 4 5 6 7 8 9 10 Important

10. Improved relationships

Not Important 1 2 3 4 5 6 7 8 9 10 Important

11. Less lonely, more friends

Not Important 1 2 3 4 5 6 7 8 9 10 Important

12. Better family relationships

Not Important 1 2 3 4 5 6 7 8 9 10 Important

13. Having a partner/sexual relationship

Not Important 1 2 3 4 5 6 7 8 9 10 Important

14. Belonging and feeling valued by others

Not Important 1 2 3 4 5 6 7 8 9 10 Important

15. Empowerment, confidence and self-worth

Not Important 1 2 3 4 5 6 7 8 9 10 Important

16. Increased confidence and self-esteem

Not Important 1 2 3 4 5 6 7 8 9 10 Important

17. Greater control over self and life

- 18. Being normal, not a psychiatric patient**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 19. Greater engagement in work and activities**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 20. Having more interesting and enjoyable things to do**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 21. Going out more**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 22. Having a job or studying – a useful role**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 23. More able to cope with day to day life**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 24. More able to do the practical activities of daily life**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 25. Improved general functioning**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 26. More independent**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 27. Improved access to help and support**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 28. Feeling safer**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 29. Having someone to share problems with**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 30. Improved material well being**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 31. Having an adequate income**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 32. Having a decent place to live**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 33. Having decent clothes and possessions**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important
- 34. Improved physical health**
 Not Important 1 2 3 4 5 6 7 8 9 10 Important

Thankyou for completing this questionnaire.

What Getting Better Means Questionnaire (Staff)

Staff Code:

Service User Code:

Date:

For the statements which follow below circle how important the different definitions of “getting better” are in terms of your service user on a scale of 0 to 10.

