STIGMA AND MENTAL ILLNESS: a comparative study of attitudes and personal constructs

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By

Carlyle London

School of Health Science and Social Care,

Brunel University

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ABSTRACT

Evidence suggests that people with mental illness experience discrimination by being stigmatised both by the general public and by healthcare professionals. The experience of stigma may result in a delay in seeking professional help, loss of self-esteem and is a serious inhibitor to recovery and social inclusion. Stigma and discrimination are pervasive and despite a number of UK based campaigns, there appears to be no reduction in prevalence.

This research compared public attitudes towards mental illness and the mentally ill with mental health service users' perceptions of stigma, identified perceptions of stigma by mental health service users, quantified and qualified these perceptions alongside reported accounts of being stigmatised and made recommendation for strategies to reduce the stigma experienced by people with mental illness.

A cross-sectional survey was undertaken and involved the use of a 35-item attitude scale, employed with 132 members of the public and 132 self-selecting service users. Semi-structured interviews and Personal Construct Psychology Repertory Grid techniques were employed with subsets of the sample.

Qualitative data was subjected to Interpretative Phenomenological Analysis. Quantitative data was analysed using inferential statistical tests and Principal Component Analysis.

The perception of stigma amongst service users was relatively high and appeared to be pervasive. Male service users reported higher perceptions of stigma than females. The combination of being stigmatised by mental health professionals and the general public appeared to result in self stigma and social exclusion.

Recommendations include addressing the causes and mechanism of stigmatisation, the inclusion of service users' perspectives in research and raising awareness, amongst mental health professionals, on how their practice may impact on service users. Further research should address why there is a higher perception of stigma amongst male service users.

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CHAPTER ONE: INTRODUCTION AND PROBLEM IDENTIFICATION

From a historical perspective, stigma has been and continues to be a feature of many illnesses, particularly those which are terminal, sexually transmitted and others which are deemed to be incurable (Deacon, 2005). At this point it is useful to broadly introduce the concept of stigma to indicate negative discrimination against people who are deemed to be deviant from a social norm (Goffman, 1963).

The stigma of mental illness has been prominent for many centuries and it is possible that just as early philosophies shaped our views of the world, so too early notions of madness, mental illness and learnt responses may be one reason why the stigma of mental illness has such a pervasive persistence in contemporary societies (Royal College of Psychiatrists [RCP], 2000). Furthermore, the stigma attached to mental illness persists despite modern approaches to treatment and better understanding of the causes of mental illness (Priory Group, 2007; Office for National Statistics [ONS], 2008).

Mental illness was viewed as an unpleasant reminder that there is an unknown side to human nature, which is not civilised or rational, and is much less well understood, and where misunderstandings persist, the usual response to something that is not understood and feared, is to hide from it, laugh at it or attack it, which is precisely what happens to some people with mental illness (RCP, 2000). Because of stigma, some people with mental illness experience discrimination, and as a result, some cannot get jobs, some lose their friends and

home (Bacharach, 1992), but worst of all, a significant amount of people with mental illness lose hope (RCP, 2000; Social Exclusion Unit Report [SEU], 2004).

It was argued that the growth of psychiatry, the medicalisation of mental illness in the 19th century asylum care, sanctioned by the public and the medical profession and the attempt to describe mental distress in terms of diagnostic categories and syndromes usually applied to physical illnesses, were the basis for the current stigma and discrimination (Hitchon et al., 2006). Of note, the idea that both the public and medical sanctioning of asylum care is interesting because it highlights a temporal change in support for people with mental illness (Allderidge, 1979), from asylum care, to a call for de-institutionalisation (Barton, 1959; Goffman, 1963). Consequently, with the large scale closure of asylums in the early 1990's, there came a rising public clamour against community care for the mentally ill (Ingamells, 1996).

Public support for community care and subsequent resistance can be explored in stigmatisation, which is deemed to be operating in psychological and anthropological ways, and was an inescapable consequence of human tendency to order the world by demarking selfhood and otherness or 'them' and 'us' categories (Gilman, 1985). Stigmatisation can be viewed as a deep-seated unconscious need to construct 'them and us' schemes, in which our fragile self-identity was reinforced through the pathologisation of pariahs, such as people with mental illness (Gilman, 1982).

In the United Kingdom [UK], political and social pressure prompted action against the poor treatment of people with mental illness, who were then treated in large asylums (Barton, 1959). Yet, social rejection was commonly experienced

by the mentally ill as community care became a reality (Brockington et al., 1993; Davison and Neale, 1996). It appeared that the public protested against asylum care, but were not accepting the mentally ill into communities.

Despite the absence of consensus on origins and theories, stigma has a significant impact on the incidence, experience, management and prognosis of mental illness and has been identified as a factor in non-compliance and help-seeking behaviour (Corrigan, 2000; RCP, 2000). Furthermore, stigma impacts not only people with mental illness, but all of society (SEU, 2004).

It can be seen that stigma, particularly its origins and mechanisms, is indeed a complex subject, with differing sociological and psychological theories on its origins (Haghighat, 2001). However, this introduction will argue that stigma is related to the perception of difference between groups which has been impacted by stereotypical connections between mental illness, mental asylums, dangerousness and psychiatry.

Also, the evidence on the stigma of mental illness is mainly related to the category of schizophrenia, which is deemed to be the most severe form of mental illness and evidently, the most stigmatised (Lyons and McLoughlin, 2000). Schizophrenia is described as a psychotic illness which affects a person's thinking, language, emotions, social behaviour, the ability to perceive reality, and symptoms could include hallucinations, delusions, disorganised speech, lack of affect and catatonic behaviour (American Psychiatric Association [APA], 2000).

Structure Of The Study

In pursuance to compare public and service users' attitudes, this study was approached as follows. Chapter one explores the concept of stigma from a historical and contemporary perspective to identify societal perceptions of stigma and issues, with both the construct of stigma and its impact on people with mental illness, and indeed, on society. Of more importance, this chapter argues that the emphasis on de-stigmatisation in health policy, health promotion and the impact of consumerism in healthcare, are drivers for change, pointing to the professional and moral duty to take action in order to minimise the impact of stigma, involve service users in their own care and evaluation of services, training, education, and indeed, in research.

Furthermore, there is a detailed examination of conceptual models, theories of stigma and stigma research, to examine factors that may contribute to stigmatisation, such as cultural aspects, labelling and stigma management. The findings from this chapter will be considered in the approach to this study.

The methodology chapter presents the philosophical underpinnings and the rationale for choosing a conceptual model of stigmatisation, the study design and methods for data collection, statistical analyses and ethical considerations. It also gives a detailed discussion of the methodology, parameters employed in searching for literature and the research methodology used in the critical appraisal of studies. Of equal importance, there are details of the rigour employed in development and pilot testing of the attitude scale. Furthermore, there are rationales for the use of research tools, such as the Repertory Grid [RepGrid] and attitude scale.

Chapter four presents a detailed layout of the results in varied formats. Chapter five entails a discussion of findings in relation to the conceptual model of stigmatisation and research in the field of stigma. Chapter six provides a summary, conclusion and recommendations, but only after addressing the unique contribution of this research, a reflection on learning which occurred during the time of the research and implications for future research.

A core aspect of this introduction demonstrates why this study is important, why it is necessary to acquire service users' perspectives, and how the lived experience of service users contribute to the discourse on stigma.

1.1 <u>Personal And Professional Development Of Interest In Stigma And How This</u> <u>Research Emerged</u>

The impetus to undertake this research emerged from professional and personal observations of stigma in clinical practice and how these impacted outcomes for mental health service users. The genesis of my contact with mental health service users started in 1989, while training as a mental health nurse in a large asylum, which with the onset of the 'Care in the Community Act' (DH, 1990) was earmarked for closure in the coming years. In fact, it was at this juncture that the apparent impact of institutionalisation on service users and public attitudes towards mental illness and the mentally ill was observed to be antagonistic forces. Indeed, it was a time when mental healthcare professionals, especially nursing staff, faced the 'new' challenge of re-integrating service users into the community.

It can be seen that while the emergent consensus on asylum care deemed it as inhumane, (Barton, 1959: Goffman, 1963), public attitudes were acknowledged to be a significant factor for the success of care in the community (DHSS, 1983). In any case, the evidence for public stigma was often present in media portrayals and reports (The Times 1995: a, b, c, d). Indeed, one of the most sensational cases in 1992 was the death of Jonathon Zito, who was stabbed in the eye at Finsbury Park Station in London, by Christopher Clunis, who was recently released from a psychiatric hospital. This incident appeared to polarise negative attitudes to the point where the government appeared to respond to negative public attitudes by enacting 'Supervised Discharge', which aimed to coerce service users to be monitored and to comply with treatment, on discharge from hospital.

Consequently, all service users appeared to be treated as high risk clients, and blame for poor outcomes, such as rare incidents of violence or homicide, was attributed to service users being unpredictable and dangerous or the inability of mental health services to manage the risk posed by service users.

To the contrary, personal observations in clinical practice and reports from service users appeared to portray a different side of stigma. From clinical experience, service users appeared to be a disempowered group, with reports of being stigmatised by society and mental health services, in their frequent admissions and discharges from acute in-patient treatment. For example, in therapeutic engagement and clinical practice, service users shared their difficulties in accessing housing, benefits, maintaining their social networks, accessing employment, fear of disclosing their mental health status and social

isolation. It can be seen that what they described was stigma, which severely impacted their motivation to set or achieve goals. From a personal, professional perspective, the lack of motivation as a result of perceived stigma was one of the major challenges in working with service users, particularly those with severe and enduring mental illness.

It was my professional clinical experience with in-patient and community mental health services, frequent admissions and discharges of clients on the caseload, community and in-patient service users' reports of stigma and the apparent negative impact on service users and indeed on mental health service which fuelled my desire to look into the topic of stigma. Initially, my thoughts about stigma were challenged by the notion that perhaps most of the clients had a diagnosis of schizophrenia and this could be a manifestation of symptoms. However, my tendency to have a stereotypical view of service users was challenged and dismissed as personal knowledge on the topic grew.

In addition, there were a number of national and local policies which impacted clinical and professional practice. For example, standard one of the 'National Service Framework' (DH, 1999) highlighted the need to challenge stigma and discrimination. Similarly, the Social Exclusion Unit Report [SEU] (DH, 2004) reiterated the high levels of societal stigma, marginalisation and social exclusion of people with mental illness and recommended specific intervention to ameliorate stigma. More recently, the Chief Nursing Officer's Review of Mental Health Nursing (DH, 2006), and the National Institute for Mental Health in England [NIMHE] (2004) both placed emphasis on adopting the recovery approach to care in mental health services. Other factors which impacted clinical

practice and had emphasis on de-stigmatisation were consumerism, service user movements and user involvement in research and education (UKCC, 1996).

Indeed, while knowledge and interest in the topic of stigma deepened as I undertook a first degree in community mental health nursing, it also became apparent that stigma was a vast topic which appeared more obscure with indepth study. What became apparent was the lack of consensus on the causes of stigmatisation and the published literature on stigma appeared to focus on public attitudes and evidence derived from public surveys (Angermeyer and Deitrich, 2006). Likewise, my subsequent MSc study, which explored public stigmatisation as a function of knowledge and social distance, followed the traditional approach of investigation, a positivistic approach which employed a public survey.

Reflections on the outcomes of the MSc research study and considerations of its implications for mental health promotion brought me to question the validity of extrapolating findings on public attitudes to mental health service users. It was at this point I realised that the service user perspective was missing from the evidence which was collected. This brought me to re-examine the published literature, where I realised that evidence of the service user's lived experience was very scarce.

I thought of the missing service users' perspective and mused on the following issues:

- 1) Is there any evidence based on service user perspectives of stigma?
- 2) Where will service users' perspectives fit into the evidence base on stigma?

3) Service users have lived experiences regarding mental illness and stigma, so are they in a better position to relate about the stigma attached to mental illness?

It was with the aforementioned experience and questions in mind that I ventured into this study.

1.2 Aims and objectives Of This Study

As an acknowledgement to the importance of understanding the issue of stigma and stigmatisation of mental health service users and to incorporate lived experiences of stigma into the evidence base on stigma, this study aims to:

- Compare public attitudes to mental illness, with the perception of stigma amongst service users. This quantitative comparison will give an indication as to whether there is a chasm between what the public reports and what service users perceive. This comparison will be operationalised by means of a hypothesis. Some similar data will be collected from the public and service users which will enable other aspects of comparisons to be made between the two groups.
- Explore and identify factors which impact service users' perception of stigma and the meaning of their lived experience. This exploration and identification will be achieved by collecting and analysing data from service users, which includes an attitude scale, semi-structured interviews and Repertory grids, as used in Personal Construct Psychology (Kelly, 1955). A mixed methodology will be employed to minimise bias and to

identify themes and similarities in findings, which may be common in the data.

To draw inferences and conclusions from the findings of the study and make recommendations aimed at promoting mental health and minimising the impact of stigma on service users.

Following on, this research will focus on a key objective, which is to include aspects of service users' perception of stigma, which will become evident in the development of the attitude scale, through the use first person accounts and service users' reports of stigmatisation. The development of the attitude scale is explored in more detail in chapter three.

This study also aims to raise the profile of mental health service users and improve their experience of mental health services. This aim is also a personal and professional endeavour to make a contribution based on the combination of clinical experience and research. Furthermore, mental health professionals already acknowledge the impact of stigma on service users (Sartorius, 2002) and therefore, need to be proactive and vigilant in tackling stigma and discrimination. This study on stigma appears to be a much needed, significant area of research, which requires attention and exploration.

For clarification, in this study, service users will have a diagnosis of mental illness and use mental health services for treatment. The public will be people who do not have a diagnosis of mental illness.

1.3 Thesis and Hypothesis

The thesis of this study is that in comparison to the public, a more valid measurement of the stigma of mental illness can be determined from mental health service users and that it is essential to establish service users' perceptions of stigma as a basis for mental health promotion. This study also supports the notion that an aspect of stigmatisation is apparent in the over-reliance on public attitudes, which appear to further marginalise, an already discriminated group in society (SEU, 2004).

It can be seen that the dependence on public attitudes as a gauge of the stigma of mental illness, does not consider whether findings from a group of people, that do not have diagnoses and experiences of mental illness, can be deemed as the only valid measure of stigma. It should be evident that to measure the stigma attached to mental illness, people with mental illness must be directly involved, because they have living experience of mental illness and would be most likely to experience stigma as a result. In other words, research into stigma, which involves people with mental illness, can be likened to putting a finger on the 'pulse' of stigma, and arguably, that is where it is most likely to be felt and more accurately measured.

Hypothesis

'Higher levels of public attitudes should correlate with a lower perception of stigma amongst service users'. In attempting to address the thesis, the following four operational elements derived from the hypothesis were constructed:

- Service users' lived experiences of stigma will be the basis for designing a
 questionnaire aimed at measuring stigmatising attitudes and perceptions
 of stigma by both the public and service users.
- 2) The results from the attitude scale, for both the public and service users, will be compared for quantitative differences and correlates.
- To test the validity of comparisons, service users and public constructs of stigma will be explored for commonalities.
- 4) Findings from the quantitative, phenomenological experiences and constructs of stigma will be explored to establish corroboration.

1.4 The Concept Of Stigma

The term *Stizein* or Stigma came from the ancient Greeks who described it as a distinguishing mark burned or cut into the flesh of slaves or criminals so that others would know that they were less-valued members of society (Simon, 1992). The term *stizein* may not have been originally applied to mental illness, but stigmatising attitudes towards the mentally ill were apparent, even in early Greek society. For example, in 'The madness of Heracles', mental illness was associated with shame, lower social status and humiliation (Simon, 1992). In the seminal work, Goffman (1963) described stigma as a trait that was deeply discrediting and the stigmatised were spoiled by the effects of stigmatisation, which occurred through an interactive, social process.

Furthermore, Goffman's (1963) seminal work was based on symbolic interactionism, which suggested that we define or interpret each others' actions, instead of merely reacting to the actions, and therefore, responses are not made directly to the action, but to the meaning attached to such actions (Blumer, 1986). Thus, human interaction was seen to be mediated by the use of symbols, by interpretation, or by ascertaining the meaning of each others' actions, within a social context. Symbols and interpretation are an important notion to this study as they are the basis for perceptions of societal stigma and attitudes toward the mentally ill, and should become evident in personal constructions of stigma.

In addition, over the last decade, the concept of stigma has grown and broadened in scope, to include behaviours and reactions of the public as well as the attitude of the person who is stigmatised (Sayce, 1998). Even use of the term stigma has been challenged as to whether it is a beneficial concept for addressing the social exclusion and discrimination which people with a mental illness experience (Sayce, 2000). Of additional concern, was the inability of the construct of stigma, to elevate the status of groups that face discrimination, because it focused on the stigmatised (Oliver, 1992). Indeed, one criticism of Goffman's (1963) seminal work on stigma, was that it placed too much emphasis on individual perception and one to one interactions, instead of adopting a broader perspective to embrace what is seen as a universal pattern of discrimination against people with mental illness (Oliver, 1992).

It has been said that the concept of stigma, in itself, appears to be stigmatising, because it implies that something is wrong with the person, whereas the alternative concept of discrimination puts the onus where it belongs, on the individuals and groups that perceive differences and act with prejudice (Sayce, 1998). The body of evidence into public attitudes and stigma has not led to the development of effective models for change as stigma seems to attach itself to the person with mental illness. It has been suggested that discrimination results from the action of others, so the mark of shame, or stigma, should solely reside with those who behave unjustly, and not toward the people with mental illness (Sayce, 2000). It can be argued that the concept of stigma or discrimination may not encompass all aspects of the injustice against people with mental illness, but it is evident that whichever term is used, for a significant amount of people with mental illness, the consequences are the same, marginalisation and social exclusion (Bracken and Thomas, 2005).

Indications pointed to a danger that the word stigma, which originally meant a mark of disgrace on an individual, may keep a reflection on the psychological experience of individual shame and away from use of the term discrimination, as evident in social and economic patterns of exclusion (Oliver, 1992). It would appear that the use of the term discrimination, as opposed to stigma, moves away from an individualistic level and broadens the discourse to communities and indeed all of society. In other words, stigma was deemed to be an issue for all of society and not just people with a mental illness.

1.5 The Problems Associated With Stigma

There is a long established body of evidence, which suggests the mentally ill are stigmatised and regarded with fear and distrust by the general public (Nunnally, 1961; Brockington et al., 1993; Huxley, 1993; Ingamells, et al., 1996;

Wolff, et al., 1996; Angermeyer and Matschinger, 1997; ONS, 2007; ONS, 2008; Priory Group, 2007). Similarly, it was reported that people with mental illnesses were described by the public as being hard to talk to, different when compared to people without mental illness, unpredictable and dangerous (Crisp et al., 2000). Of note, in this study, the perception of differences between the public and people with mental illness was explored in the personal constructs of stigma.

It tends to be the case that the experience of stigma is common among people with mental illness (Polack, 1996; Jamison, 1998; Mason, 1998; Penn and Martin, 1998; Wahl, 1999). Furthermore, the community, friends, church members, co-workers and families were identified as sources of stigma for people with mental illness (Wahl, 1999). These identified sources of stigma by Wahl (1999) were significant to this study because they informed the development of its research tools.

The words schizophrenia and mental illness both appeared to be more than diagnostic categories, indicating a major complication of living with mental illness and its treatment and seemed to be negative and derisive (Finzen and Hoffmann-Richter, 1999). For example, mental illness is often portrayed as and associated with images of acting out, of violence, of incomprehensible, bizarre or contradictory behaviour and thinking. The metaphoric association of mental illness and schizophrenia are regarded by some, as an important part of stigmatisation (Gilman, 1982; Sartorius, 2002). Similarly, the words schizophrenia and mental illness were seen as metaphors of defamation, which violated the identity of people suffering from the illness (Goffman, 1968).

Stigma can generate a hidden burden to mental health sufferers which can result in barriers to mental health care, reluctance to seek appropriate care, delay in return to wellbeing and discrimination in the allocation of resources (Rosenfield, 1997). Again, even early studies suggested that stigma created a vicious cycle of alienation and discrimination that led to social isolation (Leary et al., 1991), the inability to work (Farina et al., 1971), excessive institutionalisation (Perese, 1997) and homelessness (Bachrach, 1992). Stigma is also seen as a factor in low self-esteem and depression (Link, 1987; Wahl & Lefkowits, 1989), reluctance to seek care and help (Ben-Noun, 1996), poor compliance with treatment plans (Lysaker et al., 1994), or even death (Anderson et al., 1991).

In addition, the impact of stigma on people with a mental illness includes distress, social exclusion, poor prospect of training for a job or hope of a future in meaningful employment, loneliness, loss of self-worth, sense of hopelessness, and in extreme cases deliberate self harm (SEU, 2004). Of equal importance, the discriminating effect of stigma may lead to marginalisation in society and the inability to engage as a full citizen, free of discrimination, exclusion and oppression (Bracken and Thomas, 2005). People with mental illness are amongst the most excluded groups in society (ONS, 2003).

It can also be seen that negative public attitudes toward people with mental illness impacted the rehabilitation of service users (Sokolove and Trimble, 1986; Lyons and McLoughlin, 2001). Consequently, it was found that psychiatric diagnoses caused patients to perceive themselves as different from others, and self-stigmatisation occurred (Gallo, 1994). It can be seen how the experience of stigma can have a dual impact, as a result of societal and self-stigma.

For instance, people with mental illness described their experience and view of stigma as feeling that all of society 'tarred' all the mentally ill people with the same brush and automatically assumed that they were all dangerous or were likely to cause embarrassing scenes (Baker, 2002). Further on, in the description of the experience of stigma, they reported that people stared at them as if he had a second head, while people they knew all their lives, physically avoided them once they knew that they had a mental illness and they were extremely nervous in their presence. They also felt extremely angry and helpless by this attitude because people would not enter into conversation with them.

Here it is seen how people with mental illness are able to give descriptions of experiences of what they perceive to be stigmatisation from the public. This study aims to collect similar evidence of lived experiences to compare service users' perceptions with public attitudes.

1.5.1 Professional Aspects Of Stigmatisation

Healthcare professionals may inadvertently stigmatise service users by their use of disempowering institutional practices, that can be manifested through defensive practices and paternalistic attitudes, which hinder service users' chances of social inclusion (Campbell, 1999). Mental health service users were often deemed to be different and seen to have different needs compared to other health service users (Fox, 1999), deemed as being unable to care for themselves, childlike in behaviour and in need of someone to make decisions on their behalf (Corrigan, 2000). In addition, it was argued that the psychology of the

environment on mental health units deprived service users of opportunities and resources to maintain their skills and abilities (Bassman, 2000).

Also, service users who had frequent admissions and discharges were stereotyped by healthcare professionals, and appeared to have an increasing degree of contact with mental health services and subsequently, less contact with friends and family (Corrigan, 2000). It appeared to be not only professional attitudes which impacted service users' perception of stigma, but also prolonged contact with mental health services. For example, frequent contact with deviant social networks exacerbated the experience of stigma and deviant social network contacts were a factor which contributed to the severity and rates of hospital admissions and usage (Pattison et al., 1975; Holmes-Eber and Riger, 1990). Indeed, the notion of an increasing experience of stigma through prolonged and frequent contact with mental health services and healthcare professions was of interest to this study, and explored by comparing service users' perceptions of stigma as a function of their length of contact with services.

Furthermore, minority groups experienced higher levels of stigmatisation from mental healthcare professionals and were more likely to be compulsorily detained under the Mental Health Act (1983) (Healthcare Commission Report, 2005). In addition, the experience of stigma was also influenced by the sex of the service user (DH, 2003), their sexuality (King and McKeown, 2003) and sensory or physical disability (DH, 2005).

The health inequality of mental health service users added to the social injustice and experience of stigma. It was seen that people with mental illness experience barriers and discrimination in accessing primary health care, had

higher rates of obesity, smoking, coronary heart disease, diabetes, hypertension, strokes and respiratory disease, were more likely to die at a younger age and had a life expectancy that was ten years less than the rest of the population (Herman, 2001). Moreover, mental health service users were seen to have an increased risk of disease, but a significantly high proportion of the illnesses were undetected by healthcare professionals (Phelan et al., 2001). However, this excess morbidity and mortality appeared to be easily modifiable through lifestyle changes, health promotion and the treatment of common diseases (Connolly and Kelly, 2005).

In addition, a cycle of stigma can occur in people who are becoming mentally ill and are afraid to come forward for early treatment because of fear, perceived stigma or even an actual experience of stigma, which can go on to have a negative impact on the course of their illness (Holmes-Eber and Riger, 1990; Ben-Noun, 1996). It can be seen that the delay in help-seeking behaviour impacted the period of recovery, increased the likelihood that the person was out of employment and diminished social contact (Pattison et al., 1975; Perucci and Targ, 1975). Likewise, professionals' attitudes can add to the perception of stigma, resulting in poor compliance with treatment regimes or premature discharge, which increases the risk of relapse (Lysaker et al., 1994).

In any case, a series of admissions and discharges can lead to revolving-door type of admissions and discharges (Rosenblatt, 1984), which can have the effect of reinforcing the notion that mental illness is difficult to treat, and reinforces the stigma of mental illness (Sartorius, 2002). As a result of stigma, there may be limited resources in mental health services, which limit available therapies for service users, resulting in lower quality care, which again, reinforces

stigma and develops a vicious circle of poor resources, poor treatment and outcomes and increased stigma (Sartorius, 2002).

For instance, there are psychological therapies such as Cognitive Behavioural Therapy [CBT] and Psychosocial Interventions [PSI] which are available from healthcare professionals. In addition, there are psychopharmacological advancements in medication, which have a lower side-effect profile than older drugs, and should facilitate better treatment outcomes and positively impact attitudes. Despite the range and advances in treatment, and like the asylum walls, negative attitudes and stigma persist in excluding a significant amount of people from society, in a subtle, effective manner (ONS, 2007; Priory Group, 2007).

1.6 Mental Health Policy

The closure of mental asylums and deinstitutionalisation in the UK does not appear to have had a positive impact on public attitudes and discrimination against people with a mental illness (ONS, 2007; Priory Group, 2007). For example, the move towards community treatment in the 1960's can be seen as a recapitulation of the notions of moral treatment of the early 19th century (Bair, 1982). Similarly, there were times in the cycle of care, when public interest in the mentally ill and health policy were at high levels, followed by subsequent backsliding and disillusionment as people with mental illness were forgotten, then re-discovered (Allderidge, 1979; Sayce, 2000).

Three of the main sources for professional guidance in mental health policy and practice are the Department of Health, the National Institute for Mental Health

in England [NIMHE] and the Nursing and Midwifery Council [NMC]. Over the last ten years these agencies have produced policies geared towards mental health promotion, which included 'National Service Frameworks' (DH, 1999), 'Saving Lives' (DH, 2000), Recovery (NIMHE, 2004) and 'The Chief Nursing officer's Review of Mental Health Nursing' (NMC, 2006). However, the increase in mental health policy appears to have had no impact on attitudes, which in evidence, has deteriorated over the past ten years (Priory Group, 2007; ONS, 2007; ONS, 2008).

Interestingly, contemporary public health policy recognised the social determinants of health, such as housing and employment and drew on research evidence to address the causes of illness, whether these causes were environmental or in people's behaviour (Ham, 1999). Of importance, current policy aims to improve the health of the population by increasing life expectancy, the number of years spent free from illness and 'improve the health of the worst off in society, to narrow the health gap' (DH, 2000: 5). However, there were no specific policies on mental health, except to reduce the number of suicides by a sixth (DH, 2000).

It was evident that health policy recognised the need to address causes of illness whether these were in people's behaviour, the environment (Ham, 1999) or in society (DH, 2000). Again, in the case of mental illness this can certainly mean addressing public attitudes and stigmatisation, since public attitudes have been identified as a factor which impacts on mental health (Lyons and McLoughlin, 2001).