1. Improved mental state

Not Important 1 2 3 4 5 6 7 8 9 10 Important

2. A reduction in symptoms

Not Important 1 2 3 4 5 6 7 8 9 10 Important

3. A reduction in medication side effects

Not Important 1 2 3 4 5 6 7 8 9 10 Important

4. A reduction in danger to self and others

Not Important 1 2 3 4 5 6 7 8 9 10 Important

5. Improved understanding/insight of illness

Not Important 1 2 3 4 5 6 7 8 9 10 Important

6. Improved general well-being

Not Important 1 2 3 4 5 6 7 8 9 10 Important

7. More relaxed/less anxious

Not Important 1 2 3 4 5 6 7 8 9 10 Important

8. Happier, more contented

Not Important 1 2 3 4 5 6 7 8 9 10 Important

9. Improved memory and concentration

Not Important 1 2 3 4 5 6 7 8 9 10 Important

10. Improved relationships

Not Important 1 2 3 4 5 6 7 8 9 10 Important

11. Less lonely, more friends

Not Important 1 2 3 4 5 6 7 8 9 10 Important

12. Better family relationships

Not Important 1 2 3 4 5 6 7 8 9 10 Important

13. Having a partner/sexual relationship

Not Important 1 2 3 4 5 6 7 8 9 10 Important

14. Belonging and feeling valued by others

Not Important 1 2 3 4 5 6 7 8 9 10 Important

15. Empowerment, confidence and self-worth

Not Important 1 2 3 4 5 6 7 8 9 10 Important

16. Increased confidence and self-esteem

Not Important 1 2 3 4 5 6 7 8 9 10 Important

17.Greater control over self and life

Not Important 1 2 3 4 5 6 7 8 9 10 Important

18.Being normal, not a psychiatric patient

Not Important 1 2 3 4 5 6 7 8 9 10 Important

19.Greater engagement in work and activities

Not Important 1 2 3 4 5 6 7 8 9 10 Important

20.Having more interesting and enjoyable things to do

Not Important 1 2 3 4 5 6 7 8 9 10 Important

21.Going out more

Not Important 1 2 3 4 5 6 7 8 9 10 Important

22.Having a job or studying – a useful role

Not Important 1 2 3 4 5 6 7 8 9 10 Important

23.More able to cope with day to day life

Not Important 1 2 3 4 5 6 7 8 9 10 Important

24.More able to do the practical activities of daily life

Not Important 1 2 3 4 5 6 7 8 9 10 Important

25.Improved general functioning

Not Important 1 2 3 4 5 6 7 8 9 10 Important

26.More independent

Not Important 1 2 3 4 5 6 7 8 9 10 Important

27.Improved access to help and support

Not Important 1 2 3 4 5 6 7 8 9 10 Important

28.Feeling safer

Not Important 1 2 3 4 5 6 7 8 9 10 Important

29.Having someone to share problems with

Not Important 1 2 3 4 5 6 7 8 9 10 Important

30.Improved material well being

Not Important 1 2 3 4 5 6 7 8 9 10 Important

31.Having an adequate income

Not Important 1 2 3 4 5 6 7 8 9 10 Important

32.Having a decent place to live

Not Important 1 2 3 4 5 6 7 8 9 10 Important

33.Having decent clothes and possessions

Not Important 1 2 3 4 5 6 7 8 9 10 Important

34.Improved physical health

Not Important 1 2 3 4 5 6 7 8 9 10 Important

Thankyou for completing this questionnaire.

Instructions:

Written below is a list of statements about your illness. Please read them carefully and tick the box to show if you agree or disagree.

	Agree	Disagree
1, There was a gradual build up to me becoming ill		
2, My illness is not part of my personality.		
3, I am responsible for what I think when I am ill.		
4, I am not interested in my illness.		
5, My illness taught me new things about myself		
6, I need help to solve the problems caused by my illness		
7, My illness was caused by my difficulties in coping with life.		
8, I have had a nervous breakdown.		
9, I can see positive aspects to my illness.		
10, My illness has had a strong impact on my life.		
11, I am not frightened of mental illness.		
12, I liked some of the experiences I had when I as ill.		
13, My illness has helped me to find a more satisfying life.		
14, My illness came on suddenly, and went suddenly.		
15, My illness is part of me.		
16, I am not responsible for my actions when I am ill.		
17, I am curious about my illness.		
18, I understand myself better because of my illness.		
19, I can manage the problems caused by my illness, alone.		
20, Others are to blame for my illness.		
21, I have had a medical illness.		
22, Nothing good came from my illness.		
23, My illness has had little effect on my life.		
24, I am frightened of mental illness.		
25, I didn't like any of the unusual experiences I had when ill.		
26, It's hard to find satisfaction with life following my illness.		
27, My illness came on very suddenly.		

	<i>Agree</i>	<i>disagree</i>
28, My illness is alien to me.		
29, I am responsible for my thoughts and feelings when I am ill.		
30, I don't care about my illness now that I am well.		
31, I want to be the person I was before my illness.		
32, Others can help me solve my problems.		
33, My illness was caused by stress in my life.		
34, I have suffered an emotional breakdown.		
35, Being ill had good parts too.		
36, I'm not really interested in my illness.		
37, I liked some of the unusual ideas I had when I was ill.		
38, My life is more satisfying since my illness.		
39, My attitude to mental illness is better now, than before I was ill.		

thank you for your help

The Helping Alliance Scale
(Priebe & McCabe, 2000)

Name:

Date:

- 1. Is the treatment you are currently receiving right for you?**

	0	1	2	3	4	5	6	7	8	9	10	
not at all	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	entirely

- 2. Do you feel understood by your therapist?**

	0	1	2	3	4	5	6	7	8	9	10	
not at all	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	entirely

- 3. Do you feel criticised by your therapist?**

	0	1	2	3	4	5	6	7	8	9	10	
entirely	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	not at all

- 4. Is your therapist committed to and actively involved in your treatment?**

	0	1	2	3	4	5	6	7	8	9	10	
not at all	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	entirely

- 5. Do you trust in your therapist and in his/her professional competence?**

	0	1	2	3	4	5	6	7	8	9	10	
not at all	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	-----	entirely

- 6. How do you feel immediately after a session with your therapist?**

Worse

Unchanged

Better

The Helping Alliance Scale (Therapist version)
(Priebe & McCabe, 2000)

Name:

Date:

Professional role:

1. Do you get along with the patient?

	0	1	2	3	4	5	6	7	8	9	10	
not at all	----- ----- ----- ----- ----- ----- ----- ----- ----- -----										extremely well	

2. Do you understand the patient and his/her views?

	0	1	2	3	4	5	6	7	8	9	10	
not at all	----- ----- ----- ----- ----- ----- ----- ----- ----- -----										extremely well	

3. Do you look forward to meeting the patient?

	0	1	2	3	4	5	6	7	8	9	10	
not at all	----- ----- ----- ----- ----- ----- ----- ----- ----- -----										entirely	

4. Do you feel you are actively involved in the patient's treatment?

	0	1	2	3	4	5	6	7	8	9	10	
not at all	----- ----- ----- ----- ----- ----- ----- ----- ----- -----										completely	

5. Do you feel you can help the patient and treat him/her effectively?

	0	1	2	3	4	5	6	7	8	9	10	
not at all	----- ----- ----- ----- ----- ----- ----- ----- ----- -----										entirely	

6. What are the positive aspects of your relationship with the patient?

7. What are the negative aspects of your relationship with the patient?

Scoring Sheet for the Krawiecka Service User name:

Name of Rating	Reasons for morbid rating	Rating (0-4)
Depressed		
Anxious		
Coherently expressed delusions		
Hallucinations		
Incoherence and Irrelevance of speech		
Poverty of speech		
Flattened incongruent effect		
Psychomotor retardation		
Total mental state score		
Side Effects		(0-2)
Tremor		
Rigidity		
Dystonic reactions		
Akathisia		
Difficulties with vision		
Other (specify)		

The Service Engagement Questionnaire

Service User Code:

Staff Code:

Circle the most appropriate answer with reference to your client.

1. The client seems to make it difficult to arrange appointments.
Not at all Sometimes Often Most of the time
2. When a visit is arranged , the client is available.
Not at all Sometimes Often Most of the time
3. The client seems to avoid making appointments.
Not at all Sometimes Often Most of the time
4. If you offer advice, does the client usually resist it?
Not at all Sometimes Often Most of the time
5. The client takes an active part in setting goals or treatment plans.
Not at all Sometimes Often Most of the time
6. The client actively participates in managing his/her illness.
Not at all Sometimes Often Most of the time
7. The client seeks help when assistance is needed.
Not at all Sometimes Often Most of the time
8. The client finds it difficult to ask for help.
Not at all Sometimes Often Most of the time
9. The client seeks help to prevent a crisis.
Not at all Sometimes Often Most of the time
10. The client does not actively seek help.
Not at all Sometimes Often Most of the time
11. The client agrees to take prescribed medication.
Not at all Sometimes Often Most of the time
12. The client is clear about what medication they are taking and why.
Not at all Sometimes Often Most of the time
13. The client refuses to co-operate with treatment.
Not at all Sometimes Often Most of the time
14. The client has difficulty in adhering to prescribed medication.
Not at all Sometimes Often Most of the time

Thank you for completing this questionnaire.

East London and The City

Mental Health NHS Trust

Participant Information Sheet

A Comparison of Service Users' and Care co-ordinators' Views of Need and Getting Better.

You are invited to take part in a research study. You have been chosen to take part in this research as you are a service user of East London and The City Mental Health NHS Trust CMHT service. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You may ask as many questions as you wish. Please take time to decide whether or not you wish to take part.

The aim of the study is to understand how your ideas about getting better affect your care. To do this you will be asked to fill in four short questionnaires that will take about forty-five minutes. Examples of questions include: "Do you agree that getting better means a having more friends?" and "Do you feel understood by your care co-ordinator?" Your care co-ordinator will also be asked to complete four questionnaires. Upon completion of the questionnaires you will be given £5 to cover your expenses.

The results of the research may be published. At no time will your name or any personal information used. All information that is collected about you during the course of the research will be kept strictly confidential. All questionnaires and information gathered will have your name and address removed so that you cannot be recognised from it.

It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect any care you receive.

We believe that this study is basically safe and do not expect you to suffer any harm or injury because of your participation in it. However, *East London and The City Mental Health NHS Trust* has agreed that if your health does suffer as a result of your being in the study then you will be compensated. In such a situation, you will not have to prove that the harm or injury which affects you is anyone's fault. If you are not happy with any proposed compensation, you may have to pursue your claim through legal action.