Mental health policy proposed a national 'contract for health' involving the government, local communities and individuals, with an aim to develop a partnership to improve health (DH, 2000). The contract also suggested that people must ensure that their own actions do not harm the health of others. Indeed, the impact of stigmatising behaviour of the public comes into view, so the 'contract for health' can be seen as a mandate for addressing and minimising stigma, in order to improve the lives of people with mental illness.

From a mental health promotion perspective, the 'contract' has implications for both health care professionals and the public alike. The 'contract for health' suggests that professionals need to be aware of the impact of their interactions with service users, so that they do not convey or reinforce stigma and the public also need to be aware of how their attitudes may impact on people with mental illness. Likewise, the 'contract for health' (DH, 2000) is of particular relevance because evidence suggests that in relation to mental illness and stigma, the reaction and behaviour of others can impact people with mental illness (Janssen, 2003; Penn and Wykes, 2003).

On an epidemiological level, mental illness, including schizophrenia, represents a major public health concern, mainly because of its chronicity. Schizophrenia affects about one percent of any population (APA, 2000) and may occur in the late teenage years, so people with this condition can be disabled for fifty or more years with troubling symptoms and an experience of stigmatisation and discrimination (Lalani and London, 2006). Consequently, the long term and prolonged impact of mental illness suggests that there could be a significant number of people at risk of being stigmatised and marginalised. There are

implications and ramifications for the public regarding their role in the national 'contract for health', because their actions do harm the health of people with mental illness and also impacts their families and carers (SEU, 2004).

Furthermore, at the World Health Organisation [WHO] European Ministerial Conference on Mental Health, the Mental Health Declaration and Action Plan for Europe aimed to support the implementation of policies to improve mental health promotion, prevention, care and treatment (WHO, 2005). The WHO (2005) suggestions were of particular interest in view of stigma and are also encompassed in the UK National Service Framework for Mental Health (DH, 1999). The key factors include promoting mental well-being for all, demonstrating the centrality of mental health, tackling stigma and discrimination, preventing mental health problems and suicides, offering effective care in community-based services for people with severe mental health problems and creating a competent workforce (www.euro.who.int/mentalhealth/publications/20061124 1 accessed 28-03-2008).

It can be seen that there was an increasing amount of health policy aimed at challenging stigma and discrimination, in combination with an increasing notion of people formerly known as mental patients being transformed to service users and stakeholders. The emphasis on promotion raised the profile and status of people with mental illness. In addition, the focus on stigma and service users was given further impetus by the 'contract for health' (DH, 2000). As a result, service users were transformed to the position of an empowered group, with the ability to lobby and play an active role in service delivery and configuration. However, the health policy emphasis on de-stigmatisation and the enhanced status of service

users appeared to have made no positive impact on public attitudes (ONS, 2007; ONS, 2008; Priory Group, 2007).

The following section will explore issues which attempted to minimise stigma, and in so doing, contributed to the transformation of people with mental illness, from mental health patients to the prominence of service user. These issues were seen to be key to the empowered status of the service user, and prominent in recognising the need for de-stigmatisation and user involvement in services.

1.7 From Mental Health Patients to Service Users

The closure of asylums and the subsequent alleged failure of care in the community combined with consumer approaches to health care gave rise to the service user movement, which was observed to be a large and growing force (Everett 1994; Campbell, 1996). In any case, what started out as anti-psychiatry was transformed to an ex-patient, consumerist coalition, fighting against pharmacological treatment, coercive hospitalisation and other authoritarian practices (Rissmiller and Rissmiller, 2006).

As a result of the anti-psychiatry movement, there were now patients' councils, advocacy groups and service user involvement which came to be both an expectation and a demand, by users and service providers. Also, use of the term 'service user' was challenged by people with mental illness, who preferred to be seen and called survivors, with reference to having been through the psychiatric system (Stickley, 2006).

It can be seen that this study used the term 'service user' to refer to people who receive treatment and care from mental health services, or in other words, people who use mental health services, but it did not intend to, nor aimed to attribute or contribute towards a collective identity for this group of people, who may not choose to be referred to as service users. Indeed, the term service user is a reflection of the active role of people with mental illness, and describes an empowered, active participant in their own care.

It was argued that the adoption of consumerism in 1980's National Health Service [NHS] heath policy transformed people with mental health problems into consumers, at a time when the social and political climate favoured and gave a voice to service users (Croft and Beresford, 1992). Likewise, in the National Service Framework, service users' involvement was valued (DH, 1999). However, in practice, user involvement can be passive or tokenistic as opposed to being a meaningful collaboration and partnership between mental health service users and healthcare professionals, involved in delivering a user-led service.

Despite recommendations, there was resistance to service user involvement in nurse education, which was probably related to stigma (English National Board for Nursing and Midwifery [ENB], 1996; Stickley and Felton, 2004). For example, one shortfall existed in failing to meet the initial requirement for educational institutes to involve service users and carers when designing and delivering training programmes, and in research (ENB, 1996). Apparently, the evidence for user involvement in nurse training curricula was difficult to realise, despite the publication of guidance regarding user involvement in research, there was only limited available information about how the process of user involvement

worked in practice (Consumers in NHS Research Support Unit, 1999, 2000). Furthermore, even less evidence was available regarding the philosophical, conceptual and practical challenges of mental health service users' involvement (Premila and Wykes, 2002).

In addition, there was little evidence on the challenges and the degree of user involvement, and when translated into the arena of mental health research, meant that user involvement was specially challenging, particularly in light of the vast imbalance of power which existed between service users and health care professionals (Beresford and Wallcroft, 1997; Lindlow, 2001). Consequently, it was proposed that power was so entrenched in mental health services that working in partnership with service users may never be possible (Coleman and Harding, 2004).

A service user attending committee meetings can be isolated and excluded and feel that participation is tokenistic (Read, 2001). In a tokenistic system, service users can be disempowered, while professional power is protected, and this can reinforce the power of psychiatry as the dominant discourse in mental health (Link and Phelan, 1999; Barnes and Bowl, 2001). Likewise, the mechanisms, employed by those in positions of power, to promote user involvement within the powerful psychiatric system, is the same system which will persist to maintain overall control, and user involvement may be transformed to a structure which perpetuates the power of psychiatry, because it is designed and operated by the same, more powerful, dominant social forces (Link and Phelan, 1999; Stickley (2006).

Mental health service users and survivor groups have challenged the positivistic, medically-led, disease paradigm of psychiatric disorders, which emerged from psychiatry and clinical psychology (Corrigan and Penn, 1997). In the medical model of mental illness, there is a tendency to reduce mental illness into classifications, clusters of symptoms and dysfunctions, and a focus on biological factors which affect the course and treatment of mental illness (Barker, 2000). Here it can be seen that the medical model of mental illness, as opposed to the discrimination model (Sayce, 2000), does not incorporate the impact of stigma and lived experience, which were valued by users and survivors of mental health services (Corrigan, 2005).

Evidence in support of the discrimination model of mental illness proposed a phenomenological approach to the understanding of the stigma of mental illness, because the lived experiences of people with mental illness bring special insight and understanding of stigma and mental illness (Rapp et al., 1993; Rogers and Palmer-Erbs, 1994). It can be seen that the insights of people with mental illness are essential and vital in facilitating an understanding of self and illness, and any attempt to exclude their perspective from the discourse, would be omitting a very large and essential body of evidence. In support, it was suggested that the most authentic evidence on mental illness emanated from research involving people with a diagnosed mental illness, because their lived experiences were free from the object of theory, research, or the clinical gaze which tended to pathologise experiences of mental illness (King (2007).

In reconciling lived experience of mental illness into the discrimination model, service users have developed an interest in the concept of 'recovery'

because it is user-led and an alternative to psychiatry, which was seen to be stigmatising (NIMHE, 2004). Indeed, service users have engaged with the principles of recovery because it challenged the stigmatised view of mental illness and offered hope of an acceptable level of living, involved internal factors such as insight into the need to change, external factors such as interconnectedness and stigma, support from family and friends, empowerment and self-managed mental health care (NIMHE, 2004).

It can be seen that service users' views matter on moral grounds, because they are a vulnerable group, and if best treatment and interventions for the mentally ill are the aims, then their views and insight can be valuable in partnership and building the evidence base (Edwards, 2000). In addition, it is empowering to involve service users in their own care because this shifts the paradigm from service users being seen as 'objects of care' to having meaningful participation in services, education and in research.

There was an emphasis on user involvement and the need for phenomenological approaches to bring lived experience into the discourse on stigma and attitudes, to understand the service user perspective and to cater for their needs when attempting to minimise the stigma of mental illness (Rapp et al., 1993; Rogers and Palmer-Erbs, 1994; King, 2007). In this study it will become evident that it was recognition of the need to incorporate service users' lived experience, insight and understanding of stigma into the evidence base which shaped the approach to this research.

1.8 Mental Health Promotion

Mental health policy focused primarily on mental health promotion through the reduction of the associated stigma and discrimination (NSF, 1999; WHO, 2005) but appeared to be directed towards people with mental illness, as opposed to all of society. The nature of mental illness and stigma is relevant to all of society because of the way our actions could affect others and the subsequent impact on social capital DH, 2000).

Mental health is defined as the emotional resilience which enables us to enjoy life and to survive pain, disappointment and sadness, is a positive sense of wellbeing and an underlying belief in our own, and others' dignity and worth (Health Education Authority, 1997) and is deemed an essential prerequisite for meaningful quality of life and active citizenship (World Health Organisation [WHO], 2005). Mental health impacts on our ability to manage, to interact and to form and sustain relationships and there are ramifications for management of change and dealing with stressful life events. Thought processes and feelings have a strong effect on physical health, and on mental health, which may have the most significant impact on health (www.tameside.gov.uk accessed 30-01-2008). Here, in the definitions, mental health is seen as being central to citizenship (WHO, 2005), so people who are mentally ill, discriminated against and stigmatised, can lose 'citizenship' by being isolated and socially excluded (Bracken and Thomas, 2005).

Mental health needs are universal, and are met or not met in social settings, such as at home, in schools, at work and neighbourhoods, where people can feel respected, included and safe (SEU, 2003). Through stigmatisation, the

mentally ill can be on the margins of society, living in fear and social exclusion. If mental health needs are the same for all of society, then it may be stigma which draws the line between the public and people with mental illness, who are also often socially excluded (SEU, 2004). The aims of mental health promotion are to increase psychological well-being, competence, resilience and to promote positive mental health by creating supportive living conditions and environs for all of society (WHO, 2004). It follows that there needs to be public action, so that the environment for people with mental illness is one which is free of stigma and discrimination.

In addition, mental health should be central to public health policies and promoted via stigma reduction, a competent workforce, access to services and prevention of mental health problems and suicide (WHO, 2005). However, as mentioned earlier, this approach seems to have a focus on mental illness rather than on mental health and there is a tendency to view mental health as the absence of mental illness. It can be argued that there are only artificial differences between mental health promotion and promoting physical health. Therefore, mental health promotion and physical health promotion should be deemed total health promotion (Seedhouse, 2002).

In contention, terms like 'well-being' and 'capacity to cope' regarding mental health promotion shifts the target from organisations and communities to individuals within the community rather than mental health of the community (Mentality, 2003). The emphasis of mental health promotion with a focus on individuals detracts from the argument that to achieve a mentally healthy society, is to address human development within the social and economic determinants of

health, and what is deemed as indirect actions, such as tackling poverty, improving housing and public transport, have a positive impact on mental well-being (WHO, 2004; Cattan and Tilford, 2006). In addition, the close association between health, mental health and social capital, implies that mental health promotion can have a positive impact on social capital and social justice for all of society (Cattan and Tilford, 2006).

In the concept of social capital, relationships amongst society matters, and social networks are valuable to all of society because interactions help people to 'build communities, commit themselves to each other, 'knit the social fabric' and society benefits through everyone having a sense of belonging, social networks and notions of trust and tolerance which are all central to the process (Beem, 1999: 20). In addition, these relationships and interconnections are valuable as they then grow to become values and expectations within a society.

Likewise, building social capital is beneficial in greasing the wheels which advance social interaction in communities, in helping communities to resolve collective problems more easily and by increasing awareness of diverse ways in which fates are linked (Putnam, 2000). Furthermore, when societal connections are lacking, people are unable to test whether their views are logical in casual or formal conversations, and as a result, are more likely to be swayed by prejudices (Beem, 1999). The lack of connections in society can be extrapolated to mental health service users and the public, wherein there may not be much interaction between these two groups, which can serve to reinforce perceived differences. The notion for society to build social capital is also central to removing social

injustice and structural barriers, such as stigma, which separate people with mental illness from society.

The need for promoting mental health is essential because it is seen how inequalities can impact on people with mental illness with subsequent shorter life expectancy and reduced life chances (Herman, 2001). Many people with a mental illness also lack the opportunity to make an economic contribution, partake fully in family life or be part of their community (SEU, 2004). The evidence suggests that as a result of stigma many people with mental illness lose citizenship (Bracken and Thomas, 2005) which impacts social inclusion with ramifications for diminished social capital.

1.9 The Importance and Significance of This Study

Evidence suggests that among adults with mental illness, many of them wanted to work, and two-thirds of men under the age of thirty-five who die by suicide were unemployed (DH, 2001). Regarding the financial impact, the cost of mental illness was estimated at £77 billion a year through the cost of care, economic loss and premature death and mental illness for an individual has a wider impact on the lives of family and friends (Sainsbury Centre for Mental Health [SCMH], (2003). Over 900,000 adults in England claimed sickness and disability benefits for mental illness and this was larger than the total number of people claiming Jobseekers Allowance in England (ONS, 2004).

Of greater concern, stigma and discrimination were seen to be pervasive and despite a number of campaigns, there had been no significant positive change in public attitudes (ONS, 2003b; 2007; 2008). Furthermore, there was a

decrease in positive attitudes over the past thirteen years and younger people were less tolerant in their attitudes compared to older respondents (ONS, 2007). Likewise, seventy-two percent of adults in Great Britain associated stigma with mental illness and described people with mental illness as unpredictable, dangerous and scary (ONS, 2008; Priory Group, 2007). In addition, there was a seventy-five percent consensus that the media did not do a good job in educating people about mental illness or at de-stigmatising mental illness (Priory Group, 2007). Many people feared disclosing their mental illness, even to family and friends (SEU, 2004) and fewer than four in ten employers said they would hire someone who had a mental illness (Manning and White, 1995; SEU, 2004).

A significant number of people with mental illness faced barriers in engaging with the community and had difficulty in accessing services, such as, in housing and transport, education, sports and leisure (SEU, 2004). Also, healthcare professionals can have low expectations of what people with mental health problems can achieve and there appeared to be limited recognition that returning to work and overcoming social exclusion was associated with better outcomes for the mentally ill (SEU, 2004). As a matter of fact, stigma and discrimination were key factors in social exclusion of the mentally ill and played a key role in reinforcing self-stigma (SCMH, 2003).

It has been shown, that public attitudes and acceptance has a direct relationship with the successful rehabilitation of the mentally ill (Sokolove and Trimble, 1986; Lyons and McLoughlin, 2001). But, on a broader level, it may also be that shared beliefs of the public concerning the nature of mental illness had considerable significance for mental health promotion.

However, in order to de-stigmatise mental illness, it is important to establish baseline knowledge of attitudes to mental illness and acknowledge and understand the basis of existing views. In fact, learning how people perceive and understand the concept of mental illness is vital before embarking on any health promotion initiative, which aims to facilitate more positive attitudes.

Furthermore, it was recognised that whilst one of the aims of care of the mentally ill in the community was to reduce the social distance between the public and people with mental illness, very few attempts had been made to investigate public attitudes and opinions and there was a dearth of research involving service users and even less about their perception of stigma (Reda, 1996). It follows, that if the mentally ill are to be fully integrated into society, attitudes towards mental illness must be explored via research, prior to attempts to modify these attitudes, and certainly before appropriate interventions aimed at mental health promotion.

There was evidence which recognised the importance of service users' perspective, identified the challenge in hearing the voice of the ultimate consumers of mental health services and suggested that health care should be measured by the way it is perceived by users (Department of Health and Social Services [DHSS], 1983). Similarly, there is also a moral reason for service user involvement, because they are disabled by their illness and are a vulnerable group (Edwards, 2000). It then follows that in order to improve services, the views of service users must be considered as these can also be valid measures of the efficacy of interventions.

Accordingly, the key factors which drive and justify this study are seen within health policy, including recommendation for service user involvement in

research, consumerism and indeed from the socio-political impact of stigma. There appears to be increasing amounts of policies with emphasis on destigmatisation, yet no apparent impact on stigma (ONS, 2008).

In summary, this study's hypothesis suggests that higher levels of positive public attitudes should correlate with lower levels of stigma amongst service users. This study will aim to identify service users' perspectives on stigma and their position within the evidence base on the stigma of mental illness. The study will compare public attitudes with the perception of stigma amongst mental health service users, explore factors which impact their perception of stigma and draw inferences and conclusions from the results.

CHAPTER TWO: LITERATURE REVIEW.

The literature on stigma as a general concept is extensive, and expands to encompass a wide range of phenomena. Also, the notion of stigma can be applied to an ever growing number of situations, to the point where there is so much scope that it cannot hold its core (Weiss and Ramakrishna, 2001). In other words, stigma is deemed to be an inflated concept and this idea is well summed up in the following quote;

'Stigma is creaking under the burden of explaining a series of disparate, complex and unrelated processes to such an extent that use of the term is in danger of obscuring as much as it enlightens' (Prior et al., 2003).

Stigma is a complex construct with both sociological and psychological theories on its origins and there was no consensus on stigma or the mechanism of stigmatisation, which renders the concept of stigma as being nebulous and therefore particularly challenging (Haghighat, 2001). For example, a sociopsychological viewpoint on stigma distinguishes between stereotyping, prejudice and discrimination (Fiske, 1998), while from a psychological perspective stigma possesses cognitive, affective and behavioural components (Ottati et al., 2005). Moreover, in the sociological approach there appears to be consensus in supporting Goffman's (1963) idea of stigma as being a discrediting attribute for deviants, a notion which is not apparent in the psychological aspect (Markowitz, 2005).

Nevertheless, different theories each offer a perspective on stigma, suggesting that there is no single theory of stigma, because it is a complex interaction between social science, politics, history, psychology, medicine and anthropology (Smith, 2002). However, there were indicators of stigma, which pointed to its social origins and certain factors which perpetuated. Furthermore, there appears to be some limited consensus on the different theories on stigma, which focuses on stigma as an innate human predisposition to notice difference, the perception of difference and the dependence on predictable behaviour for safety and functioning (Smith, 2002).

This chapter explores the conceptual literature on stigma and factors in the social construction of stigmatisation, in addition to research evidence on various aspects of the stigmatisation of people with mental illness. It also examines the seminal work of Goffman (1963) regarding types of stigma, recognition and reaction and the management of stigma. In attempting to determine if the stigma of mental illness is apparent in different cultures, attention is paid to the cultural aspect of stigma. Because of the complexity of the concept of stigma, this literature review will be presented as follows:

Section (A) This section reviews the conceptual literature and theories of stigma.

Section (B) This section reviews research studies on public attitudes and the stigmatisation of people with mental illness.

The first section of the literature review endeavours to explore and understand the concept of stigma and stigmatisation from different perspectives and seeks to establish factors and mechanisms which contribute to and perpetuate the stigma attached to mental illness. The second section of the literature review explores research studies on public attitudes toward mental illness and the mentally ill and service users' perception of stigma. In this approach, any identified psychology, theories and mechanisms in stigmatisation can be observed to establish if they were apparent in the stigmatisation of people with mental illness. The findings from the literature review will be used to develop a conceptual model of stigmatisation of people with mental illness, for this study.

A poignant discovery in the evidence on stigma revealed that the concept of social distance, which refers to the perceived distance between individuals or groups through discrimination, was always closely linked with stigma and attitudes, so it was included as a key search term, deserved and is given attention in section 2.2.1, on social distance and attitudes.

2.1. Method Used In The Literature Review

As used in the published literature, the terms stigma, discrimination and attitude are used interchangeably throughout this study and all refer to negative attitudes towards the mentally ill and mental illness.

2.1.1. Literature Review Questions

The questions generated to guide the literature review were as follows.

What does the literature suggest regarding attitudes toward mental illness?

What are the factors that affect attitudes to the mentally ill?

What does the literature suggest regarding service users' perception of stigma?

What are the theories that support stigmatisation?

What factors are identified in stigmatisation of the mentally ill?

What are the manifestations of stigma in society?

How do service users manage and cope with stigma?

Is the stigma of mental illness a common concept within and between different cultures?

2.1.2. Inclusion Criteria

Published literature was eligible for this study if the following criteria were met.

- Pertinent to public attitudes toward mental illness or the stigma of mental illness.
- Written in or translated into English.
- Empirical or phenomenological in design.
- Evaluated public attitudes to mental illness, or social distance from expsychiatric patients or people with mental illness.
- Examined public knowledge and attitudes towards mental illness.
- Explored opinions and demographic variables in stigmatisation.
- Explored lived experience of stigmatisation.
- Explored factors which impacted on 'Care in the community'
- Assessed changes in attitudes towards mental illness, over time.

Studies done over the past sixty years were considered because of a sparcity of relevant articles on stigma and mental illness. Also, the published research studies appeared to follow a pattern of social interest in stigma and people with mental illness. Interestingly, most of the pertinent studies on stigma and attitudes

were carried out between 1950 and 1970, then there was a gap up to the early 1990s (Hayward and Bright, 1997; Angermeyer and Matschinger, 2006). It can be argued that the resurgence of interest in the 1990s was influenced by the large scale closure of asylums and subsequent community care of former mental health patients (Ingammells et al., 1996).

2.1.3. Searching For Literature

Searching for literature involved on-line CD-ROM and database searches and the use of internet search engines. In addition some were found through serendipity. Studies were selected on the basis of information given in the abstract, and on obtaining these studies, their reference lists were used to further identify articles. This led to a further focus on areas where the literature and debates were critical to the area of inquiry.

The conceptual literature on stigma was also derived from searching for literature, in addition to seminal studies, lectures, reference lists of journal articles, books and discussions with academics and guidance from the supervisor of this project. Later on, some of the seminal literature emerged as being strategic and was helpful in contributing to the development of the methodology of this study.

2.1.4. Databases Accessed

The following databases were searched; Medline Cinahal, Clin-Psych, Psych-Lit, Psych-Info and the Cochrane Database. The following on-line searches were made, Ovid Technologies via Athens, The British Medical Journal,

The British Journal of Psychiatry, The International Journal of Social Psychiatry, KA24HILO (the National Health Service health Information for London), The Lancet, The Schizophrenia homepage, The National Institute of Mental Health and Google Advanced Searches.

2.1.5. Key-Words and Phrases Used in Searches

The following words and phrases were used in various combinations in searching for literature:-

Opinion or belief, attitude or social distance or public attitudes, mental illness or mental disorder or schizophrenia or psychiatric disorder or community orientated treatment or care in the community or stigma, service user or patient or ex-patient or ex-psychiatric patient or consumer.

2.1.6. Critical Appraisal of Studies

Studies were reviewed by the use of the Smith and Stullenbarger (1991) model for integrative review and meta-analysis in tandem with Cormack's (2000) 'questions to ask on each section of a research paper' (see appendix iv & ivb). These tools provided a systematic approach to reviewing empirical research and used a quantifiable scale to weigh articles. These tools were used to rate the methodology, sample population, data and statistical analyses, limitations and relevant outcomes in the studies. The evaluative scores of the studies, e.g. 2.5, indicate that twenty-five items were satisfied. The highest possible score of three indicate high quality, whereas zero indicated the lowest quality. Studies with scores of less that 1.0 or10 items were omitted.

Section A: Concepts And Theories Of Stigma

2.2 Stigma and Attitudes

The word stigma is derived from the Greek for a mark branded on a slave or criminal, but is now used to describe a stain on a person's good name (White, 1998). Initially, the sign of stigma was a brand or scar burned or cut into the body, which signified that the bearer was a slave, criminal or a traitor or someone to be avoided (Goffman, 1963; Clausen, 1981). However, later on, the term stigma was used to signify the disgrace itself, rather than the physical sign. Furthermore, it was suggested that a person who was stigmatised was perceived to possess a deviation from the expected norm of a social unit, a norm being a shared belief that a person ought to behave in a certain way at a certain time, which results in a reduction of the individual from wholeness to someone who was now a tainted, discredited person (Goffman, 1963; Clausen, 1981).

Stigma was seen as a relationship between an attribute and a stereotype that linked a person to undesirable characteristics, which manifested in social interactions (Goffman, 1963), but this notion of stigma does not take into account the impact of power differences, for example, between service users and professionals or the public. It can be seen that Goffman's (1963) view of stigma does not give much attention to inequalities between social groups, status and social class, as factors in stigmatisation. In any case, there is a need to understand underlying reasons why many people with mental illness can be significantly affected by stigma.

Stigmatisation of people with mental illness occurs through interactive social processes and in a manner that can be deeply discrediting to people who

are stigmatised (Link and Phelan (2001). Again, the evidence suggests that as a result of stigma, people with mental illness, and more so, a severe mental illness such as schizophrenia, are often deemed to be less valued members of society, and are often socially excluded (Porter, 2004; SEU, 2004).

For example, if as a result of stigma, people with mental illness are deemed to be unpredictable and dangerous, then people who might attribute stigma may avoid social contact with the mentally ill and discriminate against them, in ways such as, not engaging with them in conversation or denying them access to housing and employment (SEU, 2004).

The evidence deems stigma as deviance which gives rise to inequalities between social groups, and interactive social processes create social distance between people with mental illness and the public, which can lead to social exclusion (Link and Phelan, 2001; SEU, 2004).

2.2.1 Social Distance And Attitudes Toward Mental Illness

A common concept in attitude and stigma research is that of social distance which indicates perceived levels of or desired contact between the public and people with mental illness. Social distance was not explored in this study, but it is an important concept in trying to understand the notion of public stigma. Of note, London and Garman (2007) found that people who had contact with the mentally ill, such as carers, spouses and significant others, had better knowledge of mental illness and scored higher on the 'Community Attitude towards Mental Illness' scale, (Taylor & Dear, 1981), which indicated more positive attitudes than subjects who did not know or socialised with people who had mental illness.

There is conflicting evidence, as to whether contact with the mentally ill reduces stigma, and research showed any form of social contact with the mentally ill, whether self-instigated or not, reduced stigma (Link and Cullen, 1986; Penn et al., 1994). In addition, it was found that people who personally knew someone who attended a psychiatric clinic had more positive attitudes towards mental illness (Huxley, 1993).

The idea that contact between people with mental illness and the public reduces stigma, known as the 'contact hypothesis' is supported (Trute and Loewen, 1978; Roman and Floyd, 1981). However, there is evidence to the contrary which showed no difference between the attitudes of family members who had a psychiatric patient in the family and those without (Arkar and Eker, 1992).

On a prima facie level, it would appear that, on its own, contact with mentally ill patients may not be a sufficient condition for attitude change, if there is no motivation on the part of the public to initiate interactions with people who are known to have a mental illness. However, it was suggested that a critical factor in the contact hypothesis may be the introduction of the mentally ill in a role that can be perceived as representing normal behaviour (Johannsen, 2003). Therefore, in building on the previous argument, if the public are motivated to improve attitudes toward the mentally ill and meet people with mental illness on an equal-status basis, then personal experience and contact may consistently result in more positively expressed attitudes.

On the other hand, the attitudes of mental health professionals, who obviously have more contact with the mentally ill, were found to be less optimistic

about prognosis and less positive about long term outcomes, when compared with the public (Hugo, 2001). It can be argued that professional attitudes were realistic and based on real-life and personal experience of working with service users, who often presented at an acute phase of illness or were long-term service users. In spite of this, professionals may also have developed a biased view of service users' potential.

Indeed, both knowledge of mental illness and contact with service users were deemed to be factors which positively impact attitudes (Brockington et al., 1993; Huxley, 1993). But, it would appear that the quality and depth of professional therapeutic engagement or their contact with the mentally ill, needs further exploration. It is also possible that professional contact with service users is mediated by a power imbalance and therefore may not be one of equal status or partnership, which can serve to exacerbate the experience of stigma amongst service users (Link and Phelan, 1999). This study is also interested in determining not only if the alleged power imbalance between professionals and service users impact service users' experience of stigma, but also its significance and ramifications.

In addition, studies on social distance show inconsistency in support for the contact hypothesis (Trute and Loewen, 1978; Roman and Floyd, 1981; Link and Cullen, 1986; Arkar and Eker, 1992; Huxley, 1993; Penn et al., 1994). Also, there may be confounding variables that contribute to the difference in results. However, given the current level of knowledge in this area of research, it is not possible to be certain of their impact. For example, one factor that may possibly affect the results of these studies is the operationalisation of the term social

distance or contact with the mentally ill. Other factors may include family burden, the collective coping skills of family members, support networks, professional help and the severity of the presenting illness, all of which are aspects that can affect results.

Despite the absence of consensus on the contact hypothesis, it was demonstrated that improvements in public attitudes following equal-status, cooperative contact with service users, occurred under defined conditions (Desforges et al., 1991). Thus, it appears that a general approach to research in support of the contact hypothesis, which does not focus on the specifics and nature of the contact between service users and the public, and the environment in which this is occurring, may not make a significant contribution to the discourse.

In agreement, it was found that contact between people who have a mental illness and members of the public may foster more positive attitudes, but contact between these two groups may not be forthcoming if there is a lack of knowledge about mental illness, which can perpetuate fear and maintain stigmatising attitudes (Brockington et al., 1993). So, it would appear that contact between people with mental illness and the public would provide opportunity for communication and has the potential for improving public attitudes.

2.3 The Concept Of Stigma

In one perspective, stigma was viewed as being composed of four distinct elements. In the first element, individual differences are distinguished and labelled. In the second element, cultural beliefs link labelled individuals to undesirable characteristics and negative stereotypes. In the third element, labelled individuals are placed in distinct categories so as to separate 'us' from 'them'. In the fourth element, labelled individuals experience loss of status and discrimination which leads to social exclusion (Link and Phelan, 2001). This view of stigma built on Goffman's (1963) idea, by adding that stigmatisation was contingent upon access to social, political and economic power which allowed the identification of differences, the construction of stereotypes, the separation of labelled individuals and discrimination.

Furthermore, this notion of stigma encompasses the understanding of stigma as defined by Goffman (1963) in that characteristics of the out-group are socially undesirable and its members acquire a spoilt identity which leads to devaluation and discrimination. Again, Link and Phelan (2001) reaffirm Goffman's (1963) seminal concept, wherein stigma is seen as more than an attribute, since it represents a relationship that ascribes deviance to the labelled and normalcy to the labeller.

Of significance, in Link and Phelan's (2001) model there is no differentiation between stigma and discrimination and stigma is identified only if it leads to discrimination. However, use of the word discrimination, which may better describe the process of stigmatisation, and used to define both the personal experience of being labelled and the act of being discriminated against, is favoured (Sayce, 1998). Indeed, a combination of Sayce (1998) and Link and

Phelan (2001) shows how discrimination can be used as an umbrella concept of stigma because it involves identification and labelling of differences, ascribing negative values to some types of differences and exercising social injustice via social and economic power. In like manner, the word discrimination can be of use in highlighting the social injustice against the mentally ill, putting stigma on the social agenda and facilitating change. However, for many people with mental illness, whether the term stigma or discrimination is used, the implications can be the same, and as recent evidence suggests, their perceptions and experiences of stigma or discrimination continue (Priory Group, 2007; ONS, 2007; ONS, 2008).

2.3.1 Alternative Views of Stigma

More recent views have used the term stigma in a wider sense, to refer to the reactions of other people, and to include the attitude and behaviour of both the victim and the perpetrator of stigma (Oliver, 1992; Sayce, 2000).

The concept of stigma was challenged as to whether it was the most useful paradigm for discussing the negative effects of having a psychiatric diagnosis or record. Likewise, it was argued that stigma may not be an appropriate metaphor to describe what happens to people with mental illness in social interactions. However, people with mental illness have not found stigma to be a useful concept, because it retains Goffman's (1963) idea of an individualistic approach, with a focus on the discredited and the discreditable (Oliver, 1992). In addition, it was suggested that Goffman's (1963) work on stigma was a focus on self-perception and micro-level interpersonal interactions, rather than one which

addressed widespread and patterned exclusion of the mentally ill, from economic and social life (Oliver, 1992).

Similar objections noted that user and survivor groups of people with mental illness found that the concept of stigma, which was linked with the brain-disease, medical model of mental illness, was detrimental to self-esteem, reduced lives to diagnostic terminology and lessened their capacity for recovery from mental illness (Campbell, 1992; O'Hagan, 1992). It can also be seen in one argument that the notion of presenting the public with a medical model of mental illness, which suggests that deviant behaviour is related to a diseased brain, has not been generally accepted (Hill and Bale, 1981). A further contention proposed that public rejection of the medical model of mental illness created the image of a phenomenon over which afflicted individuals had no control, and this rendered their deviant behaviour as being obviously, unpredictable (Hill and Bale, 1981).

Furthermore, it was highlighted that the concept of stigma is itself stigmatising because it implies that something is wrong with the person being stigmatised, whereas use of the word discrimination puts the onus where it belongs, on the individuals and groups that are discriminating against the mentally ill (Chamberlin, 1998; Sayce 1998).

It was concluded that the body of evidence into public attitudes and stigma has not led to the development of effective models for social change, noting that stigma appeared to attach itself to the person with mental illness, whereas discrimination resulted from the action of others, so the mark of shame should reside with those who behave unjustly, not on the person with a mental illness

(Sayce, 1998). There were indications of danger in use of the word stigma, which originally meant a mark of disgrace on an individual, in that it may keep a focus on individual psychological experiences of shame. Also, it would appear that use of the term discrimination, prevents the discourse on stigma from moving imperceptibly into discussions of individual experiences of service users in a vacuum (Sayce, 2000).

It can be seen that use of the term discrimination appears to be a better term both in directing action for change and targeting relevant social groups. On the other hand, discrimination can be seen as a general term and can point to racial, sexual, sexual orientation or ageist aspects. However, the term stigma, at least from the time of Goffman's (1963) seminal work, has been used extensively in the western world. Again, despite the nuances in the concept of stigma in the sociological, psychological and anthropological discourses, its use is helpful, because it highlights specific issues of discrimination, social injustice and social exclusion for people with mental illness.

A further challenge to the stigma concept asserted that with the closure of asylums there was also a paradigm shift in the approach to mental health care. In fact, psychiatry was based in institutional care, but the arrival of deinstitutionalisation and community care challenged the legitimacy of psychiatry and its bio-medical approach to mental illness, and in any event, institutional approaches to care, such as those used in asylums, could not be extrapolated to care in the community (Owens, 2004). Another factor which challenged the concept of stigma came in the form of consumerism which created opportunities for growth of the mental health user-survivor movements, and in combination with

hostility from service users toward the use of treatments such as electroconvulsive therapy, major tranquilisers and mental health laws to detain people without trial, the profile and cause of service users grew (Pilgrim and Waldron, 1998).

For example, user and survivor groups, such as 'Mad Pride', focused on celebrating difference and saw madness as a basic feature of life, one which is sometimes painful, but one which can also be a source of creative and spiritual insight and renewal. On the contrary, 'Mad Pride' does not accept psychiatry's attempts to medicalise madness, and view psychiatry as oppressive and dehumanising (Bracken and Thomas, 2005). Similarly, Mad Pride and other mental health user and survivor groups aspire towards full citizenship for the mentally ill and see their goal as one which requires more than just the removal of stigma, but also includes autonomy in defining themselves and setting and following their own agendas (Bracken and Thomas, 2005).

Likewise, the 'disability inclusion' model takes an alternative view of stigma by focusing on the removal of the discrimination and stigma faced by people with a mental illness in subscribing to the social model of disability. The 'disability inclusion' model views people as being disabled, not only by their impairment, be it physical or mental, but also by the hurdles and negative attitudes that society place in their way. The social model of disability incorporated the idea that it was only the barriers and attitudes erected by society that cause people to be disabled. For example, societal barriers are well described by one activist who acknowledged that being without legs was not a

problem for him, but problems arose because society denied him equal access, because of attitudes and the way buildings were constructed (Sayce, 2000).

It can be seen that mental health advocacy groups were concerned about the weakness in the use of the stigma construct as a catalyst for a change in attitudes, to redefine discrimination against their disability or to celebrate their difference. In addition, the medical model and social model appear to have shortcomings in meeting the needs of people with mental illness and to describe their unfavourable experiences.

In any case, some mental health user and survivor groups may be reluctant to embrace the disability inclusion model because they may view mental distress as being different to a disability (Bracken and Thomas, 2005). For example, Sayce (1998) suggested that user and survivor groups' rejection of the idea of describing mental illness as a disability, may lie in the fact that mental illness is not a tangible impairment, or something that one is born with, as compared to what is common in some disabilities, and to the contrary, a significant amount of people who are mentally ill do recover and survive mental illness. Likewise, it is common among mental health user and survivor groups to view the stigma of mental illness as a social injustice, in a similar manner to other forms of prejudice and discrimination, such as racism (Corrigan, 2005).

It is important to note that later concepts of stigma, such as Sayce (2000) and Oliver (1992), attempted to converge on the notion of discrimination, to try and identify both society and people with mental illness as having stigma. It would also appear that the seminal and subsequent writings on stigma were not intended to bring about social change, but served to highlight the situation of

people with mental illness. However, despite terminology, both stigma and discrimination have the same implications and ramifications for people with mental illness, namely loss of status and social exclusion (SEU, 2004).

2.3.2 Self-Stigma

It was asserted that as a result of the discrimination and stigma experienced by people with mental illness, a paradoxical situation can occur. It can be seen that a significant amount of people with mental illness, who are also labelled and stigmatised, accepted societal notions of stigma, internalised these notions and as a result suffered from diminished self-esteem and confidence, thus stigmatising themselves and creating self-stigma (Corrigan, 2005). Furthermore, it was also noted that self-stigma can lead to behavioural responses whereby people with mental illness may decline to pursue employment opportunities, or living independently, and self-stigmatisation impacts on their achievement of personal goals and life opportunities (Link, 1987).

For example, an American psychiatrist diagnosed with schizophrenia, described her self-stigmatisation in how she relegated herself to the bottom of the social ladder, and tormented herself with the thought that strangers and anyone she met did not like her and wished people with mental illness did not exist (Gallo, 1994). In addition, (Gallo, 1994) also mentioned how she avoided eye contact with anyone from the public, because she marginalised and excluded herself from society, which was the same message she experienced as a result of stigma.

Likewise, it was reported that people with mental illness are aware of the negative attributes and stereotypes which exist about their group and expect to be stigmatised (Wright et al., 2000). However, it was found that not everyone with a mental illness is in agreement with the stereotypes and attributes, so everyone with a mental illness does not react with self stigmatisation or have diminished self-esteem (Hayward and Bright, 1997). Evidently, it was argued that some people with mental illness were energised by stigma and motivated to campaign against the injustice, and others may altogether ignore the negative attributes and public attitudes (Corrigan, 2005).

It is evident that self-stigmatisation may impact help-seeking behaviour and access to mental health services, because people with mental illness may want to distance themselves from the label of mentally ill, and the experience of stigma. In evidence, it was suggested that people with severe mental illness were no more likely to participate in treatment than people with minor disorders (Kessler et al., 2001), but that there was a direct, significant relationship between stigmatising attitudes and adherence to treatment (Sirey, et al., 2001).

Of greater importance to this study is the concept of self-stigma, because of its potential to be highlighted as a factor in stigmatisation, other than that which may be experienced or perceived through social interaction. It is also important to discover if self-stigma is evident in the service user sample, and if its origin lies within service users, is a product of public stigma, or combinations of these factors in conjunction with an expectation of rejection.

2.4 The Dependence Of Stigma On Power

Stigma appears to be dependent on social, economic and political power, but the role of power is often overlooked (Link and Phelan, 1999). In many instances power differences are taken for granted, but in fact may be an essential ingredient in the social production of stigma. In addition, when attention was focused on groups who were relatively low in power, the evidence suggested that although members can engage in labelling and stereotyping, they were limited, by low power, from achieving a deeper and more complete stigmatisation of the people they meant to stigmatise (Link and Phelan, 1999).

Link and Phelan (1999) cited an example wherein patients in a treatment programme for people with a serious mental illness were likely to identify and label human differences in staff members. For instance, patients may label one staff member a 'pill-pusher' and apply stereotypes connected with the labels they create, such as the 'pill-pushers' are cold, paternalistic and arrogant. They may also treat staff they label differently, and in accordance with the conclusions they have drawn about them, probably avoid or minimise communication or exchange derogatory comments and jokes about them. It can be seen how patients may engage in stigmatising behaviour, but the staff would not end up being a stigmatised group. The patients do not have the social, cultural, economic or political power, so their cognitions are without serious discriminatory consequences.

It appears that the aforementioned scenario can exist for other circumstances in which relatively powerless groups create labels and stereotypes about more powerful groups, and vice versa, and treat members of the more powerful or less powerful group in accordance with those stereotypes. In other

words, stigma appears to involve reference to power differences, if labels and attributes are to have any impact on the stigmatised group.

The following questions were posed by Link and Phelan (1999) because of the apparent importance on the role of power in stigmatisation. Do the people who stigmatise have the power to ensure that human differences are labelled? Or, does a culture recognise and accept the stereotypes they connect to the labelled differences? Or, do they have the power to separate 'us' from 'them' and to have the designation stick? Or, do they have control of access to major life domains such as educational institutions, jobs, housing and healthcare so as to affect the distinctions they draw? If the answer to any of these questions is 'yes', then stigmatisation should be prevalent. To the contrary, if the answer was 'no', some of the cognitive components of stigma might be present, but generally what stigma means and represents would not exist (Link and Phelan, 1999).

It can be seen that the aforementioned questions about the apparent power of the public in conferring status and controlling life chances for people with mental illness were interesting. The public does not appear to have any obvious power, but somehow the outcomes for people with mental illness can be similarly negative, with stigmatisation following a similar pattern as social inequalities.

Similarly, Link and Phelan's (1999) concept of stigma and the sociological tradition both define stigma by its discriminatory effects and ways in which it functions in reinforcing social inequalities, and thereby stigma is deemed to be an agent of social control (Parker and Aggleton, 2003). This sociological approach to stigma appears to avoid individual attributes and focuses on the way in which

stigma functions to explain its occurrence. It was observed that discrimination from stigmatisation followed lines of existing social inequalities, and was viewed as part of the political economy of social exclusion, present in contemporary society, that exacerbates social divisions by stereotyping marginalised, disempowered groups (Parker and Aggleton, 2003). It would appear that stigma and discrimination reproduces relationships of social inequality which may be advantageous to dominant classes, and may be seen as being functional in maintaining the socio-political status quo.

However, this functionalist view of stigma as a means of social control suggests that the meso and macro levels of society benefit from discrimination and inequality. This may not be the case, but it could also be seen that the discriminatory effects of stigma can be useful to the dominant classes of society rather than being a desired or intended effect of stigmatisation and discrimination.

In one alternative model, stigma is seen as a basic response to danger, which helps people to feel safer by projecting controllable risk and blaming outgroups which then infuses a sense of control and immunity at an individual and group level (Joffe, 1999). Consequently, socially constructed representations of stigma can result in discrimination and reproduction of structural inequalities when factors such as opportunity and power are present (Parker and Aggleton, 2003).

Indeed, it can be seen that stigmatisation may be concurrent with existing societal inequalities and functional as an agent of social control. But, while stigma may have functionalism in reproducing unequal relations and be of benefit

to dominant social groups, its apparent functionalism does not explain why stigma occurs, its universality or the structures which perpetuate it.

It can be seen that, functionalism addresses aspects of stigma and discrimination, but leaves other aspects of this complex phenomenon, such as why it occurs, unanswered. It is not just a matter of explaining stigma in relation to illness, which as in the case of mental illness, obvious symptoms may not be evident. Although there are theories as to why and how stigmatisation occurs, the relationship between stigmatisation, social power and inequalities, mental health literacy amongst the public and the perceptions of stigma amongst people with mental illness, remain and continue to pose challenges. An exploration of the conceptual literature on stigma follows.

2.5. Theories On Stigma

2.5.1. <u>Psychological Theory</u>

There is evidence to suggest that people in groups, where reward is equally distributed, are less satisfied than people in groups that include a less fortunate person, even though group members were likely to acknowledge the unfairness of the situation (Brickman, 1975). Similarly, people who are subjected to threats, failures and frustrations in everyday life, and those with low self-esteem tend to derogate others in order to bolster their own self-esteem and feeling of well-being (Willis, 1981; Gibbons and Gerard, 1989).

Following the line of reasoning by Willis (1981) and Gibbons and Gerard (1989), it can be extrapolated to people with and without mental illness to infer that people with negative attitudes toward the mentally ill may benefit from the

presence of people with mental illness, who may provide them with psychological dividends such as self-esteem. Another example can be seen in people who might have stigmatising attitudes to the mentally ill, and may be likely to feel uneasy and uncomfortable in the presence of someone who is mentally ill, even without unusual behaviour. It can be seen that by avoiding people with mental illness, stigmatisers can reduce their anxiety, thus having a psychological gain.

Early (Nunnally, 1961) and more recent evidence (London and Garman, 2007) suggest that people with higher knowledge about mental illness and higher self-esteem were more likely to have positive attitudes toward people with mental illness. One possible explanation for this attitude may be because they already have a sufficient level of self-esteem, so there is no need for them to stigmatise the mentally ill in order to feel better about themselves.

Likewise, support for the psychological theory on stigmatisation is found in the Just World hypothesis (Lerner, 1980), which suggested that individuals need to believe that they live in a world where, generally, people get what they deserve and deserve what they get. More specifically, the Just World hypothesis has implications which help to maintain the belief that the world we live in is stable and orderly.

In addition, it would seem that the idea that people can experience illness or injury without being responsible, can threaten the understanding of justice, and furthermore, people need reassurance that the same fate is not going to befall them (Lerner, 1980). It can be argued that reasoning along lines of the Just World hypothesis allows the pursuit of psychological self-interest without the feeling of guilt (Haghighat, 2001).

In brief, the universality of stigma suggests that there may be a functional value for individuals, groups, society or all of these in relation to control enhancement, self-esteem and anxiety reduction, as the result of a downward-comparison process (Crocker et al., 1998). Indeed, for this study, downward comparison for psychological gain is an interesting idea, which can be further explored, when looking at public and service users' constructions and perceptions of stigma.

2.5.2. Psychoanalytic Theory

Psychoanalytic theory accounts for individual differences in the tendency to stigmatise by examining differences in personality, whereby stigmatisation is thought to reflect internal personality conflicts that were rooted in early childhood experiences, and linked to parental punitiveness (Sigelman, et al., 1986). Similarly, underlying conflict can be expressed through ego defence mechanisms, such as displacement, which is expressing frustrations about an out-group, when one cannot express frustration against the actual source of the frustration, and projection, which is attributing labels, to an out-group, which one cannot admit in oneself (Gross, 1994). It can be seen that personality conflict can also give rise to an authoritarian personality characterised by a hostile, rigid and conforming world view rooted in early childhood and resulting in prejudice toward different groups. In brief, both the psychological and psychoanalytic stances on stigma are concepts which are difficult to operationalise and to apply and inform a conceptual model.

2.5.3. Schema Theory

In very early seminal work on schema, it was suggested that understanding and memory of events are shaped by expectations which are mentally represented, referred to as schema, and seen as well-integrated chunks of knowledge about the world, events, people and actions (Bartlett, 1932).

Interestingly, the concept of schema was demonstrated by giving English subjects a North American folk tale to memorise. Their recollection of the folk tale was then tested at different time intervals. The North American folk tale had strange attributions and a causal structure that was contrary to Western expectations. Consequently, it was found that subjects reconstructed the story rather than remembering it verbatim and their reconstruction of the tale became consistent with a Western cultural view (Bartlett, 1932).

Similarly, schema was also defined as an abstract or generic knowledge structure stored in memory and specifies the defining features and relevant attributes of some stimulus and the interrelations among the associated structures (Crocker et al., 1984). Again, it was noted that a cognitive or affective schema, in other words an attitude, was identified and directly activated by specific stimuli or a corresponding cognitive perception or thought.

For example, one cognitive schema, which may be activated on meeting someone who has a mental illness may be 'this is a mentally ill person and they may be aggressive, dangerous, out of control, unable to communicate effectively or their behaviour may be unpredictable'. This cognitive schema may then trigger the affective schema of fear and the combined response could be one of rejection.

Similarly, schema has been implicated in perception, whereby it reduces the need to analyse all aspects of a situation (Bartlett, 1932). For example, when an everyday scene, such as a street, is viewed, there are clear expectations about what objects are likely to be present. Likewise, schema operates to reduce the amount of processing the perceptual system needs to carry out to identify expected objects, thus freeing resources for processing more novel and unexpected aspects of the situation.

It would also appear that in stigmatisation, schema can operate in a similar manner, by reducing the processing of detail when one encounters, in a real or hypothetical situation, someone who is thought to be mentally ill. Instead of analysing all aspects of the situation, schema functions to help one to make a quick assessment and take the necessary action. Again, if understanding and memory are shaped by expectation or schema, it could be that 'false' schema about mental illness and the mentally ill may have developed through the process of socialisation or social learning, to produce enduring negative attitudes.

In this study, the notion of schema is important and links with the construction of stigma by the public and service users. The idea of schema can be explored through Personal Construct Psychology [PCP] (Kelly, 1955) (see section 3.3.2). Again, if the understanding and memory of events are shaped by expectations, which are represented as schema, this infers that if service users had a negative experience and attributed this to stigma, they may continue to have expectations of rejection. The concept of Social Attribution, which also examines and builds on knowledge structures, is now explored.

2.5.4 Social Attribution

Social Attribution theory is an early model of human motivation and emotion based on the assumption that individuals search for causal understanding of everyday events (Weiner, 1980, 1983, 1985, 1993, 1995). It appears that attribution theory provides a socio-cognitive approach to stigma and frames the phenomenon in terms of knowledge structures, similar to the concept of schema. In attribution theory, stigma is seen as phenomenal representations of the public's largely negative perceptions about people with mental illness (Weiner, 1980). Indeed, central to attribution theory, in attempting to understand and explain why certain behaviours occur, are the dimensions of stability (if the cause is likely to recur), locus (who is responsible) and controllability (did the person have control over the cause (Swanson and Kelly, 2001; Weiner, 1983:1985).

Of interest, the examination of knowledge structures that represent public understanding about a variety of physical and psychiatric illnesses suggest the tendency to understand an illness in terms of its severity (Kerrick, 1969; D'Andrade et al., 1972; Crandall & Moriarty, 1995). Moreso, an illness is understood in terms of controllability, which means whether the person is responsible for the onset of the illness and coping with it (Kerrick, 1969; Turk et al., 1986; Long, 1990). Furthermore, the key distinction between illnesses was that psychological-behavioural disorders, such as mental illness, were deemed to be under relatively more personal control (Crandall & Moriarty, 1995).

For example, one might consider why mentally ill people cannot care for themselves. It can be seen that when meeting successful or unsuccessful

outcomes, people often ask themselves, why this and not something else? Moreover, encountering success or failure leads to emotional and behavioural responses (Corrigan, 2000) and an encounter with a person who has a mental illness can show this type of attributional reaction. This research is interested in the emotional response, mentioned by Corrigan (2005) of people to mental illness, which may be seen as an unsuccessful outcome in life and as a result may elicit less desirable responses.

Research has shown two main factors in attribution, stability of causality and controllability of causality, to address the why questions of human motivation (Weiner, 1983, 1995; Swanson and Kelly, 2001). Stability refers to the temporal nature of cause and whether the event will recur. Evidently, some causes remain potent over time while others fluctuate (Weiner, 1985, 1995). It can also be seen from the evidence that attributions about the stability of a cause do not affect the type of emotional or behavioural responses as much as the strength of those responses (Barnes et al., 1979; Weiner, 1995; Weiner et al., 1982). In addition, causal attributions are given more credit when they are viewed as being stable and unchanging rather than unstable and fluctuating (Corrigan, 2000). Likewise, for people with mental illness, stigmatised responses from the public have been common, and this could be part of the reason for the perseverance of societal stigma (SEU, 2004).

For instance, from its early inception, the mental illness category of schizophrenia was viewed as a rarely-improving process, and the course of schizophrenia was defined as progressively worsening, leading to a demented outcome with loss of independent functions (Kraepelin 1896, 1919).

Interestingly, Kraepelin's (1896; 1919) idea of schizophrenia appears to have prevailed even to recent aspects of mental health care. For example, the Diagnostic and Statistical Manual of Mental Disorders incorporated the 'never improving course' in their definition of schizophrenia (American Psychiatric Association [APA], 1980, 1987).

Controllability refers to the amount of volitional influence an individual exerts over the cause of an illness and people are more likely to ascribe responsibility and blame to events that are viewed as being under personal control (Weiner, 1985, 1993, 1995). For example, a driver over the legal alcohol limit who hits a pedestrian is judged more harshly and differently to a driver in a similar act, who lost control of a vehicle, because of a heart attack.

Furthermore, in attribution controllability can be divided into 'onset controllability', which refers to whether the person can be blamed for contracting an illness, and 'offset responsibility' whereby the person is trying to cope with and overcome an illness (Schwarzer & Weiner, 1991). In relation to controllability, it was proposed that moral models yield attributions which suggest that mental illness is onset controllable and people with mental illness are usually blamed for their illness and symptoms (Corrigan, 2000). For example, early notions about morals led to a focus on sin among many American Christian denominations, which led to blame attributions towards mental illness that continue into the present time (Dein, 1992). However, in contrast to a moral model, as suggested by Dein (1992), the bio-medical model of mental illness is more consistent with attributions that mental illness is uncontrollable at onset (Campbell, 1999). Anyway, even though the medical model suggests that the onset of mental illness

is uncontrollable, the public often make a link with unpredictability, dangerousness and uncontrollability in mental illness (Campbell, 1999).

In addition, it was suggested that controllability and responsibility attributions are associated with emotional responses, and people who were viewed as being able to control a negative event, such as symptoms of schizophrenia, were more likely to be held responsible and reacted to angrily (Reisenzein, 1986; Dooley, 1995; Graham et al., 1997; Rush, 1998; Schmidt & Weiner, 1988; Weiner et al., 1988). On the other hand, people who view themselves as being responsible for controlling a negative event, such as schizophrenia, were more likely to experience shame and guilt stigma, (Brown & Weiner, 1984), which, to some extent, may be a factor in self-stigmatisation. Conversely, individuals who are believed to have no control of a negative event are often pitied by others. For example, people whose mental illness can be attributed to a bio-medical cause, such as an accidental head injury, were more likely to receive help and sympathy from others (Reisenzein, 1986; Schmidt & Weiner, 1988; Dooley, 1995).

Interestingly, mental health service users have distanced themselves from the bio-medical model of mental illness, which suggests that there were pathological and neuro-chemical imbalances in their brains (Corrigan, 2000). However, the rejection of the bio-medical model by service users is at odds with Reisenzein (1986), Schmidt and Weiner (1988) and Dooley (1995) who suggested that the public should be broadly sympathetic towards people with mental illness, since there is no onset-controllability of their illness. It is possible that the stigmatisation of people with mental illness can arise from the public

knowledge that people with mental illness do not show offset-controllability in trying to cope with the effects of their illness.