Thank you for considering taking part in this study.

Deodata Monero
University College London
Department of Clinical and Health Psychology

Should you have any further questions before or after the research you may contact either of the following clinical psychologists who are involved in the study:

Deodata Monero:
Brigid MacCarthy:
Dr Janet Feigenbaum:

CONSENT FORM

A Comparison of Service Users' and Care co-ordinators' Views of Need and Getting Better.

Deodata Monero, Brigid MacCarthy, Dr Janet Feigenbaum

Sub-Department of Clinical Health Psychology, University College London

Participant name: _____

- The study organisers have invited me to take part in this research.
- I understand what is in the leaflet about the research. I have a copy of the leaflet to keep.
- I have had the chance to talk and ask questions about the study.
- I know what my part will be in the study and I know how long it will take.
- I have been told about any special drugs, operations, tests or other checks I might be given.
- I know how the study may affect me. I have been told if there are possible risks.
- I understand that I should not actively take part in more than 1 research study at a time.
- I know that the East London and The City Research Ethics Committee has seen and agreed to this study.
- I understand that personal information is strictly confidential: I know the only people who may see information about my part in the study are the research team or an official representative of the organisation which funded the research.
 - I understand that my personal information may be stored on a computer. If this is done then it will not affect the confidentiality of this information. All such storage of information must comply with the 1998 Data Protection Act.
- I know that the researchers will/might tell my general practitioner (GP) about my part in the study.
- I freely consent to be a subject in the study. No-one has put pressure on me.
- I know that I can stop taking part in the study at any time.
- I know if I do not take part I will still be able to have my normal treatment.
As a service user I give permission for my information to be shared with my care coordinator for therapeutic reasons.
- I know that if there are any problems, I can contact:

Mrs Brigid MacCarthy
Tel. No. 9

Dr Janet Feigenbaum
Tel. No. 4

Patient's/Volunteer's: Signature

Date

The following should be signed by the Clinician/Investigator responsible for obtaining consent
As the Clinician/Investigator responsible for this research or a designated deputy, I confirm that I have explained to the patient/volunteer named above the nature and purpose of the research to be undertaken.

Clinician's Name:

Clinician's Signature: Date:

Staff Code:

Service User Code:

Date:

What does “getting better” mean to you (Write as much as you like)?

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

East London and The City

Mental Health NHS Trust

Participant Information Sheet (Care co-ordinator)

A Comparison of Service Users' and Care co-ordinators' Views of Need and Getting Better.

You are invited to take part in a research study. You have been chosen to take part in this research as you are a care co-ordinator of East London and The City Mental Health NHS Trust CMHT service. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You may ask as many questions as you wish. Please take time to decide whether or not you wish to take part.

The aim of the study is to understand how your ideas about getting better affect your service user's care. To do this you will be asked to fill in four short questionnaires that will take about half an hour. Examples of questions include: "Do you agree that getting better for your service user means having more friends?" and "Do you feel actively involved with your service user?" Your service user will also be asked to complete four questionnaires. Upon completion of the questionnaires your service user will be given £5 to cover his/her expenses.

The results of the research may be published. At no time will your name or any personal information used. All information that is collected about you during the course of the research will be kept strictly confidential. All questionnaires and information gathered will have your name and address removed so that you cannot be recognised from it.

It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect any care you receive.

We believe that this study is basically safe and do not expect you to suffer any harm or injury because of your participation in it. However, *East London and The City Mental Health NHS Trust* has agreed that if your health does suffer as a result of your being in the study then you will be compensated. In such a situation, you will not have to prove that the harm or injury which affects you is anyone's fault. If you are not happy with any proposed compensation, you may have to pursue your claim through legal action.

Thank you for considering taking part in this study.

Deodata Monero
University College London
Department of Clinical and Health Psychology

Should you have any further questions before or after the research you may contact either of the following clinical psychologists who are involved in the study:

Deodata Monero:
Brigid MacCarthy:
Dr Janet Feigenbaum:

Staff Code:

Service User Code:

Date:

What does “getting better” mean in terms of your service user (Write as much as you like)?

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There is no handwriting or other markings on the paper.