In fact, the public have expressed concern about people with mental illness, which centred around the 'defects' in the brains of people with mental illness, who cannot control their behaviour, cannot be held responsible for their actions, and deemed unpredictable, which was linked to the notion of dangerousness (Campbell, 1999). Consequently, the public concern demanded the need for people with mental illness to be managed and controlled. Again, the idea that people with mental illness were dangerous and needed to be controlled can be seen to support stigmatisation and public fear of the mentally ill. In other words, attributes can cause emotive responses to mental illness, which may be deemed to be an unsuccessful, controllable outcome, linked to uncontrollability, dangerousness and fear. The study will now explore the notion of fear in relation to stigma.

2.6. Fear and Stigma

Early observations on stigma noted that in cultures that did not use the term stigma, there was an emotional reaction beyond interest or curiosity to differences, such as children who are born with birthmarks or epilepsy (Sontag, 1979). Also, certain physical characteristics or illnesses can elicit fear because their causes were unknown, unpredictable and unexpected. Of interest, there were also fears about the sexuality of certain stigmatised groups, such as people with learning disabilities and the mentally ill, whereby, if they were allowed to

reproduce, would have offspring which perpetuated similar disabilities (Gibbons and Kassin, 1982).

It was argued that in most stigmas which arise from physical illness, such as cancer and also in mental illness, people may experience fear of contagion even though they know that the illness cannot be developed through contact (Barbarin and Chesler, 1984). It can also be seen that fear can arise from a lack of scientific evidence about the aetiology, predictability and prognosis of a condition, which is precisely the case with mental illness (Boyle, 1990; RCP, 2000). Evidently, mental illness has been around for a long time, but there is still very little understanding of how the human brain works and even less about the aetiology of functional mental illnesses (RCP, 2000). At some level, most people may be concerned with mental illness and with stigma because they are fearful of its unpredictable and uncontrollable nature and because mental illness can highlight human differences, it serves as a basis for stigma, and indeed any attribute can be subject to stigma.

Moreover, the unpredictability of stigma was likened to the unpredictability of death, and the development of a stigmatised condition in a loved one represented a major breach of trust, a destruction of the belief that life was predictable (Gibbins, 1981). Consequently, stigma represents a kind of death, a social death, whereby non-stigmatised people, through avoidance and social rejection, treat stigmatised people as if they were invisible, non-existent or dead (Barbarin and Chesler (1984).

Similarly, stigma appears to remove the guises of mortality and can act as a symbolic reminder of everyone's inevitable death, and this fear of death can be

applied to the acquisition of other stigmas, such as that of mental illness, which can help to intensify and perpetuate the negative responses to most stigmatised categories (Becker, 1973). An important dimension is noted in irrational fears, which help stigmatisation to be self-perpetuating, without encouragement in the form of forced segregation from the political and social structures of society (Becker, 1973).

It would appear that addressing the cause of stigma can be sought in an examination of why people fear difference and the unknown and stigmatise that which is different and unknown. It is also worth investigating how stigmatisation may be linked to the fear of being different and how that difference might impact on relationships. In view of the strong argument for the impact of fear, this study will consider fear in the constructs of stigma. If fear of becoming ill is a reminder of our mortality, it may follow that people who are mentally ill may represent that fear, which can lead to social avoidance and stigmatisation. Indeed, fear may be a factor in the stigma of mental illness, because evidence suggests that most of the public cannot differentiate between mental illnesses, do not understand them and also have a fear of mental illness (Jorm, 2000).

Public fear of mental illness appears to be a significant factor in stigmatisation, but mental health services and healthcare professionals can also be sources of stigmatisation, which may be due to antagonistic, cultural differences between service users and professionals (Owens, 2004). Professional stigmatisation is important as it may significantly impact service users, who rely on healthcare professionals for therapeutic engagement and

interventions. Stigma from healthcare professionals during the course of treatment, also known as iatrogenic stigmatisation, will now be explored.

2.7. latrogenic Stigmatisation

Words such as mental illness and schizophrenia are not just diagnostic labels, but metaphors which represent a major complication of treatment and living with mental illness (Finzen and Hoffmann-Richter, 1999). It is seen that mental illness and schizophrenia always appear to carry notions which are negative and portray images of violence, bizarre or contradictory behaviour and irrational thinking. Early writings on stigma supported the idea that labels can be negative and the words mental illness and schizophrenia were an important part of stigmatisation, and seen as a metaphor of defamation, which violated the identity of people suffering from mental illness (Goffman, 1968).

In addition there is evidence to suggest that the metaphoric use of schizophrenia is also present in the social representation of schizophrenia, and is associated with a split personality or multiple personality disorder (Angermeyer and Matschinger, 1999). Of equal importance, people with a diagnosis of mental illness may have internalised expectations of being rejected and have a concept of what it is like to have a mental illness and associated negative consequences, long before they receive a diagnosis of mental illness (Link, 1987).

Nevertheless, the careless use of diagnostic labels is a source of stigmatisation for the mentally ill, especially where stigmatisation does not stop at diagnosis, but continues to treatment, which may also produce side effects that can mark the person much more than the original symptoms of their mental illness (Sartorius, 2002).

At the time of this study, there were no published studies which suggested that a label of mental illness can free the mentally ill from personal guilt about their condition or that it empowered the mentally ill. However, in Japan, where the term for schizophrenia was changed from the splitting of one's mind, to the term ataxic integration disorder, some people with mental illness preferred the old term of schizophrenia, as opposed to the new term. It has been suggested that this preference existed because of social pension payments of about £350 pounds per month given to people with schizophrenia, and there were fears that this payment could cease under a different diagnostic label (Nishimura, 2003).

In addition, further evidence suggests that psychiatrists and other healthcare professionals stigmatise people with mental illness by requesting higher salaries for working with the mentally ill, who they deemed to be dangerous, while suggesting that mental illness is an illness like any other (Sartorius, 2002). Yet, psychiatrists were among those who recommended special legislation, for example Supervised Discharge and the Supervision Register, to protect the public from people with mental illness, while being unaware of the effect that this stringent legislation may have on people with mental illness, on public perception and on stigmatisation (Sartorius, 2002).

Furthermore, the experience of mental ill-health appears to be fundamentally disempowering and the process of psychiatric care and treatment can add to the disempowerment of the person (Barker and Stevenson, 2000). The commonest form of disempowerment involved the failure to afford a proper hearing to individual stories of the experience of problems of living. Consequently, it was argued that the medical diagnostic model of mental illness deflects from the lived experience of the service user and translates subjective accounts into the para-language of medicine, thereby reducing

individual accounts to the level of their apparent commonly occurring parts (Barker, 2001).

Despite the increasing emphasis on evidence-based, clinical practice, the stories from service users were the most valuable, yet neglected, form of evidence (Barker, 2001) and mental health practitioners can only evaluate if a service user is making progress, when they report what has been said, heard, noticed or otherwise presented as evidence, by the service user, to the healthcare professional. However, everyday evidence from service users was often discounted in favour of counting, rating or framing diagnostic abstractions from personal, lived experience of mental illness (Kirk and Kutchins, 1997).

The application of diagnostic labels to persons with mental illness can be a source of stigmatisation and disempowerment, because it limits the representation of lived experience and condenses lives into diagnostic terminology (Sartorius, 2002). Also, health care professionals can also have negative attitudes about certain mental illnesses and may behave accordingly once they know that a person has an illness to which they have a prejudice.

It can be argued that if service users perceive stigma from their interactions with healthcare professionals, who are meant to be caring, understanding and supportive, then it is more likely that they will experience or perceive stigma from the public, who have less responsibility for caring about people with mental illness. It can be seen that the attitudes of health care staff are important because early and more recent evidence suggested that healthcare professionals needed to be aware of stigmatising service users, and recognising and treating service users as individuals plays a crucial role in

their recovery and sense of well being (Lovejoy, 1982; Lyons and McLoughlin, 2001; DH, 2006).

2.8 Goffman's (1963) Seminal Work On Stigma

2.8.1 Types of Stigma

Goffman's (1963) seminal work on stigma distinguishes between three different types of stigma: (1) physical defects and deformities, (2) blemishes of character (including mental disorders and suicide attempts), and (3) tribal stigma related to race, nationality and religion and the ways in which each stigma was carried. In the seminal work, the term 'discredited' described an individual whose difference was evident. However, for people who were stigmatised, the stress from being discredited caused isolation into subgroups, so that their attributes were normalised and they looked for benefits in challenging and resisting the status quo (Dudley, 1983).

Secondly, the term 'discreditable', described an individual whose difference was not immediately apparent. However, a potentially discreditable attribute was only relevant if it was perceived in that manner by the person who may be deemed to be discreditable (Schneider and Conrad, 1980). People with physical or tribal stigma tend to be discredited, rather than be discreditable, whereas, individuals with behavioural stigma, such as that attached to mental illness, were more likely to be discreditable than discredited (Goffman, 1963).

In a similar manner, stigmatisation was seen as a process wherein a person possesses or was believed to possess a trait which was devalued in a specific social context (Crocker et al., 1998). Indeed, stigmatising attributes may

be invisible or visible, and people who were stigmatised, were devalued in a specific social context, which suggested that stigma might be pertinent to social relationships in a social context and may not be a feature in the person who was stigmatised (Major and O'Brien, 2005).

Stigma appears to bear similarities with the concepts of marginality and deviance. For instance, marginality was defined as belonging to a group which was both statistically unusual and centrally defining (Frable, 1993), while deviance was seen as 'a perceived behaviour or condition which is thought to involve departure from a putative standard' (Archer, 1985: p 748). However, deviance and marginality can also arise as a result of unusual positive characteristics, for example extreme wealth, as well as negative traits (Crocker et al., 1998). Also, when deviance is associated with a negative quality it may not produce stigmatisation unless there is an association with the bearer's identity which in itself was discrediting (Jones et al., 1984).

It would appear that stigma involves more than the perceptions of deviance but also includes notions of a less desirable character and identity. While stigmatisation can foster unity amongst an out-group, many people with mental illness who experience stigma, often report that it leads to marginalisation and social exclusion (SEU, 2004), even though they may not exhibit any overt signs of mental illness. The recognition and reaction to stigma will now be explored.

2.8.2. Recognition and Reaction

Individuals may recognise they possess a stigma in two ways. Firstly, they

may recognise stigma through a process of self-recognition (Goffman, 1963). Consequently, they would be in a position to compare their own conduct or appearance with existing stigma types. It was also argued that people with mental illness expected to be rejected and had ideas of what it was like to be mentally ill, even before they received a diagnosis (Link, 1987). It can be seen that self-recognition also highlights the importance of the label of mental illness and brings a focus on interactions between social representations of mental illness, self-recognition and self-stigmatisation (Corrigan, 2005).

The second way in which individuals come to recognise that they possess a stigma is through the reactions of others (Goffman, 1963). These reactions may be direct, for example, a mentally ill person being called 'crazy', or indirectly, such as an individual hearing about the negative attitudes and attributes towards people with a mental disorder. Evidently, many people with mental illness come to recognise that they have a stigma by a combination of self-recognition and audience reaction (Goffman, 1963). People who were stigmatised felt that others were not willing to make contact and reported that shame, self-hate or self-derogation became a central feature of their stigma (Gallo, 1994; Corrigan, 2005).

It would appear that social situations can be made uneasy by the reactions of both the stigmatised and the stigmatiser in anticipation of contact, and this may cause the public and people with mental illness to avoid contact with each other. Consequently, the lack of salutatory feedback of daily social interactions with the public, may cause people with mental illness to isolate themselves and become suspicious, depressed, hostile, anxious and bewildered (Goffman, 1963).

Interestingly, people appeared to have cognitive adaptations which caused them to stigmatise people who may have actual or perceived attributes, which suggested that they were poor partners for social interaction, may possess a contagion, a physical deformity or may be a member of an out-group, and this can be exploited for in-group gain (Jones et al., 1984; Crocker et al., 1998). Of particular concern, the stigmatisation of people with mental illness is often identified with other stigmatised conditions such as poverty, being in an ethnic minority group, and other factors which supported social disadvantage and discrimination (Parker and Aggleton, 2003).

It was contended that Goffman's (1963) notion of stigma usually referred to enacted, perceived or anticipated social judgement, because the seminal work was based on examples from a rich source of deformity, disability, criminality, addictions, mental illness and racial issues, which at that time, were concerns and issues for society and social research (Weiss et al., 2006). Nevertheless, Goffman (1963) shifted the focus of stigma from symbols to social interaction and the notion of spoiled identity and social exclusion for the stigmatised are indeed, contemporary (SEU, 2004).

It can be seen that the ramifications of stigma were a loss of citizenship and downward social mobility (Bracken and Thomas, 2005). Similarly, the outcomes as a result of diminished contact with society can be social exclusion, unemployment, rejection and discrimination (SEU, 2004). In any case, social exclusion and self-stigmatisation may be a frequent outcome of stigma, but for others, having a mental illness can be seen as a positive experience, where societal stigma is ignored or used to empower user and survivor groups (Sayce,

2.8.3 Stigma Management

'Passing' and 'covering' are two ways in which individuals manage stigma (Goffman, 1963). Passing involves deliberate concealment of the stigma and is used when the stigma attached to the mark is great and the mark is easily concealed, while covering involves subtle strategies to keep the stigma from being overly intrusive (Goffman, 1963). For example, people with mental illness, employ 'passing' and the decision to 'pass' is often a deliberate, planned response to minimise the likelihood of detection, in order to maximise social acceptance.

There are a number of factors which impacts stigmatisation and includes the concealability of the stigma, its visibility, the course of the condition, the strain it places on interpersonal relationships, if it affects the appearance of the person, whether the condition is congenital or acquired and the dangers associated with the stigmatised condition (Jones et al., 1984). It can be argued that when the aforementioned factors are considered in the light of mental illness, they indicate challenges for mental health service users, particularly in concealment of their condition, interaction with friends and the public and their perception of dangerousness (Link and Phelan, 1999).

The degree of psychological strain involved in 'passing' may be greater for those who believe in the therapeutic benefits of disclosure and even when successful, 'passers' may face prejudice from their peers (Goffman, 1963). It can

also be seen that the 'passer' also faces the danger of discovery when the deceit is revealed, and those from whom the stigma was concealed can feel resentment (Jones et al., 1984).

A friend of someone with mental illness may feel angry about secrecy, if there is a close friendship with the person who concealed their illness, since disclosure may be treated as an obligation of friendship (Corrigan and Lundin, 2005). On the other hand, the desire for disclosure can place people with mental illness in an awkward position, because they are at risk of losing friends if they disclose, and at equal risk if their illness is kept a secret, then discovered. This is a dilemma for people with mental illness, whose friends may be accommodating on disclosure of the illness, but the individual may choose to conceal their illness because of an expectation of rejection or fear of rejection (Link, 1987). Whatever the decision is on disclosure of mental illness, when the 'passer' is found out, the discredit of a deceit and lack of trust is added to the burden of the stigma (Goffman, 1963).

Complete 'passing' or total disappearance of stigma is rare, as it tends to be the case that, because of stigma, mental illness is concealed from some and revealed to a select circle of family and friends. Obviously, the danger in selective disclosure is the potential confrontations between those who know and those who do not. If the stigmatised person generates a double identity, the segregation of identities may break down through a number of circumstances. For instance, Goffman (1963) provided an example in noting 'that every exmental patient must face having formed, in the hospital, some acquaintances that may have to be greeted socially on the outside, leading a third person to ask,

'Who was that?'

The mechanisms of 'passing' and 'covering' were early concepts by Goffman (1963) and this study is interested in finding out if such coping mechanisms were currently employed by service users in managing stigma. Furthermore, and recently, mental health service users and people in mental health survivor groups have challenged the discrimination as a result of stigma and feel more comfortable to divulge their diagnoses of mental illness (Sayce, 1998).

Evidently, there was a deleterious effect of secrecy for people with concealable stigma, because attempts at hiding a diagnosis of mental illness activated a set of cognitive processes that led to an obsessive preoccupation with the secret (Wegner and Lane, 1995). On the other hand, disclosure negated the need for concealment and helped the person to avoid the secrecy cycle, with the added benefit of increased self-esteem, which enhanced interpersonal relationships (Jones, 2000).

In addition, the concept of self is challenged with the diagnosis of a mental illness, particularly the experience of being hospitalised. An admission to a psychiatric hospital or mental health unit can be disempowering (Barker, 2000) and may challenge service users to make sense of why they are in hospital and impact on their identity. As a result, the struggle with a mental illness and contact with services becomes one of defining self-concept, while the nature of mental illness may involve particular challenges. For example, in schizophrenia there can be issues regarding coping with hallucinations and delusions, and their impact on the concept of self.

2.9 Labelling

A central theme of labelling theory is that social groups create deviance through making rules which, if infracted, constitutes deviance. Inherent in labelling theory was the notion that a label of deviance depended upon who defined, what and how an act or individual was defined as deviant (Becker, 1963). Hence, deviance can be a relative condition and what is deviant to one group or individual may not be so for others. It can be seen that in many cases the individual may be acting in a rational manner, according to his own standards, but not to the standards set by the wider society.

For example, in a classic study (Rosenham, 1973), pseudo-patients pretended to be hearing voices, to gain admission to a psychiatric hospital, where they were given a diagnosis of schizophrenia. When the reports of the experiences of the pseudo-patients were examined, findings showed that once a person was labelled mentally ill, there was very little that person could do to shake off that label and revert from insane to sanity. Another interesting finding was that despite the overt display of sanity, the pseudo-patients were never detected, which suggested that 'normals' were not detectably sane and the diagnostic label tended to override all displays of 'normal' behaviour, once someone was admitted to a mental institution (Rosenham, 1973).

Labelling theory suggested that the consequences of being labelled 'mentally ill' was malevolent (Weinstein, 1983), but to the contrary, it was

contended that labelling and the patient's role in hospitalisation and treatment was, in the long run, beneficial or benign (Gove, 1975). There was an association between labels, beliefs about the cause of mental illness and dangerousness, in that there was a strong stereotype of belief that the mentally ill were violent and the public had a desire for safe social distance from people with mental illness (Link et al., 1999). It was also asserted that even in the absence of abnormal behaviour, the label of mental illness, on its own, was enough to activate stigma (Corrigan and Nelson, 1998).

To date, even though there is less emphasis on labelling, there does not appear to be any emergent consensus on benefits versus the ill effects of labelling. However, labelling was an interesting point to consider in light of service users who were labelled and had prolonged contact with mental health services or frequent admissions and discharges, which also meant frequent contact with deviant social groups. These were important factors which impacted the perception of stigma (Perucci and Targ, 1975) and will be considered in the quantitative aspect of this study.

2.10 Factors That May Contribute To Stigma

There is a sizeable body of evidence which supports the prevalence of public stigmatisation of people with mental illness (Rabkin, 1974; Roman & Floyd, 1981; Link, 1987; Greenley, 1984; Madianos et al., 1987; Bhugra, 1989; Brockington et al., 1993; Hamre et al., 1994; Hugo, 2001), and stigma was also evident amongst mental health professionals (Page, 1980; Mirabi et al., 1985;

Scott and Philip, 1985; Keane, 1990; Ziviani, 1995; Link et al., 2000; Lyons & McLoughlin, 2001).

It was demonstrated that many people with schizophrenia lacked the basic social, coping and problem-solving skills needed to manage the demands of independent living, and while they may have acquired appropriate social skills, they lacked attention and memory functions, which lead to recognising and understanding the subtleties of interpersonal situations (Corrigan and Nelson, 1998). Likewise, the lack of memory and attention resulted in their inability to understand social cues, which diminished their ability to select social skills that met the demands of a social situation (Penn et al., 1997).

There is research evidence which suggested that people with schizophrenia were significantly less able, than comparison groups, to recognise and process facial affect (Kerr & Neale, 1993; Morrison et al., 1988), non-verbal cues (Monti & Fingeret, 1987), social knowledge (Cutting and Murphy, 1990; Cramer et al., 1992), situational features (Corrigan et al., 1996) and social cues (Corrigan & Green, 1993; Mueser, et al., 1993). It was also highlighted that deficits in social cue recognition were crucial, showed high correlation with and significantly predicted interpersonal problem solving in people with mental illnesses, such as schizophrenia (Corrigan & Toomey, 1995).

Accordingly, one study showed that social distance was best statistically predicted by perceived strangeness, which in turn, was best statistically predicted by ratings of overall social skills (Penn et al., 2000). It can also be seen that negative symptoms of schizophrenia appear to have a more robust association with desired social distance than positive symptoms. Likewise, interpersonal

factors, such as overall social skills, negative symptoms, and perceived strangeness contributed to the stigma of mental illness. However, it may be argued that this was not the case for many people with mental illness, such as schizophrenia, who may not fit this stereotype. The next section will explore credence in stereotypes of mentally ill people.

2.11. <u>Does Stigma Represent A Kernel Of Truth?</u>

Allport (1954) and Campbell (1967) suggested that there was a tendency for stereotypes to contain a kernel of truth, and function as rational categories that 'grow up from a kernel of truth' (Allport, 1954, p. 22). In other words, if a group possesses real and objective differences, it would not be surprising that stereotypes can reflect these differences. For example, if people with mental illness were more bizarre, dangerous, incompetent, and irresponsible than the general public, then it would be reasonable for these traits to be attributed to people with mental illness. However, it would appear that assessment of the 'kernel of truth' argument was a matter in the accuracy of the stereotype.

Corrigan et al., (2001) cited that examples of stereotype accuracy were apparent in people's perception of a variety of social groups. For example, professional basketball players are stereotyped as tall and objective measures confirm that the average player is indeed taller than most people. Indeed, the same may be true when considering stereotypical perceptions of mental illness and the mentally ill. Perhaps people with mental illness do possess traits that are commonly attributed to them. But, if this were true, there would be evidence to support the case of mentally ill people as being more dangerous, homicidal,

incompetent and unable to care for themselves to a greater extent than the general public.

To the contrary, it was shown that people with mental illness were not more unpredictable or dangerous than the general public (Hafner and Boker, 1973). It appears that stereotypical traits regarding a group were often seen as beliefs about the average member of that group. Thus, the belief that people with schizophrenia were dangerous implied that the average person with schizophrenia would be more dangerous than a member of the general public. However, the evidence suggested that the increased risk of violence associated with mental illness was modest and comparable to that which was associated with age, education, gender and a previous history of violence, in populations that were not labelled mentally ill (Link et al., 1992). In addition, the risk of a person with schizophrenia committing a homicide was five in ten thousand of such offences, if anything, people with mental illness were far more likely to be victims of crime (Walsh et al., 2003; Lalani et al., 2006).

It appeared that negative attributes were ascribed to minority groups, solely on the basis of group size and negative traits erroneously appeared to be related because these occurred less frequently and was used to explain the association between mentally ill people and negative stereotypes (Hamilton and Gifford, 1976).

So on a prima facie level, the 'kernel of truth' argument appeared to have some substance, but as the assertion was unravelled, it did not appear to be a basis for relation to people with mental illness. For example, there was no average person with mental illness and symptoms can vary greatly from person

to person (AMA, 1998). There is also no stereotypical person with a mental illness who has typical traits of mental illness. This becomes more apparent with the difficulty in telling if someone has a mental illness from appearances only.

2.12. Cultural Aspects Of Stigmatisation

Mental health was defined as encompassing different perspectives and concerns, such as the absence of incapacitating symptoms, integration of psychological functioning, effective conduct of personal and social life and feelings of ethical and spiritual wellbeing (Kakar, 1984). In addition, it was argued that culture determines both the perception and level of concern about mental illness and different types of inner experience, which were seen as acceptable, desirable states of consciousness within the culture of Asia, Africa and pre-Columbian America, may be perceived in the West as 'abnormal' experiences, or even as mental illness (Fernando, 2002).

Of even greater interest, it was observed that despite cultural variations about what constituted health and illness, every culture had a concept of deviation from health (McQueen, 1978). Similarly, observations point to the Western model of illness, which developed in a Christian culture but had no connections to Christian concepts such as 'salvation', because religion and illness were in separate cultural compartments (Fernando, 2002).

It can be seen that in non-western cultures, concepts of mind, body, illness and medical beliefs have developed differently. For example, in China, illness can be seen as an imbalance between the forces of 'yin' and 'yang', two complimentary poles of life energy, to be restored by establishing balance of

these energies. Also, in Tibetan culture, which is based on Buddhism, the most important psychological factor in insanity is similar to what is essential for pursuing 'enlightenment' (Clifford, 1984).

Furthermore, culture has been described as being both static and dynamic, and is seen as a result of the interactive process between individuals and the social environ (Keller and Greenfield, 2000; Lopez and Guarnaccia, 2000). In fact, over a period of time, key aspects of culture, such as cultural values and attitudes, are more resistant to change when compared to visible aspects such as behaviour and knowledge (Rosenthal and Feldman, 1992).

Indeed, culture appears to relate to social groupings within which norms are developed, and in the case of mental illness, each culture may have a limit as to their tolerance of deviant behaviour. But, of interest, mental illness by any other name, was recognised, even though there were varying levels to which it may be stigmatised. It can also be argued that societies which tend to emphasise individualism, may express higher levels of stigma compared to societies which place emphasis on society as a coherent group (Fernando, 2002).

Despite there being more research evidence on cross-cultural information on schizophrenia than any other mental illness, there were no known longitudinal studies that explored the course of a cultural construct among different ethnic groups (Lin, 1996). Nevertheless, early ethnographic studies suggested that in ethnic minority communities positive socio-cultural patterns lessened the impact of severe mental illness and stigma (Perelberg, 1983; Swerdlow, 1992). This is an interesting idea in that it lends support to the idea that non-Western cultures

can be more supportive of deviants and as such may be less stigmatising of people with mental illness. This study explored this notion by comparing attitudes between different ethnic groups.

study examined cross-cultural symptomatic differences in schizophrenia, and found that ethnic minority groups, African-Americans and Latinos, had lower levels of symptoms than the non-minority group and that these differences were mediated by higher levels in the socio-centric variables of empathy and social competence among the ethnic minority patients (Brekke and Barrio, 1997). This finding can be extrapolated to suggest that the cultural response in non-White cultures enhanced the prognosis for people with mental illness. It can also be seen that because of higher levels of empathy, mental illness may be less stigmatised in non-White cultures. In support, evidence suggested the popular understanding of mental illness and the social response, may determine the actual outcome of severe mental illness, independent of any recourse to medical treatment (Littlewood, 2004).

There appears to be an emergent consensus in early findings by Cooper and Sartorius (1977) and a recent study by Littlewood (2004) which suggested that schizophrenia has a better prognosis in the Third World. In evidence, these studies (Cooper and Sartorius, 1977; Littlewood, 2004) observed that the value placed on the autonomous individual in industrialised, Western cultures, accentuated the social extrusion of a chronic, mentally ill patient, who had to assume personal responsibility for their illness, and this worsened the prognosis.

Similarly, it was proposed that the prognosis of schizophrenia is related to gender roles, class, social identity, and labour dynamics, because the

unemployment of the mentally ill in capitalist economies led to a loss of selfesteem, social status and independence, while in third world societies, the mentally ill is extruded to a lesser degree, because of a graduated accommodation of work to presumed ability (Warner, 1994).

An interesting notion on the enhanced outcome of illness in Third World societies was found in an early study, which argued that non-industrialised societies were more cohesive and had clear social roles and categorisations of illness attribute and external causes, such as sorcery, which removed the responsibility from the individual (Waxler, 1976). In agreement, Waxler's (1976) findings were more recently supported by further research evidence which suggested that in non-western societies, the environment was supportive and tolerant, with little risk of prolonged rejection, isolation, segregation and institutionalisation (Cooper and Sartorius, 1977).

It is interesting that in third world societies, the idea of an external causation of mental illness, such as sorcery and witchcraft, can remove responsibility for mental illness and its stigma from an individual, who as a result, had a better prognosis. Indeed, there are also Western models of mental illness which attribute the cause of mental illness to external factors such as stress from the environment, social learning and infections. However, the medical model of mental illness seems to prevail in the understanding of mental illness, where Western societies and medicine appear to subscribe mainly to the notion that there is pathology in the brain. As a result, mental illness leads to the notion that because of a pathological, deviant state, society needs to manage people who

are mentally ill and this may be one of the reasons why mental illness is more stigmatised in Western, than in non-Western societies.

For instance, in Japanese culture mental illness carries, not only a very heavy burden of stigma for the family and for the person who is mentally ill, but it also raises the question of eligibility for marriage (Mitchell, 2004). As mentioned earlier (page 89), in Japan, the stigma of mental illness was so severe that at the World Psychiatric Association Congress [WPAC] in 2003, the Japanese term for schizophrenia (*Seishin-Bunretsu -Byo*) which meant 'splitting of one's mind or fragmentation of the soul' and was associated with a disorganised, destructive personality and a sense of certain fatality, was changed to 'togo-shiccho-sho' translated as 'loss of integration disorder' (Nishimura, 2003).

Similarly, in Chinese culture, aetiological beliefs about mental illness intensify the stigma focused on people with schizophrenia, and their family members (Lin & Lin, 1980), as the popular 'moral view' considers mental illness a punishment for ancestral misbehaviour or for a family's current misconduct. Also, in rural areas, the association of mental illness and malevolent spirits means that many seek the help of shamen (Li & Phillips, 1990). Also, in urban areas of China, psychosocial factors such as breakdown in family relationships and beliefs about genetic inheritance led to the discrimination of individuals with mental illness as well as their family members (Phillips, 1990).

In the traditional Arab world, mental illness can be associated with sorcery, while some precipitating factors are linked to social relationships (Al-Adawi et al., 2002). Furthermore, it was suggested that concepts of mental illness were dictated by the philosophy of the time and there was a dearth of research

evidence to substantiate how mental illness was perceived in the Arab world (Harpham, 1994). For example, Moroccan families of individuals with schizophrenia experienced stigma in a manner similar to that of western cultures (Kadri et al., 2004). Despite the lack of consensus, it was argued that research on stigma from Western and non-Western countries, including Arab and Muslim countries, produced similar results (Murphy, 1976; Shurka, 1983; Weiss et al., 2001). Of interest, one finding showed that in Arab and Muslim countries stigma had no relation to religion, compared with its relation to social and cultural aspects (Haj-Yahia, 1999).

Accordingly, there was little knowledge regarding culture and nationality and how these influenced the stigmatisation of mental illness (Littlewood, 2004). So, in any cross-cultural comparison of attitudes toward mental illness, there needs to be consideration as to whether mental illness, or a similar category, is recognised in all societies. However, there was consensus that in all societies, there were conditions similar to mental illness and chronic schizophrenia, which were recognised as distinct and undesirable states, but there were oral and written traditions in Ireland, China and India which placed a positive value on insanity (Littlewood, 2004).

2.13 <u>Section B: Review Of Research Studies On Stigmatisation Of</u> People With Mental Illness

This section of the literature review presented an analysis of research findings on stigmatisation of people with mental illness and attitudes towards mental illness and its treatment. An analysis of the research on stigma in section

(A), in combination with findings from this section (B), were used to develop a conceptual model of stigmatisation and approach for this study.

Evidently, major studies in the field of attitudes to mental illness were conducted in the 1950's, and it was noted that at that time the community mental health movement in the United States of America [US] received its impetus from experiences from the Second World War, in the restoration of psychological casualties to combat function on the battlefield (Elpers, 1987). It took another forty years before the United Kingdom activated care in the community for the mentally ill and the closure of large mental asylums (DH, 1990).

Consequently, it was suggested that American asylums were emptied at a greater rate and earlier than the UK. So, care in the community for the mentally ill in America had a longer experimental period, and consequently, more research into public attitudes and stigma had been carried out (Bean and Mounser, 1989).

It appeared that most of the UK studies were done in the early 1960's and 1970's, while those from the 1990's emerged during the initial phase of 'Care in the community' (DH, 1990). However, there was a dearth of published UK research studies on the stigma of mental illness beyond this period. This section of the review will explore the evidence from early studies to more recent research. This time span was necessary because of the scarcity of studies on stigma and attitudes towards mental illness.

2.13.1. Public Attitudes Towards Mental Illness And The Mentally III

2.13.1.1 Early Studies

From very early research on attitudes there has been a dissonance between reported and actual attitudes. For example, La Piere (1931) accompanied by a Chinese couple, visited hotels and restaurants in the U.S. seeking accommodation, and drove over ten thousand miles visiting 250 hotel establishments. Of note, only one hotel refused to accommodate them. Six months later, the establishments that were visited were re-surveyed and asked if Chinese guests would be accepted. Consequently, responses were almost uniformly negative. In this study, the dissonance between reported and actual attitudes, will become evident.

Early studies carried out in the US, found that public feelings about the mentally ill were characterised by fear, stigmatisation, rejection and a desire to avoid the mentally ill at all costs (Allen 1943; Bingham, 1951). In contrast, there were studies which showed that the public was moving toward a more humanitarian approach towards the mentally ill and were also beginning to adopt a scientific point of view about mental illness (Ramsey and Siepp, 1948; Woodward, 1951).

Amongst the early studies, the most quoted and published according to Crocetti et al., (1971) was that of Star (1955) who interviewed 3500 people in a national sample and employed case descriptions or vignettes of mentally ill people. Star (1955) concluded that subjects in the sample only labelled someone as being mentally ill and psychotic if they exhibited assaulting and threatening behaviour. Of note, Star's (1955) vignettes achieved standard use in many subsequent studies.

Interestingly, the terminology and case descriptions used in many studies about mental illness referred mostly to those whom professionals would describe as psychotic or schizophrenic (Rabkin, 1974). It followed that when research cases presented a scenario of a disturbed, mentally ill patient, members of the public were more likely to view these as unpredictable and dangerous and wanted to maintain social distance. Of greater interest, the clinical scenarios described and presented were situations that the general public were hardly likely to encounter (Rabkin, 1974).

A consensus view of what it meant to be mentally ill was observed in some public samples, which adhered to a single operational definition of a mental patient to mean someone who had been a patient at a psychiatric institution, but the term 'mentally ill' was not used for people who were seen in private consultations or clinics (Johannsen, 1969). It can be argued that public attitude towards the mentally ill was shaped, at least to some extent, by the image of madness presented to the public, which was also a reflection of the attitudes of researchers, in their stereotypical portrayals of disturbed, psychotic patients, portrayed in case vignettes.

Early studies, such as those by Star (1955) used case scenarios, which were almost invariably describing a patient with simple or paranoid schizophrenia (Rabkin, 1974). It can also be seen that attitude scales, such as the 'Opinions about Mental Illness' scale (Cohen and Struening, 1962) stated that use of the term 'mental illness' referred to hospitalised patients only and the term 'mental illness' was popularly used to identify psychotic conditions, such as schizophrenia, which lead to hospitalisation (Rabkin, 1974).

An early longitudinal study, which explored what the public knew and felt about mental illness, found that the mentally ill were regarded with fear, distrust and dislike by the general public and the stigma associated with mental illness was pervasive across social groups and attitude indicators such as age, social status and level of education (Nunnally, 1961).

Despite similarity in results, with more modern studies, such as the Office for National Statistics [ONS] (2007; 2008), early studies were criticised on methodological issues concerning population sizes and significance of effects, particularly where results were presented in percentages (Rabkin, 1974). Also, the case vignettes presented to research subjects appeared to be emotive and overloaded with negative descriptions of acute, severe mental illness. In order to declare that the public rejected the mentally ill on a social distance scale, the level of social distance that constituted rejection was not established. In addition, the proportion of respondents that chose the social distance as rejecting was not defined. Nevertheless, similar studies (Allen, 1943; Bingham, 1951; Star, 1955; Nunnally, 1961; Crocetti and Lemkau, 1963) suggested that negative attitudes toward mental illness prevailed.

The following table (Table 2.1) is a summary of studies on public attitudes towards mental illness, which met the inclusion criteria and scored favourably on evaluation. The evaluative scores were derived from the use of a quality of study instrument which was adapted from Smith and Stullenbarger (1991) and used in conjunction with Cormack's (2000) literature review questions (see appendix iv).

Table 2.1a Key Literature Summary

Author/	Research	Docian	Findings	Evaluative Score
Date	Objectives	Design	Findings	(0-3)
Cumming & Cumming, (1957)	To evaluate public attitudes to mental illness before and after a 6 month educational campaign	Survey (n=X)	Programme rejected by the community	1.0
Nunnally, (1961)	To examine public knowledge and attitude towards mental illness	Survey (n=400) knowledge scale and an attitude scale	General stigma attached to mental illness. Everyone, regardless of age and education, regard the mentally ill as being worthless	1.0
Crocetti et al. , (1971)	To examine attitudes and social distance from ex-mental hospital patients	Survey (n=937) Data collection included Star's case vignettes and a social distance scale	Very positive attitude towards mental illness and optimism about treatment outcomes	1.0
Huxley, (1993)	To assess attitudes towards mental illness and knowledge of a local mental health facility	Survey (n=154) included Star's case vignettes and a questionnaire	There's a degree of openness about mental illness, but a stigma remains pervasive. Negative attitude towards mental health facility.	1.5
Murphy et al. , (1993)	To assess the public's attitudes towards mental illness and expsychiatric patients	Survey (n=200) Data collection included an attitude scale and a familiarity scale	Higher knowledge of mental illness meant less fear and more sympathy toward the mentally ill	2.0

Table 2.1b Key Literature Summary (Cont'd)

Author/ Date	Research Objectives	Design	Findings	Evaluative Score (0-3)
Ingamells et al. , (1996)	To assess public attitudes towards people with mental illnesses	Survey (n=208) Data collection included a social distance scale, an experience scale, Star's case vignettes and a questionnaire	Disturbed behaviour correlated positively with negative attitudes	2.0
Brockington et al., (1993)	Opinions about mental illness and its demographic correlates	Survey (n=1987) Data collection included an attitude scale, Star's case vignettes and a questionnaire	Positive attitudes towards the mentally ill. Personal experience is associated with tolerance	2.5
Wolff et al., (1996)	To assess attitudes toward the mentally ill and a proposed group home.	Survey (n=215) Data collection included an attitude scale and an interview about mental illness.	Lower educational and social classes had more negative attitudes as did ethnic minority groups	2.5

Table 2.1c Key Literature Summary (Cont'd)

Author/ Date	Research Objectives	Design	Findings	Evaluative Score (0-3)
Green et al. , (2003)	To assess services support for clients to deal with stigma	Interview (n=27)	All subjects reported being affected by stigma and a fear of stigma. Stigma more restrictive than overt discrimination	2.0
Knight et al. , (2003)	To assess personal reports of stigma in people with schizophrenia	Interview (n=06)	Themes of judgement, comparison and personal understanding of mental health emerged. Stigma was evident as public stigma and self-stigma.	2.5
Angermeyer and Dietrich (2006)	To review population-based attitude research in psychiatry	European Studies (n=62) Mainly descriptive studies	Evidence needed for interventions to reduce stigma and improve attitudes	1.5
Lauber et al. , (2006)	To assess the influence of sociological and psychological factors on community care	Public opinion telephone survey (n= 1737)	Most respondents had positive attitudes towards community care. Individual traits and emotive issues impact public attitudes toward community care	2.0
Office for National Statistics, (2008)	Monitor time trends on public attitudes	Survey (n=1703)	Attitudes are broadly positive, whilst attitudes about fear of patients have worsened	2.0

2.14 More Recent Studies.

Recent studies on public attitudes to mental illness tended to employ methodology which was surprisingly similar to that of early studies, namely the employment of Star's (1955) vignettes, attitude scales and an exploration of socio-demographic variables. However, one essential difference between early and more recent studies was the use of more powerful psychometric testing, such as correlations, regression analysis and analysis of variance.

Since the 1980s, studies have shown some consensus that benevolence, authoritarianism and fear of the mentally ill were the main aspects of public attitudes to mental illness (Taylor and Dear, 1981; Brockington et al., 1993; Huxley, 1993; Wolff et al., 1996). In contrast, one argument observed that previous studies had methodological limitations, namely the survey method, attitude scales and case vignettes, which all failed to recognise the complexity of expressed attitudes likely to be encountered in real-life community care contexts and the way in which protagonists structured their arguments (Cowan, 2002).

Despite the criticism of methodological shortcomings of early studies, Cowan's (2002) study produced similar results to those which were criticised. Consequently, Cowan's (2002) view warranted attention when addressing public attitudes in contemporary society, particularly in the context of shifting paradigms in treatment, health service configurations and service-user involvement in the delivery of mental health services.

Some evidence reported positive attitudes towards community care (Lauber et al., 2006). Similarly, the latest 'Attitudes to Mental Illness' survey by the Office for National Statistics (2008) found that the public were generally

sympathetic to the mentally ill, but since 1994 fear of the mentally ill has increased. In contrast, one study noted that the public had a sophisticated view of mental illness and different types of mental illness attracted different types of prejudice, however, all of these prejudices were predominantly negative (Crisp et al., 2000).

It was seen that in early studies, the use of case vignettes and attitude scales did not unravel complex attitudes and confronted research subjects with scenarios based in clinical psychiatry and the institutional management of mental illness, scenarios which very few subjects were likely to encounter (Cowan, 2002). It was also proposed that case vignettes served to engender hypothetical reactions and attitudes, which strongly deviated from real life situations (Guimon et al., 1999).

In any event, the absence of consensus in more recent evidence was patent. For instance, it was suggested that there were predominantly negative attitudes towards the mentally ill (Angermeyer and Matschinger, 2005), public attitudes had become more liberal (Huxley, 1993), whilst others suggested that these were stagnant (Brockington et al., 1996; Ingamells et al., 1996), but more recent evidence found that attitudes have deteriorated (ONS, 2007; ONS, 2008; Priory Group, 2007).

2.15 United Kingdom Studies

Brockington et al., (1993) employed quota sampling and used the Market Opinion Research Institute [MORI] to carry out a house to house survey, but this study sample was not representative nor was it random, even though two

thousand subjects were interviewed. Results via factor analysis were similar to those of an early Canadian study by Taylor and Dear (1981). In fact, both of these studies identified benevolence, fear of the mentally ill and authoritarianism as key factors affecting attitudes.

In addition, this study found predominantly tolerant attitudes towards the mentally ill, but these positive attitudes needed to be examined in light of methodological shortcomings of interviewer bias and possible socially desirable responses. Of note, the Brockington et al., (1993) study was carried out in two areas of Birmingham, in which one area had a traditional mental asylum, where attitude results were more positive. The other area had community-based mental health facilities only and attitude results were more negative. It appeared that in the first instance, attitudes were more positive because of less social interaction between residents and the mentally ill, and residents were 'happy' as long as the mentally ill patients were contained in asylums. In the study, fear and social exclusion of the mentally ill were also found to influence attitudes towards the mentally ill, and corroborated similar findings from Taylor and Dear (1981).

A similar study also explored the attitudes of the residents of two streets in Lambeth, prior to the opening of group homes for the mentally ill, by employment of interviews and the Community Attitudes to the Mentally Ill (CAMI) inventory (Taylor and Dear, 1981). Results showed that any intervention aimed at changing attitudes to mentally ill people should be aimed at non-whites, younger people with children and older people, because these groups showed more negative attitudes towards the mentally ill and the citing of the community mental health facility in their community (Wolff et al., 1996). Of further interest, higher

education levels amongst the public sample were consistent with higher tolerance of the mentally ill.

There were a number of factors which could have impacted the results from Wolff et al. (1996). For example, there was a spate of negative media publicity regarding care in the community, around the time of this study (Ritchie et al., 1994; Holloway, 1996) and negative publicity about the mentally ill, combined with the introduction of 'Supervised Discharge', a restrictive legislation regarding mental health patients (DH, 1994; 1995; 1996) may have fuelled already intolerant attitudes which could have resulted in a polarisation of fears about personal safety. Of particular interest, in the Wolff et al. (1996) study, one third of the sample population was aware that a community facility for the mentally ill was about to be opened in their community. Furthermore, it was demonstrated that a survey of residents prior to setting up a group home for the mentally ill had higher responses in negative attitudes (Taylor and Dear, 1981). In addition, Wolff et al., (1996) acknowledged that the community residents had been exposed to many people behaving oddly in the streets, shouting and approaching them to ask for money, and this behaviour negatively impacted attitudes.

Similarly, Wolff et al. (1996) identified attitude factors such as benevolence, fear of the mentally ill and authoritarianism, results that corroborated those of Taylor and Dear (1981) and Brockington et al. (1993). Also, these results should be considered in the light of their population samples. It was evident that Taylor and Dear's (1981) sample came from the metropolitan area of Toronto in Canada, while the Brockington et al. (1993) sample came from the Midlands of England, and the Wolff et al., (1996) sample was drawn from

Inner London, which contained a disproportionate number of people of higher social class, few elderly people and an ethnic mix of West Indians, Africans and Asians (ONS, 2000).

Indeed, attitudes toward mental illness in non-western cultures had been less frequently explored, but varied widely (Gray, 2002). Also, there were no published studies which showed specific differences in attitudes toward mental illness between ethnic groups and cultures, in a similar environment. But, the finding that non-whites have more negative attitudes toward mental illness was at odds with those of Crisp et al., (2000) who found predominantly negative attitudes in their sample, of which ninety-five percent were white British.

It can be seen that culture can influence many aspects of mental illness, including how people from a given culture express and manifest their symptoms, their style of coping, family and community support and willingness to seek treatment (Fernando, 2002). In any case, the lack of evidence on the effect of culture on attitudes meant that there was no consensus on which culture had more negative attitudes. This study noted the lack of evidence in this aspect of stigmatisation and explored and compared attitudes between different ethnic groupings in its sample.

Another study used vignettes and included a social distance scale to identify variables that influenced public acceptance and attitudes towards people with mental illness, found that the social rejection of the mentally ill was influenced by the behaviour described in the vignette, the respondent's judgement about this behaviour and previous contact with mentally ill people (Ingamells et al., 1996). Furthermore, the findings also suggested that the mere

physical presence of someone with mental illness within the community was insufficient to produce negative attitudes and only people with behaviours deemed as disturbed were likely to be rejected by others in society (Ingamells, et al., 1996). Evidence which corroborated Ingamells et al., (1996) showed that those who reported little previous, personal, contact with the mentally ill were more rejecting than those having higher levels of contact (Trute and Loewen, 1978).

Evidently, the contact hypothesis, which suggested that exposure and social contact with the mentally ill, resulted in more positive attitudes, was supported by Trute and Loewen (1978) and Ingamells, et al., (1996), even though there was an absence of consensus in the review of the conceptual literature. Other evidence proposed that social acceptance of the mentally ill related positively to exposure to psychiatric services, and training former patients to assume non-patient roles resulted in a high degree of community acceptance (Roman and Floyd, 1981; Peterson (1986).

However, there were studies that did not support the contact hypothesis. For example, there were two studies which did not find any evidence to support the positive influence of psychiatric exposure on public attitudes to mental illness, nor any differences between the attitudes of the family members who had a psychiatric patient in their families and those of a control group, who did not have psychiatric patients in their families (Sellick and Goodear, 1985; Arkar and Eker, 1992). A similar study demonstrated that equal-status cooperative contact with a former mental health patient resulted in attitude change amongst students who

initially had negative attitudes, whereas merely being present in the same classroom did not produce any changes (Desforges et al., 1991).

Although there appeared to be some consensus in support of the contact hypothesis, there was no advancement towards a resolution as there continued to be conflicting evidence and inconsistencies about what contact with the mentally ill meant, and its impact on attitudes.

2.16 Recognition of Mental Illness

Evidence suggested that many members of the public cannot recognise specific mental disorders or different psychological distress, did not know the meaning of psychiatric terms and differed from professionals mental health workers about the causes and treatment of mental illness (Jorm, 2000; Brandli 1999; Hillert et al., 1999). It was also common for mental illness, such as schizophrenia, to be associated with a split personality (Angermeyer and Matschinger, 1999). It can be argued that if the public found it difficult to recognise mental illness, then levels of stigmatisation should be relatively low.

To the contrary, with regards to treatment, recovery and prognosis of mental illness, stigmatising attitudes were not always based on a lack of knowledge about mental disorder, and negative attitudes predominated because people with schizophrenia were seen as dangerous and unpredictable. (Crisp et al., 2000).

Likewise, professional attitudes towards mental illness were less optimistic about prognosis and long-term outcomes, when compared with that of the general public (Hugo, 2001. It can also be seen that mental health professionals

had more contact with the mentally ill, compared to the general public, but this did not support the 'contact hypothesis'. In argument, although attitudes expressed by professionals were more negative, these could have been a reflection of an informed or stigmatised view. However, one early study showed that mentally ill patients were more rejecting of people with mental illness than were their family members or professional staff, and patients were as negative in their opinions about mental illness as the public (Warner, 1985).

While some of the evidence suggested that mental health literacy was low amongst the public (Jorm, 2000), others proposed that there were negative attitudes which were not based on low levels of knowledge about mental illness (Brandli, 1999; Crisp et al., 2000). The contact hypothesis was not supported by the attitudes of healthcare professionals while service users also appeared to have more negative attitudes about mental illness, than the public.

2.17. Media Influence

Mental illness and people with mental illness were frequently depicted in the mass media, wherein portrayals of the mentally ill tended to be inaccurate, unfavourable and played a significant role in perpetuating harmful misconceptions about people who were mentally ill (Gerbner et al., 1981; Steadman & Cocozza, 1977; Monahan and Arnold, 1996). For instance, in a survey about experiences of stigma, members of the National Alliance for the Mentally Ill consistently cited media sources, particularly films and news stories about mentally ill killers, as primary contributors to the stigma of mental illness (Wahl and Harman, 1989). Interestingly and possibly linked to stigma, sources

on publicity about mental illness were also most often reported to be from television news and newspapers respectively (ONS, 2008). Another example was seen in an analysis of prime-time television in the USA, which showed that the mentally ill were portrayed to be about ten times more violent than other television characters (Diefenbach, 1997). The media also portrayed people with mental illness as having a negative quality of life and making an undesirable impact on society.

In addition, forty-six percent of national press coverage linked mental illness to violence and criminality and the representation and dramatic reporting by the media, particularly television, radio and newspapers, of a few rare cases of homicides committed by people who were mentally ill, was shown to exert a negative influence on the public's attitude to mental illness (Ward, 1997; Guimon, 2001).

In contention, public fears may reflect an inaccurate and exaggerated view of the association between mental illness and violence, but it would be wrong to dismiss such beliefs on the basis of their inaccuracy (Monahan, 1992). The public perception of a strong link between mental illness and violence was important, because they impacted laws and policies, which attempted to control the behaviour of the mentally ill, which in turn determined our informal responses and ways of interacting with people perceived to have mental illness (Monahan and Arnold, 1996).

For instance, in the United Kingdom, in 1995, there were two particular cases of homicide, committed by people with mental illness, which received much attention by the media and the government. 'Insanity over the care of the

mentally ill' (The Times, 1995a), 'Sanity is a return to the asylums' (The Times, 1995b) and 'Mental Hospitals ignored killers fifteen years of violence' (The Times, 1995c) were some of the headlines of that time. These headlines appeared to invoke public fear and resentment of community care to the point where the minister for health was in the spotlight for a prolonged period, defending 'Care in the Community'. Subsequently, the Mental Health Act was amended to incorporate the 'Supervised Discharge' of mentally ill patients. Again, at that time, Health Authorities and NHS Trusts feared that the cost of relocating mentally ill patients into the community would escalate, after a judge ruled that homeowners in proximity to community group homes for the mentally ill could be entitled to compensation, if there was a fall in their property value (The Times, 1995d).

Contrary to public fear of the mentally ill, was the fact that there was little fluctuation in the number of people in England and Wales, with a mental illness, who committed a homicide during the period 1957 to 1995, and furthermore, there was a three percent annual decline in the contribution of people with a diagnosed mental illness to the official crime statistics (Taylor and Gunn, 1999).

However, the risk of a person with mental illness committing a serious, violent offence was very small, in fact, people with mental illness were far more likely to be victims of crime ((Hafner and Boker, 1973; Walsh et al, 2003). It seemed that the evidence of an increased risk of danger from people with mental illness was not apparent, and it was stigmatising and discriminating to claim that mentally ill people living in the community put residents at greater risk.

In an alternative view, it was argued that personal experience was a stronger influence on beliefs and attitudes, than the negative messages which were presented by the media (Philo, 1997). However, respondents who had non-violent experiences with the mentally ill, which were then overlaid by media influences; traced their beliefs mostly to violent portrayals in fiction or to the negative reporting of incidents involving people with mental illness (Monahan and Arnold, 1996).

It was argued that the negative impact of stigmatised, sensationalistic reporting of rare incidents involving the mentally ill, may be compounded by the rarity of positive portrayals of people with mental illness, combined with a failure to acknowledge that people with mental illness have an increased risk of being victims of violence and crime (Day and Page, 1986; Read and Baker, 1996; Walsh et al., 2003).

Furthermore, and of significance, news reports about mental illness and violence provided a model for thinking about violence, its causes and solutions and the news media had the unique ability to tell people what to think and how to think about violence and mental illness; and these factors had a critical impact on public health practice and policy (Taylor and Sorenson, 2002).

Newspaper stories about homicides and violence by people with mental illness provided and searched for an explanation, because in their rationale, neither suicide nor homicide should happen without an explanation. As a matter of fact, 'causal searching', or how and why an event occurred, was a main factor in some newspaper accounts of crimes by mentally ill people (Coyle and MacWhammel, 2002). Consequently, media reports usually linked mental illness

with danger and violence and the need for social control, the failure of community care, inadequate supervision in the community and poor management of mental health services (Taylor and Sorenson, 2002).

In another example, following the murder of Margaret Muller, who was jogging in Victoria Park in London, an article titled '400 Care in the Community Patients Living by Murder Park' appeared in the 'Daily Mail' on February 21st 2003. Therein, the lead police superintendent admitted that officers were very surprised to discover that so many 'care in the community patients' lived so close to the park. Subsequent to this revelation, the police came up with the theory that Margaret was 'murdered by a deranged psychiatric patient living in the There were no crime statistics available for reported violent community'. incidents within the precincts of Victoria Park; but given the high number of 'care in the community' mental health patients that lived nearby, and if there was an increased risk of public danger, then there should be a relatively high number of violent incidents in that area, given the high concentration of people with mental illness that lived there. Articles such as the one which appeared in the 'Daily Mail,' was speculative and sensational in content, but also portrayed a very false and negative picture of people with mental illness, which as the evidence suggested, reinforced public fears and thinking that everyone with a mental illness was dangerous (Rethink, 2006; Lalani et al, 2006).

Likewise, in September of 2003, Frank Bruno, former world heavyweight boxing champion was admitted, under a section of the Mental Health Act (1983), to a mental health unit in Essex. Subsequently, 'The Sun' newspaper ran an early edition headline titled 'Bonkers Bruno Locked Up'. This scoop caused

much public outrage and condemnation from mental health charities, such as SANE and MIND. Later on that day, the Sun realised its mistake and changed the second edition headline to 'Sad Bruno in Mental Health Home', decided to set up a special charity for people with mental illness, and made an initial donation of ten thousand pounds.

It can be seen that there was a positive outcome from this incident; probably because of the celebrity status of Frank Bruno and probably because he was admitted for treatment of depression, which has been found to be less stigmatised than schizophrenia (Link, 2001). However, public support and positive attitudes toward mental illness seemed non-existent when someone with a diagnosis of schizophrenia was involved in violence.

It would appear that sensationalistic headlines made it worse for people who were trying to come to terms with mental illness and created barriers towards the de-stigmatisation of mental illness. There seemed to be no worse form of insult than to label someone 'mad'. It would seem that being 'mad' whatever that meant, carried a stigma that appeared to be indelible (Rethink, 2006).

For another reason, the artistic portrayal and iconic images of mental illness have always been negative, with madness seen as an undefined construct, with icons for treatment and representation that changed over time, but interrelated and reappeared to represent mental illness as an undifferentiated sense of deviancy (Gilman, 1982). The iconography of mental illness was seen in the use of a 'straightjacket', an old item for physical restraint, which caused public rejection when used as an anti-stigma icon by Rethink, a mental health

advocacy group (London et al., 2006). In fact, the icons of madness were extended to any deviance from society's norms for sanity, such as, the maniac, the idiot, the melancholic, the wild man or the possessed and aspects of the imagery of each group permeated the others, creating an interchangeable set of icons by which the insane were observed and identified (Gilman, 1982).

It appeared that the media, including the arts, were imbued with the power to reinforce opinions and influence attitudes and beliefs (Lalani and London, 2006; Lalani et al., 2006), were an important source of information on mental illness (Stark et al, 2004) and impacted on knowledge and understanding of public health issues (Taylor and Sorenson, 2002).

There is now clear consensus that negative media representations of mental illness reinforced prejudice and correlated with negative public attitudes towards people with mental illness (Cutcliffe and Hannigan, 2001; Olstead, 2002), and also evident in stereotypical portrayal by movies of people with mental illness, including the rebellious free spirit, violent seductress, mad scientist, narcissistic parasite and sly manipulator (Schneider, 2003) and these portrayals of stereotypical crazy behaviour appeared to fuel stigma.

In the past, negative media coverage of mental illness acted as a catalyst in the polarisation of fear of mental illness and the mentally ill and reinforced misconceptions and ignorance leading to an erroneous link of violence with mental illness (SEU, 2004). One reason for media sensationalism may be because the media was economically driven and often produced sensational and dramatic headlines, which could be at odds with factual coverage of mental health issues and portrayal of people with mental illness (Lalani et al., 2006).

In a recent survey, the media was cited as being mainly responsible for the stigma surrounding severe mental illness, and one respondent argued that it was difficult to know whether the media caused or reflected stigma, but whatever was true, the media had the power to change it (Rethink, 2006).

Evidence showed that a divergence emerged in attitudes towards media coverage of people with mental illness and media coverage of people with common mental health problems was becoming increasingly balanced and sympathetic, while more positive coverage of serious mental illness appeared to be evolving at a slower pace (National Institute for Mental Health in England [NIMHE], 2006).

2.18. <u>Service-Users' Perspectives</u>

For service users, all types of discrimination had a detrimental effect on mental health, not only after the illness developed, but also at the onset of the illness (Penn and Wykes, 2003). Perceived alienation was also implicated as being crucial to the onset of psychosis, with an increased rate of reported delusional ideation in people who experienced more discrimination, which appeared to be invasive, even before the onset of the illness (Janssen et al., 2003).

Of equal importance, it was demonstrated that after the onset of symptoms of mental illness, there was a further effect of discrimination and perceived stigma through contact with mental health services, which showed an increase in the delay to initial treatment, with subsequent impact on the long-term recovery rates in psychosis, particularly schizophrenia (Norman and Malla, 2001).

Consequently, being linked to stereotypes and being labelled mentally ill may affect an individual's self-esteem, and the diminished self-efficacy which resulted from self-stigmatisation, interfered with aspects of rehabilitation, including the pursuit of independent living opportunities and motivation to obtain competitive employment (Link et al., 1987; Link, 1982; Wahl, 1999).

2.18.1 Perceived Stigma

The following qualitative study by Knight et al. (2003) was used as a basis for exploring service users' perception of stigma, because there was a dearth of published evidence on the lived experience of stigma from service users' and moreover, this study aimed to capture the subjective, lived experience and perceptions of stigma and discrimination in people with mental illness, which was also central to the enquiry in this study.

Knight et al (2003) used semi-structured interviews to capture an account of the life experiences of six people with a diagnosis of schizophrenia, with a focus on their personal issues on stigma and discrimination. Interestingly, and similar to one aspect in the data analysis of this study, Interpretative Phenomenological Analysis [IPA] which focused on an interpretation of subjective cognitions and experiences to arrive at personal perception, was also used in the analysis of the data. Results from Knight et al. (2003) showed three super-ordinate themes, 'judgement', 'comparison' and 'personal understanding of the issue of mental illness' which were explored to illustrate the service user perspective on perception of stigma.

The theme of 'judgement' emerged from anticipated and actual reactions that subjects encountered from friends, family and people in authority, which were represented in medicine, the police and society in general. It can be seen that these responses were congruent with a social cognitive perspective of public stigma, which meant they were comprised of stereotypical attitudes, prejudices and discrimination. Again, attitudes were found to be predominantly negative and similar to findings which illustrated a paucity of knowledge about mental illness (Jorm, 2000). Paradoxically, for service users, sources of stigma were often from where they were seeking help, which corroborated evidence which suggested that iatrogenic stigmatisation was evident through diagnostic labels, mental health legislation, in mental health services and in the treatment of symptoms (Sartorius, 2002).

In addition, for service users, discrimination was perceived and experienced through familial and social interactions, with ramifications for their living and work environments. For example, one service user reported that being diagnosed a schizophrenic, meant that you could not move into alternate housing and you were not accepted when you went back to work, nor did it matter that you could do the job, because you were not treated as an equal and people were always a bit wary of you (Knight et al., 2003).

The theme of 'comparison' was representative of service user's intra and inter-personal dilemmas. For example, subjects explored how their lives were, are and would be affected as a result of their illness. In particular, service users reflected on their earlier life as a person unaffected by mental illness, but contrasted issues of normality, ability and happiness with their current life

situations, and acknowledged how their lives had undergone a qualitative shift, which for many appeared irreversible (Knight et al, 2003). However, a few of the participants believed that their experience of mental illness afforded them the opportunity for intellectual and personal development, from which they felt a sense of liberation. Despite this positive aspect, for many participants, perceptions of future life were similarly grounded in the expectation of continuing mental illness and stigmatisation (Knight et al, 2003).

In the theme of 'personal understanding of mental illness', service users reflected on whether they viewed their situation as being illness and explained that it was a decision in which they played a passive role. Service users identified three primary methods of coping, which were 'avoidance-withdrawal', 'education' and 'secrecy' which involved elements similar to 'passing' and 'covering' (Goffman, 1963) and was shown to produce more harm to the individual, than benefit (Link et al., 1999). In addition, although avoidance was seen as a protective strategy against stigma, in so doing, mental health service users reinforced social exclusion, and in cases where self-stigmatisation occurred, it proved to be self-consuming and potentially life-threatening (Gallo, 1994).

Furthermore, the theme of 'education', which referred to informing people about one's individual life situation, was advocated to pre-empt potentially negative situations, but to the contrary, seemed to have the opposite effect. To illustrate, one subject said 'I don't tell members of the public, I mean people don't know, not any more' (Knight et al, 2003 page 217) and for others, the wish to disclose information about their illness was over-ridden by concerns about the

effects of disclosure. The impact of secrecy was seen in an early study which demonstrated that service users who believed others knew about their psychiatric history, performed tasks less adequately and felt less appreciated in their efforts and it also became apparent that a negative cycle was perpetuated, as neutral observers then viewed the service users as being more tense and poorly adjusted (Farina et al., 1971).

Indeed, this study by Knight et al (2003) demonstrated service users' intra and inter-personal aspects of perceived stigma. For the group of service users, who had diagnoses of schizophrenia, public stigma was evident through prejudice and discrimination from a number of sources, which included family, friends, society, the police and mental health professionals. It was also seen that self-stigmatisation meant low self-esteem and an ongoing struggle for acceptance by society.

Of more concern, it was noted that although clients were given a diagnosis of schizophrenia, it became apparent that they had either not been given in-depth explanations of what schizophrenia was, or had been given information that was difficult to understand. Subsequently, service users attempted to assimilate their personality, moods and life status into a model of dissociative identity disorder, believing that they had a split personality (Knight et al., 2003).

2.19. Summary Of Findings

The following was a summary of findings from the literature review. It was important to note that the theories examined in this review had differing perspective on stigma, but neither accounted for the origins and mechanisms of

stigmatisation in people with mental illness. In one account, stigma was deemed to be a social construct, probably a reflection of the process of social interaction, and not a property of people who are stigmatised (Link and Phelan, 1999). Stigmatisation occurred within the context of a particular culture and appeared to be framed in an economic, political, historical and social context. However, the contemporary meaning of stigma did not deviate much from its original meaning, which was that of moral disapproval.

It appeared that different societies created hierarchies of desirable and undesirable attributes and appeared to set rules for the management of such attributes. For example, the use of avoidance to reduce contact with stigmatised persons. In other words, there appeared to be some consensus in how people with mental illness, were stigmatised, are treated.

An early notion in psychological theories supported the concept of stigmatisation in suggesting that self-interests were basic elements and sources of conflict in social life which caused divisions and exclusions that can lead to struggles amongst members of society. While this line of reasoning may give some rationale for the existence of stigmatisation, it does not clarify why all types of social discrimination appear to be present amongst disempowered groups in society.

Psychological and psychoanalytic theories suggested that there was competition for resources and internal personality conflict which caused anxiety within people who might stigmatise. While this appeared to have some credence, it failed to account for people who did not stigmatise and the mentally ill. It was

also notable that personality conflict was used to illustrate how stigmatisation may develop.

Knowledge structures, chunks of knowledge and schema were employed to explain the presence of learnt actions and behaviour, but did not explain how behaviours and actions were linked or the processes which may be involved. Attribution theory explored motivation and emotions and introduced an essential element in stigmatisation.

Goffman's (1963) seminal work on stigma spawned refinements, elaborations and research which continued to show the negative impact of stigma (Link & Phelan, 2001). While early use of the word stigma portrayed individuals who deviated from a social norm, were discredited and had 'spoiled identities', later on the stigma of mental illness was also associated with shame, lower status and humiliation of people who were stigmatised (Simon, 1992).

Goffman (1963) postulated that stigma arose through symbolic interactionism, but somehow, stigma was transformed and seen as a mark or something about the stigmatised person (Link & Phelan, 2001) which rendered difference and deviance from society's norms.

Most of the evidence regarding stigma was on schizophrenia, which was seen to be the most stigmatised of mental illnesses and in combination with this dimension, rendered an additional burden to the experience of mental illness, which led to social isolation, limited life chances and delayed help-seeking behaviour (Lyons and McLoughlin, 2001).

Research on stigma attempted to unravel the process of stigmatisation and the effect of labelling, but much of the knowledge on stigma can be sourced

to research on attitudes and belief about mental illness among the public, which conceded that attitudes were primarily negative (Nunnally, 1961; Brockington et al., 1993; Huxley, 1993; Ingamells, et al., 1996; Wolff, et al., 1996; Angermeyer and Matschinger, 1997; Crisp et al., 2000; ONS, 2007; ONS, 2008; Priory Group, 2007).

A review of research on attitudes to mental illness from 1990 to 1994, reported that the body of evidence on the attitudes of service users or people with mental illness was very limited (Angermeyer and Deitrich, 2006). While people with schizophrenia were often perceived as dangerous, unpredictable and frightening, the research evidence did not provide any evidence of the relationship between public attitudes and actual behaviour towards people with mental illness, but hypothesised on what may occur if the public came into contact with someone who was suffering from a mental illness. The research on attitude towards mental illness employed theories and concepts that were uniformed by the lived experience of people with mental illness (Angermeyer and Deitrich, 2006).

2.19.1 Public Attitudes

Research methods on the stigma of mental illness included surveys, social distance scales and case vignettes to illustrate the degree of mental illness portrayed, and meant to show the social situations in which people with mental illness were tolerated or excluded (Rabkin, 1974). However, a more recent review on attitudes towards mental illness observed the use of cross cultural comparisons, time trends and the testing of theory-based models of

stigmatisation (Angermeyer and Deitrich, 2006). Despite the time difference between Rabkin (1974) and Angermeyer and Deitrich (2006), the result of both reviews provided similar results, suggesting that the public continue to have misconceptions about mental illness and attitudes were negative (ONS, 2007; ONS, 2008).

In addition, research studies appeared to be a biased in their use of case vignettes. For instance, in portrayals of schizophrenia, a biological explanation and psychotropic medication was favoured, whilst in depression, psychosocial stresses and psychological therapy was favoured (Angermeyer and Deitrich, 2006). It can be seen that the use of biological pathology and recommendation of a more austere treatment for schizophrenia may also be a reflection of a more stigmatised condition or researcher prejudice.

There were methodological limitations in researching stigma and social distance. For instance, it was not clear whether the evaluated attitude towards mental illness and mentally ill people were valuable in actually predicting social behaviour toward mentally ill people. Secondly, a person doing a cognitive task, such as a paper and pencil survey, functioned on a different level, compared to facing real-life, disturbed behaviour (Guimon et al., 1999). Apart from the failure to relate attitudes to behaviour, earlier and later research on attitudes to mental illness appeared to be mainly cross-sectional and atheoretical (Angermeyer and Deitrich, 2006).

Despite the methodological shortcomings, research on attitudes to mental illness have explored demographic variables such as age and ethnicity, and findings showed that attitudes to mental illness were negative and the mentally ill

were seen as dangerous and unpredictable (Nunally, 1961; Huxley, 1993; Ingamells, et al., 1996; Angermeyer and Matschinger, 1999; Crisp et al., 2000). It became evident that in the United Kingdom little research had been carried out on attitudes to mental illness and even less on service users' attitudes or perceptions of stigma.

Link and Phelan's (2001) model of stigmatisation was useful because it encompassed aspects of Goffman's (1963) view of stigma, loss of status and social exclusion and also entailed the notion of a power imbalance between people who were stigmatised and stigmatisers. Of more importance, Link and Phelan's (2001) model, viewed stigma by its discriminative effects and ways in which it functioned to reinforce existing social inequalities (Parker and Aggleton, 2003).

The literature on theories and models of stigma appeared to focus either on an individualistic or functionalist approach to stigma. Functionalist arguments have been used to support the relationship between discrimination and social power. However, the social control model defined stigma only as that which led to discrimination and social inequality. It was also seen how people with mental illness could experience stigma, not only from the public, but also from healthcare professionals. As a result, the combined social and professional stigma may also act to inhibit social inclusion and recovery.

It was also evident that models and theories of stigmatisation did not take into account the three sources of stigmatisation for people with mental illness, which was stigma from the public, stigma from healthcare professionals during the course of treatment, and self-stigmatisation.

2.19.2 Labelling and Stigma

Since the emergence of the labelling theory as a deviance paradigm, one of the central issues sought to be resolved was whether mental patients suffered stigmatisation and social rejection as a consequence of labelling (Link, Cullen, Frank and Wozniak, 1987; Link et al, 1989; Huffine and Clausen, 1979; Scheff, 1974). However, there was no apparent consensus on the impact of labels in people with mental illness.

Stigmatisation can result from either the expectation or enactment of rejection or from discrimination and feelings of devaluation (Link, 1987). Coping mechanisms employed usually involved withdrawal, secrecy, and the education of others (Goffman, 1963; Knight et al, 2003). This study was interested in finding out if coping mechanisms of 'covering' and 'passing', as described by Goffman (1963) were still used by service users, and endeavoured to explore this concept. Indeed, the choice of secrecy may extend to deliberately concealing the deviance (passing) or employing subtle strategies to keep the stigma from being overly intrusive.

Furthermore, the evidence on stigma indicated that it was a factor which led to discrimination (Link and Phelan, 2001). Interestingly, what the public believed and intended as behaviour, was measured by reports. Therefore, discrimination against the mentally ill was measured indirectly and assumed that this was as a result of stigma.

Again, there were issues with this approach to stigma research because what people reported as belief and intended behaviour may not come to pass, possibly as a result of the potential consequences for such behaviour. There was

no evidence of a direct correlation between stigma and discrimination even though stigma can lead to discrimination. It must also be noted that apart from stigmatisation, a person with mental illness can also be refused a job on other grounds, for example, because of racism or sexism.

Another issue concerned the attempt to connect service users' reactions to stigma and the measured level of stigma that existed in the general population. A person who expressed stigmatising attitudes might never act on these and whatever stigma someone with a mental illness perceived cannot be directly related to discrimination from the public. In other words, service users' response to public attitudes may not necessarily be directly related to levels of stigma in the population, but can also be related to perceptions and expectations of rejection.

Another challenge lay in defining stigma as something which led to discrimination. This approach facilitated the use of functionalist models of stigmatisation which generated a circular argument whereby the effect of stigma was also defined as its cause. Stigma can be viewed in terms of its functionalism, which included the social processes linked to the reproduction of inequality and exclusion that can be used by groups to maintain their dominant status within existing structures of social inequality (Parker and Aggleton, 2003). It can be argued that the functionalist argument for stigma suggested that there may be a social need to perpetuate inequality, which caused stigma that led to discrimination.

While each culture had explanations regarding mental illness, in all cultures there were conditions similar to schizophrenia, and recognised as distinct and undesirable states (Littlewood, 2004). In explaining mental illness in

western culture, emphasis was placed on psychological factors, life events and the effects of stress, but non-western cultures also included social and religious factors such as spirit possession, witchcraft, divine retribution and religious taboos.

2. 20 Directions For This Research

An examination of the findings of this review indicated a number of issues which significantly informed this research on stigma. Initially, it was apparent that the study should focus, not only on public attitudes, but moreso, on the lived experience of service users, which was missing from the evidence base. It was also seen that much of the evidence on stigma research was derived from the public. But, the current climate of service user involvement and empowerment warranted a re-orientation to widen service user participation, especially as they had the most intimate understanding of experiences of the stigma of mental illness. In addition, the value of public attitudes towards mental illness and the mentally ill in impacting attitude change or predicting behaviour towards people with mental illness was not apparent, nor can such findings be directly applied to people with mental illness.

Past studies employed case vignettes and attitude scales, but as observed, subjects usually relied on hypothetical reckoning as opposed to experience, in their responses (Guimon, 1999). Of more importance, many attitude scales were developed from clinical psychiatry, with overtones of overladen, stigmatised statements or case vignettes and there was criticism of studies for being atheoretical (Angermeyer and Deitrich, 2006).

Regarding methodology, many of the past studies tended to be reductionist and quantitative, and without acknowledgement of essential qualitative elements that warranted exploration. In fact, the legacy of research on attitudes and stigma towards mental illness represented a myopic view, as insights into lived experiences, such as stigma, were best evaluated through the use of qualitative methodology and with informants who experienced the mental illness and stigmatisation (Smith et al., 1999). In other words, it became clear, that to reduce individual experiences to quantitative data linked to cause, effect and correlations of factors, through the use of a single paradigm, would be replicating the methodology of past studies and unhelpful to what this study aimed to achieve.

CHAPTER THREE METHODOLOGY AND DESIGN

This chapter explores the philosophical underpinning and approach of this study, and also examines the scientific paradigms and theories which provided a rationale for choosing an approach. In addition, this section addresses issues with the attitude construct and challenges in operationalising and measuring attitude.

There is a detailed account of the study's design, sampling, data collection and procedures, ethical considerations, research tools and rationale and strategies for analysing the data. Special attention was given to the development of the study's attitude scale, including its psychometric properties, reliability and validity.

Research into the stigma of mental illness was criticised for lacking a theoretical basis (Angermeyer and Deitrich, 2006), so in attempting to address this deficit, this study adopted an evidence-based conceptual framework (Section 3.6; Figure 3.1) which hypothesised and tested a model of stigmatisation of mental health service users.

3.1 <u>Paradigmatic Discussion And Justification For Mixed Methodology</u>

Inherent in this study's thesis and its aims was the need for using different epistemological approaches and methods of enquiry. Both the quantitative and the qualitative paradigms were central to this study because of the element of measuring stigma in the public and service users and in comparing their constructs of stigma. In fact, the quantitative and qualitative paradigms,

frequently employed in research, are essentially different philosophical approaches and views about knowledge and scientific enquiry (Guba and Lincoln, 1994). Each area of scientific enquiry is based on a set of theoretical perspectives or paradigms which consists of a set of assumptions on which the research question is based, and are essentially ways of looking at the social world.

Paradigms are underpinning knowledge which help to shape the way people perceive and make sense of experiences (Kuhn, 1957). Paradigms are not based on logical criteria but on their adequacy as devices for summarising information, their ability to provide emotional satisfaction and thus inspire commitment, their usefulness for generating predictions of additional observations or as a framework for the organisation of knowledge (Kuhn, 1957). Also, the test of scientific enquiry must be measured in terms of workability and falsifiability, since scientific paradigms are tentative in nature (Popper, 1959).

For a theory to be scientific, rather than ideological, it must clearly rule out specific possible consequences, so that there was no question as to whether or not it was falsified, if these events did, in fact, come to pass (Popper, 1959). The more a theory survives attempts to refute it, the more highly corroborated it becomes, and this means that a theory can become increasingly reliable as a guide to predicting future events, and increase confidence, to some degree, if it reflects the regularities that actually exist. But, there is no guarantee that this would then be a complete and true reflection of reality (Hutcheon, 1995).

The debate on science in the acquisition of knowledge shows that any investigation starts with assumptions and accepted ways of doing things, which

helps to make thinking on an issue more explicit and systematic. This study employed a positivistic paradigm to gather and summarise information, generate predictions and to test the falsifiability of the hypothesis for the quantitative aspect. But, like any enquiry, the use of just one adopted stance, such as positivism, while being able to provide one perspective, within parameters, is less likely to produce a holistic view of public and service users' perception of the stigma of mental illness.

In this study, the need for a holistic view also focused on the increasing emphasis for research on how health service users participate and interact with services and the social context of healthcare delivery, which were deemed to be crucial to health outcomes (Tritter, 2008). A holistic approach to health research had implications and ramifications for research methods which needed to address what was a complex issue. A broader view of health means that researchers increasingly use patient narratives and experiences as valid data, which help in the meaning and understanding of an illness and how it impacts lived experience (Frid et al., 2000; Bury, 2001).

Implications for health research included finding ways to incorporate social aspects of an illness, for example stigma, and the usual epidemiological data, in addition to conceptual theories for the explanation of findings and results (Tritter, 2008). The challenge for this study, as in contemporary healthcare research, was how to incorporate clinical knowledge and experience with social science to unravel complexities in stigmatisation. Herein lay one valid reason for not adopting a single paradigmatic approach.

For example, the qualitative paradigm emphasised that reality was socially constructed and acknowledged the value-laden nature of inquiry, which aimed to address how social experience was created and given meaning (Denzin and Lincoln, 2005). To the contrary, the quantitative paradigm did not address processes but focused on measuring differences between groups and exploring relationships between variables, and claimed to operate within a value-free framework (Denzin, 2005). Preference for a quantitative or qualitative approach constituted different approaches to similar issues, but at times, choice of approach can be determined by the 'politics of research and the power to legislate correct solutions to social problems' (Becker, 1996: page 11).

However, constant social change and diversification pose new challenges to researchers within varying contexts and perspectives, and the use of quantitative approaches, which started from theories and tested hypotheses, could only be applied to specific data and interpretation (Flick, 2002). It can also be argued that while the quantitative and qualitative paradigms encompassed individual perspectives, the qualitative approach suggested a higher degree of proximity through observation and interviewing techniques, inferring that quantitative researchers relied on distant, inferential methods of arriving at data (Denzin and Lincoln, 2005).

It was seen that the qualitative paradigm valued descriptions of the social world, whereas the quantitative paradigm thrived on nomothetic commitment, and did not focus on individual descriptions, as these inhibited the process of generalisation (Denzin and Lincoln, 2005).

As far as this research was concerned, a pure positivistic approach introduced a major problem, the issue of gauging individual experiences, emotions and perceptions, which upheld the notion of multiple realities and were beyond the realms of positivism. Despite the need for employing different paradigms in this study, the initial measurement and comparison of attitudes required quantitative data, fell under the positivistic approach and a hypothesis was indicated for this aspect of the study.

If this study employed a pure positivistic approach, it would have faced the problem of extrapolation of findings to service users and the public, particularly in the context of individual behaviour, individual interpretation and perception of events.

The thesis of this study argued that service users can provide a better measurement of stigma, than the body of evidence into public attitudes and stigma. The comparison of measurements in public and service users' attitudes warranted a quantitative measurement through a positivist approach. The quantitative aspect was also essential to show measurable differences, the magnitude of the difference and relationships between variables which supported theories and corroborated other research evidence.

A positivistic approach informed the study about measurable differences and inter-relationships between variables, but these did not contribute to the meaning of differences between the public and service users. For example, the positivistic approach could not inform if the public and service users had similar concepts of stigma, if people who stigmatised and those who are stigmatised had

different expectations and conceptions, or if it was a similar phenomenon of stigma that was being measured between the two groups.

A mixed methodology supported the thesis by capturing measurable differences between service users and the public, explored the lived experiences of stigma by service users only (because in this study the public are people who do not have a diagnosis of mental illness) and established if the phenomenon of stigma was similarly constructed by service users and the public. Indeed, it was also vital to establish that the phenomenon of stigma was similarly constructed; otherwise the measurement, comparison and meaning to service users would have been less valid.

The sole reliance on quantitative methods would have been an inappropriate method to explore subjective experiences and perceptions of stigma. Likewise, the perception of stigma was an experience, and hence, was subjective and differed between and amongst individuals. Therefore, any attempt to understand subjective experience warranted a phenomenological approach. In fact, little would be derived by the employment of a purely quantitative approach in the exploration of subjective experience (Flick, 2004).

This research appreciated the value and benefits of different epistemological approaches, was not biased towards positivism or phenomenology, but employed both paradigms which informed the design of the study and was complimentary, in showing different aspects of the enquiry. In essence, the mixed method approach was used to embrace the strengths and minimise any weaknesses of positivism and phenomenology.

3.2 Philosophical Underpinning For Employing The Mixed Methods Approach

Mixed methods research is a method of combining quantitative and qualitative research techniques, methods, approaches or concepts. In this study mixed methods is seen to be beyond contentious issues surrounding positivism and phenomenology, because it offers a logical and practical solution to some paradigmatic issues (Johnson and Onwuegbuzie, 2004). Mixed methods research aims to amalgamate the insights from quantitative and qualitative research into a workable solution and thereby attempts to respond to some of the metaphysical disputes between positivism and phenomenology (Johnson and Onwuegbuzie, 2004).

In the mixed methods approach of this research study, nomothetic and idiographic approaches are combined in attempting to make generalisations, and at the same time, acquire a deeper understanding. This approach will facilitate the understanding of social regularities from a larger sample, while giving depth of understanding from a smaller sample.

Implicitly or explicitly, both positivism and phenomenology postulate that their differing paradigms and associated methods, were incompatible, and should not be mixed (Howe, 1998). Similarly, accommodation between paradigms were seen to be impossible and led to 'vastly diverse, disparate and totally antithetical ends' (Guba, 1990: p. 81). However, both paradigms, positivism and phenomenology, employ empirical observation, describe and construct arguments from their data, speculate on observations and findings and attempt to minimise bias and maximise validity (Sandelowski, 1986).

From a philosophical viewpoint, this study's mixed methods research is based within Pragmatism, which originated with Charles Peirce and was developed by William James and John Dewey (Johnson and Onwuegbuzie, 2004). Pragmatism is a theory of meaning which proposes that an intrinsic connection exists between meaning and action, and the meaning of an idea is to be found in its conceivable sensible effects; and humans generate belief through their habits of action (Peirce, 1878).

Pragmatism comes from the Greek word *pragma* which means action, and from which words like practice and practical can be sourced (www.wikipedia.com accessed 08-11-2008). Pragmatism questions the practical difference that might exist if one alternative or another were true, and uses this question when examining philosophical or moral arguments, to find that there is no significant difference in consequence (Teddlie and Tashakkori, 2003). A central idea in pragmatism is the notion of truth, which is seen as the usefulness of the consequences of an act, rather than anything metaphysical. Truth is seen as being constantly updated through our store of experiences, so there is no static or objective truth (Peirce, 1998).

The initial thinking on pragmatism was built on and given direction to become a theory of Truth, and also suggested that true ideas led through experience in ways that provided consistency, orderliness, and predictability (James, 1907, 1995). In pragmatism, practical consequences or real effects were seen to be vital components of meaning and truth; and a theory or concept should be evaluated in terms of how it works and its consequences as the standard for action and truth (Peirce, 1998). In essence, pragmatism is a

straightforward practical way of thinking about things or dealing with problems and focuses on results rather than theories.

Moreover, pragmatism criticised traditional notions of truth, which were seen as attempting to construct an exact, logical theory of concepts and judgements, in various forms, by considering how thought functioned in the experimental determinations of future consequences; and consequent to this criticism, also known as instrumentalism, the essence of logic was deemed to be inquiry, rather than truth or knowledge (Dewey, 1920, 1948). Pragmatism endorses practical empiricism as a means to determine what works.

Pragmatism rejects the quest for foundational truths and the construction of abstract philosophical systems, favouring a plurality of dynamic truths, grounded in concrete experiences and language, where truth is appraised in terms of consequences or use-value (James 1907). Even though pragmatism prefers action to philosophising, it also recognises the bio-psycho-social domains of human existence, has high regard for individual experience and views knowledge as being constructed and based on the reality of the world that we experience (Johnson and Onwuegbuzie, 2004). Of importance to this study, the construction of knowledge, based on reality is related to Personal Construct Psychology and further developed in section 3.2.2.

In pragmatism, current truth and knowledge are deemed to change over time, while Truth, or absolute truth, will be the final opinion, and will be realised, perhaps at the end of history (Johnson and Onwuegbuzie, 2004). Mixed methods, based on action, is a practical outcome-oriented mode of inquiry which

leads to further action and the elimination of doubt, as it offers a selection of methodologies that addresses relevant issues.

Criticism was directed towards mixed methods research, because it was seen to presume a methodological hierarchy, with quantitative methodology at the top and qualitative methods taking second place, in an auxiliary role of finding out and supporting evidence (Howe, 2004). Also, through mixed methods research, qualitative methods appear to be removed from within their critical, interpretative framework, and inquiry is divided into dichotomous categories of exploration, via qualitative methods, and confirmation, via quantitative methods (Teddlie and Tashakkori, 2003).

Nevertheless, this study has a different basis, because the quantitative attitude scale employs a bottom-up approach and will be developed from phenomenological data from people with mental illness. Also, there is a two-pronged qualitative approach, semi-structured interviews and PCP RepGrids, which provides both quantitative and qualitative data. Instead of restricting, mixed methods research is a non-limiting and expansive approach, which is inclusive, pluralistic, eclectic and complementary (Johnson and Onwuegbuzie, 2004). An awareness of the limitations in both the qualitative and quantitative paradigms facilitated the choice of mixing appropriate methods that address the research questions and the hypothesis in this study.

The logic of inquiry in mixed methods research use induction, discovery of patterns, deduction, or testing of theories and hypotheses, and abduction or best explanations for vital components of meaning and truth; and as such, a theory or concept should be evaluated in terms of how it works and its consequences as

the standard for action and truth (Peirce, 1998). As mentioned, pragmatism is a straightforward practical way of thinking about things or dealing with problems, suggesting that whatever works is likely to be true.

The fundamental principle of mixed methods research suggests the collection of multiple data by employment of various methods, strategies and approaches, so that the resultant combination shows complementary strengths and non-overlapping weaknesses (Johnson and Turner, 2003). As in this study, mixed methods research is justified by effective use of the aforementioned principle, because the outcome will be superior to a single method of inquiry (Brewer and Hunter, 1989).

In addition, mixed methods research can facilitate the testing of consistencies in findings from the different research instruments and data, clarify and illustrate results from one method through another method, challenge results from one method over another and provide richness and detail to the study by exploring features of each method (Green et al., 1989). Also, in using one method, for example, a quantitative approach, the researcher can miss out on important phenomena that occur during the investigation, because of a single focus, as in the testing of a hypothesis, rather than hypothesis generation. This effect is known as confirmation bias, but in this study, was kept at a minimum through the mixed methods approach.

However practical mixed methods research are, they still need to formerly establish philosophical positions, strategies for validity, procedures for mixing and integrating, rationale, designs and data analysis (Johnson and Onwuegbuzie, 2004).

3.3 The Quantitative Paradigm

The quantitative paradigm is based on positivism, a rejection of metaphysics, which held that the goal of knowledge was simply to describe and measure phenomena that were experienced. So, a positivist holds that knowledge of anything beyond describing and measuring, is impossible (www.socialresearchmethods.net/kb/positivism.htm accessed 30-07-06).

Positivism assumes that social behaviours are a response to external stimuli, and social phenomena can be observed and measured based on empiricism and the hypothetico-deductive method (Bowling, 1997). In addition, the preferred methods of enquiry in the quantitative approach were the testing of hypotheses, to establish cause and effect, in addition to relationships between factors (Denzin and Lincoln, 2005).

Positivism upholds a single objective reality and that it is possible to observe and measure social phenomena, based on empiricism by evidence gathered through the senses (Bowling, 1997). Social observations were considered to be entities, in a similar manner to physical phenomena, wherein the observer was detached from the entities under observation, as a method of maintaining objectivity (Johnson and Onwuegbuzie, 2004). Within the positivistic paradigm, the aim of enquiry was to eliminate bias, avoid involvement with the subjects of study and to test hypotheses.

Also, positivism did not aim to measure the meaning of situations, because it assumed that meaning cannot be measured objectively. So, as mentioned earlier, the favoured methods in positivistic research were surveys, experimental methods and statistical analyses of data.

3.3.1 The Qualitative Paradigm

The qualitative paradigm can be sourced to phenomenology or subjective experience of reality, which was well defined as follows:

'reality is multiple and socially constructed through the interactions of the individuals who use symbols to interpret each other and assign meaning to perceptions and experience; these are not imposed by external forces'.

(Bowling, 1997:112)

Phenomenology is the philosophical approach to the study of experience, with a particular focus on what it is like to be human, and things which mattered to us and made up our lived world (Smith et al., 2009), and is valuable in helping us to understand experiences of the world. Interpretative Phenomenological Analysis, which is used to analyse the interview data, is informed by hermeneutics and phenomenology, both evident in the work of Heidegger (Smith, 1996).

Heidegger challenged the existence of knowledge without an interpretative stance, grounded in the lived world of people, things, relationships and language, focused on the ontological question of existence itself, the activities and relationships people engaged in, and through which their world appeared and had meaning (Smith et al., 2009). In 'Being and Time' the key concept proposed is that 'being' always has a perspective, is always temporal and in relation to something, and as a result, the interpretation of people's meaning-making activities were central to phenomenological enquiry (Heidegger, 1962, 1927). Here, it was seen how Heidegger aimed to articulate the case for hermeneutic phenomenology (Smith et al., 2009).

An etymological deconstruction of phenomenology renders two words, phenomenon and logos, both of Greek origin (Heidegger, 1962 / 1927). For Heidegger, appearance had two meanings, things can have visible meanings, which can be deceptive, but can also have concealed meanings. Consequently, Heideggerian phenomenology aimed to examine things which were hidden or disguised as it emerged into light and manifested things as they appeared at the surface, because of connections to the latent form, which it was a part of and apart from (Smith et al., 2009). 'Phenomenon' is primarily related to perception, while 'logos' relates to reason and judgement or making manifest what one was talking about in discourse (Smith et al., 2009). So the aim of Heideggerian hermeneutic phenomenology is to examine the thing as it appears to show itself and the use of analytic thinking, which helps to grasp the phenomenon.

It can be seen that phenomenology seeks meaning which could be latent, because of the mode in which a thing appear, and the best way to seek meaning is in the interpretation of text, and it is for this reason that hermeneutics is linked with phenomenology (Moran, 2000). It can be seen that phenomenon presents in a manner which is also self-concealing, so how things appear or are concealed merits detailed study.

In the course of this study, it became apparent that to only use the tools of natural science, via positivism, would be to distort individual perception of reality. Phenomenology supports multiple realities, and context-free generalisations were not desirable or possible, in fact, research was seen to be value laden, and cause and effect were difficult to differentiate (Johnson and Onwuegbuzie, 2004).

Phenomenology suggests that in the quantitative paradigm, measurement scales and questionnaires are not optimal, does not include all of the important domains and miss out on the subjectivity of human beings (Bowling, 1997). But, the qualitative paradigm acknowledges multiple realities, where the knower and what was known are independent and values are important. To the contrary, quantitative research seeks to make measurable connections and argues that it is not possible to go beyond objective observation.

This research employs a positivistic and phenomenological perspective to bring a richer meaning to the statistical analyses in the context of attempting to understand the notion of stigma amongst service users and members of the public and to triangulate the methodology. Qualitative methodology is also important in the exploration of new topics and obtaining insightful and rich data on perceptions of stigma, which is a complex issue.

A qualitative approach is also essential in the initial stage of constructing this study's attitude scale, wherein the lived experience of service users via first person accounts, will be analysed for themes, from which attitude statements will be generated. Even though the main results of this study will be quantitative, qualitative techniques are employed to check their accuracy, content, validity and meaning to the subjects in the sample.

3.3.2 Personal Construct Psychology

Personal Construct Psychology [PCP], which is rooted in phenomenology, proposes that we view the world through templates, and fit these templates over realities of our world (Kelly, 1955). However, these

templates do not always have a good fit, but without them, the world appears undifferentiated and we are unable to make sense of it. In addition, the meaning attached to events (constructs) are hierarchical, with broad constructs (superordinate) subsumed by narrow constructs (subordinate). PCP postulates that a person's processes are psychologically 'channelised' by the ways in which that person anticipated events.

Central to personal construct theory was the notion of the person as a scientist, putting their own interpretation or theories on events and regularities of their life in an attempt to make them understandable, and as predictions or hypotheses about future events (Kelly, 1955). Similarly, our actions or behaviours, as independent variables, were tests of hypotheses which we constructed, and subsequent behavioural experiments were determined by the validation or invalidation of our hypotheses (Fransella, 1981). It can also be seen that in stigmatisation, mechanisms of validation that were central to reinforcing stigmatising behaviours, operate in societies.

Likewise, people were deemed to be actively arranging their perception of events on the basis of recurring themes, which had meanings attributed to render them interpretable, so that they were able to recognise similarities and differences in events, in ways that were personally significant and also shared by relevant others (Neimeyer and Bridges, 2003).

In essence, the theory of Personal Construct Psychology suggests that meaning is a matter of contrast, in that a person not only attributes meaning to an event by construing what it is, but also by differentiating it from what it is not. For example, one's unique description of a colleague as being 'laid back' can only be

fully understood in the context of its personal contrast which might be 'uptight' or 'ambitious'. On a larger scale, individuals, social groups and cultures share constructs which form a basis for identity and social interaction. One key value of personal construct is centred on idiosyncratic meanings and the way in which these arose and found validation within familial and cultural contexts (Neimeyer and Bridges, 2003).

Indeed, the notion of meaning of an event being a contrast with labels of what that event was or was not, is important in PCP and forms the basis for personal construction of an event in Repertory Grid techniques [RepGrid] (Neimeyer and Bridges, 2003). For example, in RepGrid technique, a subject is presented with three elements, such as (1) a person with a mental illness, (2) a person who does not have mental illness and (3) a person one admires. In keeping with the notion of meaning and difference in PCP, the subject is challenged to report how two of the aforementioned elements were the same and how the third element differed.

Previous research employed qualitative and quantitative methodologies in exploring stigma, but up to this current time there was no published research evidence which used personal construct psychology in the stigma of mental illness, in comparisons with service users and a public sample.

3.3.3 Symbolic Interactionism

Blumer (1969) first used the term 'symbolic interactionism' and set out the following principles:

- Human beings acted toward things on the basis of the meanings they ascribed to those things.
- 2. The meanings of such things were derived from, or arose out of, the social interaction that one had with others and the society.
- 3. These meanings were handled in, and modified through, an interpretive process used by the person in dealing with the things he/she encountered.

Here it can be seen that in symbolic interactionism, individual meaning was given to the world.

Symbolic interactionism is a distinctive character of interaction as it takes place between humans. One peculiarity for humans exists in the fact that we interpret or define each other's actions instead of merely reacting to each other's actions (Blumer, 1969). Therefore, response is not made directly to the actions of one to another, but instead, is based on the meaning which they attach to such actions. Thus, human interaction is mediated by the use of symbols, by interpretation, or by ascertaining the meaning of one another's actions.

It was suggested that an individual ascribed meaning to their world by defining and interpreting it, so their world was never directly experienced, but only through the notions that were held about it (Mead, 1927). In other words, the meaning of reality was the meaning that an individual chose to give to it.

3.4 Interpretative Phenomenology and Interpretative Phenomenological Analysis

This section is also the philosophical lynchpin for section 3.12 Interpretative Phenomenological Analysis [IPA] framework for interview data analysis.

Interpretative phenomenology deems human existence to be interpretative and aims to understand lived experience (Heidegger, 1962). In other words, it endeavours to understand an experience, as understood by the person who experienced it. Also, the term hermeneutics is used to refer to phenomena of the world, as presented to us, how we go about understanding what is presented to us and attempting to understand being itself. Another aspect of phenomenology focuses on how phenomena are interpreted and argues that phenomenology is the study of what people wrote down, said and the symbolic activities in which they engaged (Gadamer, 1989).

Interpretative Phenomenological Analysis [IPA], which is rooted in interpretative phenomenology, is connected both to phenomenology and symbolic interactionism (Smith et al., 1999). Phenomenology focuses, not on facts, but on individual perception or account of an object or event, while symbolic interactionism suggests that the meaning individuals ascribed to events were acquired by interpretation of those events, which is mediated by social interaction (Natanson, 1973).

One observation on IPA noted that the combination of phenomenology and symbolic interactionism gives an insider's perspective on how personal events are seen, but these personal events cannot be accessed directly or completely by the researcher (Conrad, 1987). It can be seen that access

depends on and is complicated by the conceptions, which are required to make sense of the subject's personal world, through a process of interpretative activity. It is envisaged that the combined quantitative and qualitative methodologies with perspectives of members of the public and service users could give this study an original and unique perspective on the stigma of mental illness.

It can be seen that the epistemological lynchpin of IPA is phenomenology (Smith, 1996). In the context of this study, the self identity of service users is threatened as they reflect on why mental illness occurred, what they were experiencing and what it would be like in the future. IPA draws on the inherent human propensity for self reflection, and allows participants, using their own words, to relate their lived experience of stigma. So, IPA in this study is a focus on discovering meaning in service users' reports on stigma. In IPA the search for meaning requires interpretation by the researcher, so in essence IPA is an interpretation of a reflective account (Smith, 1996).

In IPA the research process is dynamic, in that the researcher has an active role in attempting to acquire an insider's perspective on an event, yet acknowledging that this is never fully attained (Conrad, 1987). Indeed, access to subjective, lived experience relies on and is convoluted by the researcher's own conceptions, yet both processes are vital to make sense of the meaning service users ascribe to events (Smith and Eatough, 2006). Hence, In IPA, there is a mechanism of double interpretation; the subject is attempting to relate meaning ascribed to an event, while the researcher attempts to interpret the subject trying to make sense of that event (Smith and Osborne, 2003).

Consequently, in IPA, it is assumed that there are links between, a condition such as mental illness, cognition and verbal response. Therefore, autobiographical documents or conducting semi-structured interviews will provide richer data on how people consider and deal with the stigma of mental illness (Smith, 1996).

In addition, IPA operates at an idiographic level of analysis (Smith et al., 1995). It is seen that the quantitative empirical aspect of this research will only be able to draw probabilistic inferences about the different population groups, but in the IPA aspect, specific statements can be made because these will arise from the individual case studies.

3.5. Issues With The Attitude Construct

There are links between attitudes and opinions, values, beliefs, emotions and personality (Oppenheim, 1996; Ribeaux and Poppleton, 1978; Rokeach, 1968). It can be seen that in a multi-faceted concept as attitude, poses a particular challenge, when attempting to quantify attitudes and perceptions by the use of an attitude scale. For example, in attitude scales, there should not be any general statements to which there could be agreement, because attitudes are linked to beliefs, values and emotions, so statements should be phrased to rouse emotions such as fear, hope and dislike (Oppenheim, 1996). This brings into focus the phenomenological approach of personal constructs of stigma, which is helpful in determining how subjects conceive and construct elements of stigma by using polar opposites to describe differences and similarities between elements

in the repertory grid. Indeed, the very nature of attitudes reinforces the need to employ different methodologies to capture personal meanings of stigma.

In addition, early writings expand on the notions of attitudes by suggesting that attitudes and motives are interlinked and depends on one's motives (Katz, 1960). It was postulated that attitudes serve the following four functions, and issues which arose for this study, follow each proposal:

 Attitudes provide a framework within which new information and experiences can be assimilated (Knowledge).

This is an interesting notion, for both service users and the public. Public knowledge about mental illness can be based on false perceptions, and service users' attitudes can also be based on expectations of rejection by the public.

- Attitudes enable individuals to communicate their values to others (Expressive).
 - In terms of measuring and comparing attitudes, this is valuable, because expressed attitudes can be used to convey values and therefore measured. This study aims to measure expressed attitudes towards mental illness by use of an attitude scale, interviews and personal constructions of stigma.
- 3) Attitudes maximise rewards and minimise sanctions, thus behaviour or knowledge which satisfies needs are more likely to result in a favourable attitude (Instrumental).

This may not be the case with service users or the public. If for example, public stigma meets the criteria for functionalism, then public attitudes may be mainly negative. If service users' attitudes are negative, this can also be detrimental to their wellbeing, as it may lead to self stigmatisation and social isolation.

4) Attitudes may be held to protect the ego from an undesirable truth or reality (**Ego-Defensive**).

This notion is interesting, in particular for the public. Its validity can be examined in the personal constructions of stigma, as these can provide a link between the quantitative and qualitative data.

There seems to be a wide variety of attitudes that people can hold, and while some attitudes appear to be central to the person, for example, a religious belief, which may be very resistant to change, other, more peripheral attitudes appear easier to change with new life experiences. We may have experienced situations where we thought that someone portrayed a negative or a positive attitude, but that attitude might only have been directly observed or inferred. It can be seen that there is a tendency to infer attitudes from verbal and non-verbal communication and behaviour, but this inference can be seen as informal,

spontaneous and based on a subjective analysis of what may be seen in symbolic interactionism.

The aforementioned line of reasoning raised the issue whether the perceptions of people with mental illness are valid, or in other words, was stigmatisation actually occurring, was it only perceived or might it be part of mental illness? However, the body of research suggested that stigmatisation was prevalent and people with mental illness are the most marginalised of people with disabilities (SEU, 2004). This study recognises the deficit in service user involvement in stigma research and employs their lived experience in the development of its hypothesis, research tools, methodology, and outcome measures.

The formerly explored notion of attitude (Katz, 1960) appears to be a tendency to respond in a particular way to a situation and involves a cognitive, emotional and behavioural component (Oppenheim, 1996; Ribeaux and Poppleton, 1978; Rokeach, 1968). It should also follow that if we can infer attitudes from verbalisations and actions, we should be able to predict behaviour from attitudes, since there appears to be a correlation between cognitive, emotional and behavioural components of attitude.

To the contrary, using expressed attitudes as a predictor of behaviour might not stand up to rigorous scrutiny. Furthermore, attitudes appear to be just one determinant of behaviour or pre-disposition to behaviour and how we behave may be determined, to a greater extent, by the consequences of our actions and how we think others will evaluate our actions and usual responses to such a situation. For example, to openly discriminate against someone with a mental

illness, may not be socially acceptable, but the same can be discriminated against in subtle ways, such as, by refusing employment. The La Piere (1931) study is a classical example of the dissonance between reported attitudes and actual behaviour. Similarly, notions of stigma may also be subtly communicated to service users and may manifest in ways unknown to would-be stigmatisers, which includes healthcare professionals and the public.

An attitude may be behaviourally expressed in a number of ways, for example, having a positive attitude towards a political party may not mean becoming a member or attending public meetings. However, if you do not vote for that party, your attitude becomes questionable (Gross, 1992). So, an attitude should predict behaviour to a certain extent, even if limited and specific.

Of even greater concern to the comparisons aspect and thesis of this study, attitudes which are based on direct experience have greater predictive value than those based on indirect experience, because attitudes from direct experience are more easily retrieved from memory, there is more information about the attitude object, and this is seen as reasons for their higher predictability of behaviour (Fazio and Zanna, 1981).

The idea of direct experience was of particular interest to this study because of service users' experience of stigma. Indeed the intention of this study was to capture service users' direct and lived experience of stigma. As argued in the hypothesis for the quantitative aspect of this study, the direct experience of people who are stigmatised may be a better measure of public stigma and it would also make an interesting comparison to reported public attitudes, which may be based on hypothetical reckoning (Guimon, 1999). Accordingly, the

argument indicated that this could be a comparison between lived experience and possibly hypothetical reckoning.

Attitudes based on direct experience had stronger predictive value (Fazio and Zanna, 1981), which suggests that the reported experience of stigma, by people who experience mental illness, may be more valid than public attitudes towards mental illness and the mentally ill. This notion formed a lynchpin of this study, which argues that service users' perception of stigma can be a better measurement of public attitudes. Indeed, the attitude scale of this study will be based on first person accounts of service users' experience of stigma, which should give a picture of the situations in which people with mental illness are most likely to experience or perceive stigmatising attitudes. It also appears logical to think that if these were prime situations for stigmatisation, it meant that the public were also be able to comment on service users' perception and service users' comment on public perceptions in the given situations.

As an illustration to understand what this means in real terms, a statement from this study's attitude questionnaire is now explored. (see appendix ii).

Statement:- I think most people would feel uncomfortable working with someone who has a mental illness. A member of the public may need to consider what most people believe, but can only base their response on personal experience and knowledge or hypothetical reckoning. Because the majority of the public cannot recognise specific mental disorders or different psychological distress, associate schizophrenia with a split personality and disagree with health care professionals about the aetiology of mental illness (Jorm, 2000), it was likely that responses were hypothetical. A service user's response would be more

likely to be based on actual experience because their experience of mental illness is current and lived.

If there is an attitudinal disparity between an experience of mental illness by service users and 'no experience' of mental illness by the public, then this may be a factor in determining levels of positive public attitudes and the perception of stigma amongst service users. On a prima facie level, it appears that if there was a gap between service users' perception of stigma and public attitudes towards mental illness and the mentally ill, this gap may be based on knowledge and experience of mental illness.

The notion of knowledge and experience as a basis for attitudes also suggests that members of the public who had favourable attitudes towards the mentally ill are also in a better position to become acquainted with facts about mental illness, than those with more stigmatising attitudes. It may also be true that the kind of facts one learns about mental illness and the mentally ill are connected to one's particular attitude.

In summary, it can be seen that the nature of attitudes was and still is a challenge to researchers. The positivistic approach draws on standard approaches, for example measured attitudes, an attitude scale and analyses of variables to determine relationships, while the phenomenological approach is intended to bring out depth of meaning to what stigma personally mean for service users and members of the public.

3.6 Conceptual Framework (Model Of Stigmatisation)

The conceptual framework developed for this study is illustrated in the following figure 3.1, and drew on findings from the literature review as a basis for its formation. The literature evidence and explanation for the framework now follows and begin with public attitudes, at the bottom left corner.

Public attitudes can have a negative impact on service users (Lyons and McLoughlin, 2001; ONS, 2007; Priory Group, 2007; SEU, 2004) who can either have a healthy or unhealthy coping response. It was postulated that a healthy response resulted in a very limited experience or perception of stigma, so there was no significant psycho-social ramifications for such service users. On the other hand, an unhealthy response to stigmatisation can lead to self-stigmatisation which impacted negatively on service users (Corrigan and Lundin, 2001; Corrigan and Matthews, 2003; Gallo, 1994; Guimon et al; 1999; Link and Phelan, 2001).

The explanation for the framework moved to the top left section.

Research evidence indicated that these were significant factors in stigmatisation, which were also variables for this study. Early findings suggested that the length of contact with services was a factor in the severity and rate of hospital admission for mentally ill people and the development of deviant social networks (Pattison et al, 1975; Perrucci and Targ, 1982). Education was another significant factor in stigmatisation of people with mental illness (Brockington et al., 1993; Wolff et al., 1996) and there were inconsistent findings about the association between stigma and sexual differences (Angermeyer and Matschinger, 2006).

This study made logical deductions from the research evidence regarding deviant social networks and the severity and rate of hospital admissions (Pattison et al., 1975; Perrucci and Targ, 1982). Consequently, it deduced that service users, who were compulsorily detained for treatment under a section of The Mental Health Act (1983) would be less likely to be employed, more likely to have deviant social networks and therefore interacted mainly with other service users and healthcare professionals, and consequently, would be more likely to have longer spans of care in secure, forensic environments. All of these factors impacted on the experience of stigma and indeed life experiences, with ramifications for living arrangements and relationships (SEU, 2004). The aforementioned factors or service user variables were impacted by negative public attitudes. For example, public attitudes impacted service users' access to housing (living arrangement) and on employment (SEU, 2004). This study was based on this framework (Figure 3.1) which showed a model of stigmatisation of mental health service users. The evidence for this model was based on the evidence from the literature review.

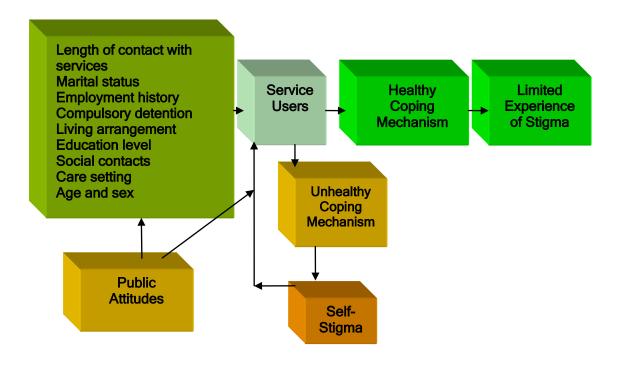


Figure 3.1 Conceptual Model of Stigmatisation Showing Service User Variable

The activities of this study were centred on the conceptual framework. These activities include the sampling frame, development of research tools and the collection of data and statistical analyses. From this framework came an operationalisation of the hypothesis for the quantitative aspect of this study.

The hypothesis - Higher levels of reported public positive attitudes to mental illness and the mentally ill should correlate with relatively lower levels of perceived stigma amongst service users.

After testing the hypothesis from the quantitative aspect, this study explored the phenomenological aspect through semi-structured interviews and

personal constructions of stigma. Triangulation of methods and results were also addressed.

3.7 Study Design

This study incorporated a three-pronged design. Firstly, a cross-sectional survey employed an attitude scale, which was analysed using inferential statistical tests. Secondly, semi-structured interviews were analysed using Interpretative Phenomenological Analysis, and thirdly, Personal Construct Psychology Repertory Grid techniques which captured personal constructions of stigma, were analysed using Principal Component Analysis, also known as Factor Analysis.

The survey method is most often used to document the prevalence of particular characteristics of a population. For instance, it could be used to find out about the frequency of behaviour or the number of people who held particular attitudes or beliefs. However, frequency is not a key issue, as the associations between variables and the causal processes that gave rise to those associations. In any case, cross sectional surveys not only provide for assessing relationships between variables, but also differences between sub-groups in a population, and the testing of causal hypotheses via regression techniques (Visser et al, 2000).

A mixed methods approach was chosen for this study because it provided a means of examining relationships between variables as they naturally occurred, that was, without manipulation or control, and while it did not aim to establish causal links, the additional use of semi-structured interviews and personal constructs of stigma enhanced the understanding of the quantitative results by

providing explanations for the same. The quantitative survey aspect also facilitated the examination of factors in isolation and various combinations and supplied more information about relationships between variables, which gave the study construct and predictive validity. The results of all three approaches were triangulated to strengthen the overall validity of the study and its results.

3.7.1. <u>Hypothesis</u>

The hypothesis for this study was developed from its thesis along with observation on research regarding the continued prevalence of public stigma of mental illness (ONS, 2003; SEU, 2004) contrasted with reported high levels of positive attitudes in some public surveys such as ONS (1998; 2003). It appeared that high levels of reported positive attitudes were elicited from people who did not appear to know about mental illness or did not know anyone with a diagnosed mental illness (London and Garman, 2007). Of equal importance, there was no published research on service users, to compliment, add balance and put the research on public attitudes into perspective. The hypothesis aimed at establishing a link between public attitudes and service users' perception of stigma. It was therefore logical to conclude that positive public attitudes towards mental illness and the mentally ill should correlate with lower levels of perceived stigma amongst service users, and vice versa.

Methods In Data Collection

3.8. Sampling

Subjects for the public sample were recruited from the British Telecom telephone directory. This involved the use of probability sampling. This meant that every name in the directory had a specified non-zero probability of being included in the sample, or in other words, a statistically equal chance of being selected (Coolican, 1994). This was achieved via a random sampling method. A list of random numbers was used to match numbered names in the directory.

Names from the directory were numbered and matched with numbers on a random number list and matched numbered names were targeted as potential respondents. This method, within the constraints of time and money, was best suited to minimise sampling bias.

Subjects received, via post, a package containing a cover letter explaining why they received the questionnaire, research tools and a stamped return addressed envelope. The main advantage of this method was the low cost of collecting data, the ability to reach widely dispersed subjects and the elimination of interviewer bias (Oppenheim, 1996). Postal surveys can have low response rates but it was not necessary to send out a large volume of questionnaires to achieve a sufficiently large response. The endorsement of West London Mental Health NHS Trust, in the form of a cover letter, with the Trust's logo, was secured with the aim of raising the profile of the study and hence, increased the likelihood of a high response rate.

Service users in the sample were recruited via consultation with the lead clinician in day care centres and wards within West London Mental Health NHS

Trust. This process was in two stages. Clinicians were asked to assist in identifying potential clients who could be approached. Clients who expressed interest were informed about the study and if a desire to participate was expressed, the client was asked to give consent for further information to be supplied and if in agreement, was then asked to sign a consent form. Subjects for the interview and Repertory Grid were a self-selecting subset of the main sample.

3.8.1 Sample Size

The study aims to have half the number of subjects from the general public and the other half were people with a diagnosed mental illness. Analyses such as multiple regression requires large volumes of data and suggests an acceptable ratio is ten subjects per predictor variable, but also noted that this could be as high as forty subjects per variable (Brace et al., 2000). It is essential to get the sample size correct in order to have sufficient data to detect differences and to save time, energy and emotions which will be invested by subjects. Problems can occur when there are too few cases relative to the number of predictor variables. For example, analyses may produce large parameter estimates and standard errors (Tabachnick & Fidell, 1996).

Because there was no apparent consensus on sample sizes for regression analysis, a power calculation was used to calculate the ideal sample size. The power calculation gave the smallest number of subjects that were needed to detect differences in the population and included the use of standard deviations,

means, significance levels and average attitude score to arrive at the ideal sample size.

3.8.2 Power Calculation For Sample Size

The main outcome of the study was the comparison between the reported public attitude and perceived stigma of people with a diagnosed mental illness. Previous research (London, 2002) using the 'Community Attitude to Mental Illness' scale (Taylor and Dear, 1982) suggested that the general public had a mean attitude score of 150 and a standard deviation of 30 (SD=30). This research was interested in finding a difference of at least ten units between the two groups, with a five percent (5%) significance level and ninety percent (90%) power. Calculations based on these parameters revealed that N=132 per group. Thus, the total sample size was 264 subjects.

The following formula was used to calculate sample size for the study.

n = number required in each group

m1 = mean in group 1

m2 = mean in group 2

s = standard deviation

ca = constant for significance level (a)

cb = contant for power (1 - b)

Constants used in power calculations depend on the choice of significance level and power used in calculation.

Common values:

ca = 1.96 for 5% significance level

= 2.58 for 1 % significance level

cb = 0.84 for 80% power

= 1.28 for 90% power

3.9. Research Tools

This study employed three tools for the collection of data. The perceived stigma inventory measured stigma as experienced by service users and the attitude scale measured reported attitudes of people who did not have a diagnosed mental illness. The inventories were essentially the same, except that demographic data was collected for service users. The second tool for collecting data was a record of interview data from service users and the third tool was the Repertory Grids [RepGrids], which recorded and scaled personal constructions of stigma.

One advantage of using the attitude questionnaire was the easier coding and management of data, especially with the management of the large sample and data, on the Statistical Package for the Social Sciences [SPSS] programme. Because all subjects completed the same questionnaire, it was easier and more logical to have comparisons between the two sample groups. It would not be good practice to compare the findings of two different tools on two different populations, but it made sound methodological sense to compare findings from the two populations which used the same tool.

It was not possible to employ established scales, for example, the 'Community Attitude to Mental Illness' scale (Taylor and Dear, 1981) because it was designed for use with community samples only, that is, people who did not have a diagnosed mental illness and therefore would not be relevant to service users with mental illness. With this deficiency in mind, this study developed an attitude scale which covered the spectrum of community and service users' attitudes.

The attitude questionnaire was developed from service users' narratives and autobiographical accounts from 'Schizophrenia Bulletin', a Journal of the International Schizophrenia Research Society, and other research articles used in this study. These items were included because they helped to capture and reflect the lived experiences of people with mental illness.

3.10 Methods in Quantitative Data Analysis and Statistical Techniques

Statistical techniques that could be applied to quantitative data were dependent on the level of measurement achieved by the study instrument and the degree to which data could be meaningfully quantified (Coolican, 1994). This study's instrument yielded interval level data, which meant that the distance between any two numbers on the scale was a known quantity. Interval level of data meant that more sophisticated statistical analyses could be applied. Interval data compared favourably as opposed to nominal and ordinal data, which can only be counted and ranked and cannot be subjected to more robust statistical analyses (Coolican, 1994).

This study's quantitative data was subjected to non-parametric and parametric analyses. Parametric analyses suggested that there were built-in parameters about the population, such as the variances were homogenous and the distribution was normal. Analyses included tests for normality of distribution, parametric T-tests, non-parametric and parametric correlations, multiple regression analyses, which included the 'stepwise' method of regression, which was the most powerful method in regression analysis.

3.11 Rationale and Strategy for Data Analysis

Correlations, Analysis of Variance and Multiple Regression techniques were used to analyse the quantitative survey data. The principle was the same in all of the aforementioned tests.

In Analysis of Variance the aim was to account for the variance in the scores that were observed. With the use of correlations, Analysis of Variance and Multiple Regression it was possible to construct models about precisely which combination of variables had the strongest effect on the dependent variable. All of these statistical tests were seeking to do the same thing, that is, to explain the variance in the level of one variable on the basis of the level of one or more other variables (Brace, et al., 2000).

Multiple regression did not make assumptions about the distribution of the predictor variables which did not have to be normally distributed, linearly related, or of equal variance within each group. But of note, multiple regression was especially useful when the distribution of responses on the dependent variable was expected to be non-linear with one or more of the independent variables. For example, the probability of heart disease may be little affected by a ten-point difference in people with low blood pressure but may change quite a bit with an equivalent difference amongst people with high blood pressure. In this example the relationship between heart disease and blood pressure was not linear.

Multiple regression was applied to this study's data in which the predictor variables were correlated with each other and with the dependent variable of stigma, to varying degrees. This was the case in the survey data, where the virtue of regression analyses was realised.

3.11.1. Significance Levels

In this study, when results are significant, it means that the results are statistically significant at the 95% confidence level or higher. Results that are statistically significant means that there is 95% confidence that observed differences are real and the probability of getting such results by chance is 5 % or lower.

3.11.2 Normal Distribution

Evaluation of the normality of a distribution in a variable was always essential, particularly where statistical inference was planned, because some statistical tests assumed a normal distribution existed in the population for the variable measured. If this was not the case, then conclusions from the test may be in error (Coolican, 1994).

Normal distribution is the term used when variables fit a bell-shaped, mathematical curve, with symmetry at the point where the mode, median and the mean lie. Statistical inferences become less robust as distributions depart from normality (Bradley, 1982). Thus, having a normal distribution enhances the analyses and inferences that are extrapolated from this study's data. This also means that the data can be subjected to more robust statistical analyses.

3.11.3 Test For Normality of Distribution

The Kolmogorov-Smirnov test for normality of distribution was used to assess the normality of the distribution of scores in the stigma variable. A non-significant result, greater than 0.05, indicated normality. A smaller result for a

variable suggested violation of the assumption of normality (see Table 4.2). However, in large samples, such as this study's, violation of normality of distribution was quite normal, and did not impact statistical inferences (Pallant, 2005). In the test for normality of distribution, skewness indicated a tendency to have scores to the left of the median and Kurtosis indicated a tendency for flattened scores at the tails of the normal distribution bell curve.

3.11.4 Effect Size Statistic

The effect size statistic used was 'eta squared' and provided an indication of the magnitude of the difference between two sample groups, and showed more than just a difference in statistical significance, which only indicated whether the difference could have occurred by chance. The 'eta squared' statistic can range from zero to one and represented the proportion of variance in the dependent variable that was explained by the independent (group) variable (Pallant, 2005). The following formula demonstrated the calculation of eta squared.

Eta squared was calculated from the formula:

The example below is from the main 'stigma' t-test in the sample.

t statistic = 10.13

N1 = 132

N 2 = 132 Eta squared = 0.28

The magnitude of the difference in this example of public versus service users was relatively large (eta squared = 0 .28) which is equivalent to 28 %.

3.11.5 Correlations and Regression

A parametric T-test illustrated the statistically significant difference of scores between two groups in the sample, but it did not assess the degree of relationship, if any, between the independent variable and other dependent variables. A correlation can assess the strength of association in the amount of variance in the dependent variable that was associated with levels of the independent variables.

To further assess the strength of correlations, the more stringent parametric correlation test (Pearsons Rho) was applied. In parametric correlations the criteria was that the variances were homogenous, there was normality of distribution and the data was at the ordinal level (Coolican, 1996).

Multiple regression analysis was employed to determine which of the predictor (independent) variables best influenced the criterion variable (stigma). A regression was similar to a correlation. Correlations were used to measure the size and direction of the relationship between two variables, but regression was used to predict a score on a variable from the score on another variable. If two variables were correlated, knowing the score of one variable allowed the

prediction of the score on another variable. The stronger the correlation the closer the scores were to the regression line and the more accurate the prediction (Brace et al., 2000).

When attempting to predict human behaviour it was useful to have more than one predictor variable because actions were usually influenced by a combination of factors. Multiple regression facilitated the development of models or theories about which variables were influencing a behaviour (Tabachnick & Fidell, 1996). Measuring the scores on a number of predictor variables, and observing which variables gave rise to the best prediction of the criterion variable was the process in multiple regression.

Regression was not flawless and did not imply that relationships were causal. However, an apparently strong correlation between variables can stem from many sources, including current unmeasured variables. Indeed, an easier solution would have been to use T-tests to examine whether there was a significant difference between the means of scores. However, this would have involved making comparisons of several variables which correlated with each other and with the dependent variable to varying degrees. In any event, multiple T-tests were not employed, because these would undercut the logic of inferential statistical assessment, which rested on estimating the probability of a significant difference between two means only (Coolican, 1996).

In the enter method of regression, all the variables were entered simultaneously and assessed in terms of their predictive power, over and above that of the other predictor variables. The enter method also gave the amount of variance which can be attributed to the predictor variables (Brace et al., 2000).

In 'stepwise' regression each variable was entered in sequence and its value assessed. If adding the variable contributed to the model, then that variable was retained, but all other variables in the model were re-tested to determine if they still contributed to the model, if they did not significantly contribute they were removed (Tabachnick & Fidell, 1996). Stepwise regression ensured that the smallest numbers of statistically significant predictor variables were retained in the model (Brace et al, 2000).

In regression tables the standardized beta coefficients gave a measure of the contribution of each variable to the model. A large value indicated that a unit change in this predictor variable had a large effect on the criterion variable. The t-value and significance p-value gave an indication of the impact of each predictor variable. A big t-value and a small p-value suggested that a predictor variable had a large impact on the criterion variable.

3.12 <u>Interpretative Phenomenological Analysis [IPA] Framework For Interview</u> <u>Data Analysis</u>

IPA has its roots in phenomenology, yet does not operationalise a specific version of it, but there is an idiographic aim to demonstrate divergence and convergence, so that data from each subject is captured and portrayed in the analysis (Smith et al. 2009).

IPA was chosen for the analysis of the interview data for the following reasons;

➤ IPA draws on the wider body of phenomenology and does not attempt to operationalise any specific version of it.

- ▶ IPA is interpretative in that it explores what was apparent as well as the hidden meaning.
- ➤ IPA has an ideographic aim of giving a detailed analysis of divergence and convergence across cases, which captures the perception of each participant.
- The results of an IPA analysis will take the form of an ideographic interpretative commentary.
- Similar to IPA, Van Manen (1990) connects phenomenology and hermeneutics, because of their merits in helping us to understand people within the context of their lifeworld, and this approach was shown to be especially useful in education, health and nursing.

The philosophical underpinning for IPA was discussed in section 3.2.4. In this study, the IPA conceptual approach for analysis of interview data was thematic. A thematic approach meant that the data was examined for elaborated statements or themes, which emerged from subjective reports. Subsequently, common themes were linked and interpreted.

IPA employed flexible guidelines for analysis and there was no prescriptive approach for working with data, because the essence of analysis lay in its analytic focus, which was the informant's attempt to make sense of experiences (Smith et al., 2009). Nevertheless, in the interest of rigour the following, non-linear stages of analysis, adapted from Smith and Eatough (2006) were employed.

- The data will be read several times, in order to get a holistic perspective of the concerns claims and understanding in the service users' account, so that interpretations remain rooted within the account.
- Themes will be identified for each case and subsequently with all cases and then organised into clusters based on connections, commonality and convergence. The clusters will also be cross referenced with the data source.
- Development of an exchange between the researcher, the data and what it means for service users to have expressed such concerns. This was a key aspect to the development of an interpretative account.
- Themes will be examined, refined, condensed and clustered based on their relationships with other themes.
- Organisation of the material which facilitates a trail from data to themes to clustered themes to super and sub-ordinate themes.
- The condensed themes will be interpreted and presented as super and subordinate themes.

Adapted from Smith and Eatough (2006)

The pathway through the IPA was not linear, but a process that involved intuition to encourage reflective engagement with the informant's account (Smith et al., 1996). Throughout the analysis the researcher reflected on clinical experience to interpret and decode service users' accounts. Some themes

emerged almost immediately on first reading, but others did not surface until attempts were made at the clustering.

The interview data was read several times over to pick up on themes that emerged, were interesting or outstanding. The IPA approach to analysis was helpful because each reading gave new insights into the subjective accounts, which helped to start the process of linking and making associations between statements and emerging themes. The next stage was moving on to search for connections between and the grouping of themes. The challenge in the IPA analysis was arriving at valid interpretations to understand and reflect the informant's interpretation of their experience of stigma, while putting an interpretation and categorisation to what was reported. It was useful to reexamine the data and its interpretation for consistency, moreover, to ensure that the integrity of the subjective account was preserved, within the limits of IPA, so that an analytic track was apparent from the data to interpretation.

3.13 RepGrid Method and Data Analysis

3.13.1. Personal Constructs of Stigma

The primary method used for eliciting personal construct was the repertory grid [RepGrid] technique (Kelly, 1955). The repertory grid was a blank matrix which was filled with 'elements' or labels at the top of each column, and 'personal constructs' labels on the side of each row, and ratings which showed how the subject construed each element in relation to each construct (Fransella, 2005). The repertory grid reflected Kelly's (1955) fundamental postulate 'a person's processes are psychologically channelised in the way he or she anticipates

events. The 'ways' were the 'constructs' and the 'events' were the 'elements' of the Repgrid.

Most Repgrids were designed to elicit how a person construed people or events in their lives (Fransella, 2005), so it was appropriate to use the Repgrid to elicit how the public construed the stigma of mental illness and how people with mental illness constructed stigma. The elements of the grid, which was provided, were shown to the subject, in groups of three, at a time, and the same question 'How are two of these similar and the third one different?' was asked. The answers became constructs of how the subject differentiated the events or constructs.

Table 3.1 Example of a RepGrid

	Ме	Му	Good	Most	An	Mentally	Person		
		Manager	friend	successful	asylum	healthy	who is		
				person	seeker		different		
							to me		
trustworthy	5	3	4	5	1	4	1	1	Dishonest
impetuous	1	2	4	4	2	2	5	5	Careful
rational	4	3	3	4	2	2	4	5	Irrational

3.13.2 Subjects

Service users who signed the consent form and completed the questionnaire were asked to partake in the RepGrid. Arrangements were made to revisit service users who were willing to further participate by completing the Repgrid.

3.13.3. Procedure for RepGrids

Each interview comprised of the presentation of a set of elements to elicit personal constructs. By this method, data was analysed in order to explore how subjects construed meaning, and made personal sense of themselves in relation to the elements of stigma.

3.13.4 Role Construct Repertory Grid [RepGrid]

In PCP, there were a variety of techniques to explore an individual's personal construction of meaning (Winter 1992). The most common approach and the one used in this study was the Role Construct Repertory Grid [RepGrids] (Costigan 1985; Winter 1992). The RepGrid was a set of representations of the relationships between the set of items a person construed (elements) and the set of ways the person viewed these items, the constructs (Bell 1990). In essence, they were 'a unique way of guiding and documenting a conversation' (Melrose and Shapiro, 1999; 1453).

In RepGrid, elements were presented in combination, commonly in groups of three or triads, in order to encourage the Subject to consider similarity and contrast between them, in a structured or constructive conversation or interview (Fransella and Bannister 1977; Pollock 1986).

The appropriate selection of elements, upon which a grid should be based, was vital (Fransella and Bannister, 1977). In this study, elements were consistent with the objectives for study and was homogenous, that is, they were drawn from the same category, sufficient in number but recognising that the presentation of too many elements could be very time consuming, was relevant

to the subjects, was within their realm of experience and afforded contrast elements to ensure relevancy and personal meaning (Costigan 1985).

This study presented subjects with twelve elements which were sufficient to generate constructs by subjects relating to their 'Self' - how they construed themselves; how they construed others; and how they construed other's construction of themselves. This was reflective of the notion that, in PCP, the self can be considered a real object or person that can be analysed separately from the cognition of the individual (Bannister 1983; Buckenham 1998). Subjects were required to generate seven constructs with polar opposites and rank the triad of elements, using a five point Likert scale (1,2,3,4,5) where one was the construct on the extreme left and five was the polar opposite, as defined by the subject, of the construct on the extreme right of the grid. After the presentation of seven triads, subjects ranked the remaining elements based on their constructs from the triads.

Statistical analyses were undertaken to explore relationships between elements, between elements and constructs and between constructs, using Principal Component Factor Analytic methods. However, as each RepGrid was comprised of elicited constructs which were individual to the subject at a particular period of time, it was not logical to compare constructs between individuals. Even so, a RepGrid afforded an insight into the personal construing for each individual at each time sampling period.

The use of RepGrids to elicit personal constructs of stigma was undertaken to enhance the quality of this study's data by producing both

qualitative and quantitative data and facilitating the quantification of qualitative data.

3.13.5 RepGrid Elements Used To Elicit Constructs

The following elements were used to elicit constructs of stigma:

Self

Asylum seeker

A person you do not understand

A person you would like to know better

A person with schizophrenia

The most successful person I know

A mentally healthy person

A person I feel sorry for

A person I'm comfortable with

A person I admire

A person who is acutely mentally unwell

A person I dislike

3.14. <u>Interview Methodology</u>

Interviews with service users will be carried out at the time of collecting quantitative data. This data will be used as part of the triangulation of result when exploring a deeper meaning of stigma for service users. All of the 15 service users recruited for the semi-structured interviews were concerned about the tape-recording of interviews and unwilling to participate under this condition.

Subjects were happy to be interviewed if the conversation was not recorded on tape and some agreed to write a short personal statement. Questions seeking clarification about personal statements were asked as necessary. The interview data consisted of written personal accounts and contemporaneous notes from the semi-structured interviews.

All service users who agreed to participate in the study and signed the consent form were invited to be interviewed. The interview took place in private rooms at clinical areas or community resource centres. Service users were asked about the impact of mental illness on their own lives, their family and significant others and how mental health services had affected the same. This approach was thought to be helpful in that it not only led service users to talk about stigma, but gave them the opportunity to speak about what was most important to them and the most significant impact on their lives. Responses were recorded in the form of notes and personal accounts, where given. Fifteen service users were interviewed.

At interview, subjects were asked the leading question 'Can you tell me how mental illness and stigma impacted your life?' or 'Regarding mental illness, what does stigma mean to you?' and sometimes, this was the only cue that was needed. Other questions, if necessary, sought clarification of their experiences of stigma.

3.15. Triangulation

This study employed methodological triangulation, which was evident from the quantitative survey, interviews and personal constructions. Triangulation, as used in this study, was a method of combining different research methodologies to study the same phenomenon and had origins in a navigation technique of employing several markers to pinpoint a single objective location (Campbell and Fiske, 1959). The use of a single method to explore a phenomenon may have a weakness or intrinsic bias which can be overcome by the use of different methods, tools and a variety of data. Triangulation can also be viewed as a method of assessing data from multiple sources to look for similarities and themes which are common (O'Donoghue and Punch, 2003).

For example, triangulation can be seen as the mapping out and deeper explanation of the complexity of human behaviour by studying it from diverse angles, which enhances the credibility and validity of results (Cohen and Manion, 1986). The emergent consensus on triangulation proposed a balance and detail to the situation being studied (Altrichter et al., 1996) and added confidence and credibility when consistent findings are corroborated by the collection of different data, which converges on a single proposition (Knafl and Breitmayer, 1989).

Four types of triangulation were identified, data, investigator, theory and methodological. Methodological triangulation, which is the use of more than one method for the collection of data, was employed in this study. Data was collected via the attitude scale, semi-structured interviews and personal constructs. If triangulation produced similar results, then much stronger inferences and conclusions could be drawn (Cormack, 2000).

3.16. Ethical Considerations

The research proposal for this study was subjected for peer review and was also sanctioned by the Research Ethics Advisory Committee of Brunel University. In addition, the proposal was submitted to the Central Office for Research Ethics Committees [COREC], which is the body that sanctions all research within the National Health Service, and was given ethical approval.

Consent from the public to participate in the study was implied by the return of the questionnaire. The telephone directory contained the names and addresses of people over the age of eighteen, so this eliminated the possibility of questionnaires being sent to minors.

A cover letter was supplied to all potential subjects for the public sample. The cover letter and consent form to service users explained that they retained the right to decline to participate or could withdraw at any time from the study and that this would have no impact on the care and treatment they received.

It was not possible to give information to members of the public or to service users regarding the likely level of discomfort, if any, they might have experienced as a result of completing the questionnaire. There was concern from COREC that service users or members of the public might experience distress as they recalled their experiences of stigma. To address this issue, members of the public were reminded of their right to refuse to participate for whatever reason. Contact details of the researcher and mental health support groups, via the cover letter were given to service users (see appendix ii). Service users were observed as they filled out the questionnaire and reminded that they could stop at any time, if they experienced distress, or for any other reason.

The researcher was obliged to give the participant every chance not to participate, both before and during the experimental procedure and working against this was the position of power, prestige and influence of the researcher (Coolican, 1994). This study employed a two-stage consent form (see appendix i) and reminded participants that they could withdraw consent by stopping at any time. Indeed, the unilaterally controlled research context was politically authoritarian and some of its spectacularly well-conceived findings concerned responses to authoritarianism (Torbert, 1981). The approach of this study was to give service users every opportunity to not participate.

People with mental illness can be vulnerable and often feel disempowered (Barker, 2000), so care was taken in order to minimise the possibility of further disempowerment. To this end, the cover letter and two-stage consent form was employed to minimise the possibility of exploitation of this group. In this study, service users that were identified as potential subjects were also required to give written consent and verbal consent after ensuring that they understood their rights and what was required regarding participation in this research (see appendix i).

Confidentiality and anonymity regarding returned questionnaires were maximised by not sending any follow up communication to remind subjects about returning the questionnaire, nor were the questionnaires coded as a means of tracking subjects who did or did not respond. This was important so that subjects did not feel pressured to participate, and could also serve to minimise socially desirable responses. It was also noted that during the course of data collection, researchers may be given information which was confidential and because of the

assurance of confidentiality and anonymity, rich quality data can be obtained (Cormack, 2000). Confidentiality and anonymity could have been broken if any information given could have averted harm to others, including the subject that gave the information.

A participant information sheet and cover letter was sent with the questionnaires as a means of explaining how subjects were chosen, what action can be taken if potential subjects experienced distress and to raise the profile of the study. Another reason for the letter was to avoid conveying the impression that participants were specially chosen for the study.

There was a special responsibility of the researcher to ensure that nothing jeopardised the wellbeing of participants. There was also an obligation to ensure that the investigation contributed to further knowledge in the area of stigma and attitudes and was disseminated to all groups and stakeholders. Because this study into stigma and attitudes was warranted, there is an onus for the researcher to publish and disseminate the results accordingly. It would also be unethical to use people for no apparent cause, especially where they invested time, energy and emotions, and therefore deserved feedback (Cormack, 2000).

This research was identified as essential in capturing the lived experience of people with mental illness because there was a dearth of research in this area, particularly in the United Kingdom. The results of this research will be published in peer-reviewed journals and presented to health care professional and service users in various settings

3.17 <u>Development Of The Attitude Scale</u>

Early research has shown that stigma and attitudes to mental illness are multi-dimensional (Wolpert et al., 1975; Boekch et al., 1980). With the aforementioned in view, the focus was on four dimensions of attitude, benevolence, authoritarianism, social restrictiveness and community mental health ideology (Taylor and Dear , 1981), that were the most strongly evaluative and hence best discriminated between positive and negative attitudes towards the mentally ill. These four factors were key elements in the development of the stigma scale.

3.17.1. Measuring Stigma

Stigma cannot be measured directly so the process of measurement was indirect. As a multi-dimensional construct, there was no single variable that encompassed the notion of stigma. Instead, the measurement relied on grouping a number of variables as indicators, each of which represented an element of the overall construct. Measurement implied the application of a standard scale to each variable, ascribing numerical scores, which were then combined into an overall score. The first step in developing the stigma scale, and subsequently the questionnaire, was to identify themes relating to the construct of stigma. The scale construction warranted the use of published accounts of narratives, because these formed a starting point of lived experience of mental illness, from which themes could be extracted. Furthermore, themes from narratives could be piloted with service users for validation of the scale items.

3.17.2. Theme Development

Themes were generated from the published autobiographical, biographical accounts and qualitative studies about life experiences of individuals with schizophrenia or other mental illnesses, and from concepts identified in the literature on stigma. The intention in using qualitative techniques is to focus on the experiences of individuals with schizophrenia in order to understand and depict their meaning of personal experiences of stigma and discrimination.

Some of the qualitative studies reviewed were based on the experiences of people with a mental illness, though not always schizophrenia. The use of data relating to general mental illness was justified because the stigma literature suggested that all mental illness elicited similar social responses. For example, Farina (1998) found that all forms of mental disorders elicited feelings of rejection and degradation and feelings intensified with increasingly severe disorders.

3.17.3 Personal Accounts

Thirty-one narratives by individuals with schizophrenia published from 1987 to 1997 were analysed. A search of the journal 'Schizophrenia Bulletin' revealed twenty-eight personal accounts. This journal was chosen as a primary source of data because it includes publications of first person accounts of people who have schizophrenia or other mental illnesses.

Twenty-six of these narratives were obtained from the 'Schizophrenia Bulletin' (Anonymous, 1989a; 1989b; 1990a; 1990b; 1990c; 1990d; 1992; 1994; 1996; 1997; Bayley, 1996; Blaska, 1991; Bowden, 1993; DeMann, 1994; Fleshner, 1995; Fortner & Steel, 1988; Gallo, 1994; Herrig, 1995; Jordan, 1995;

Leete, 1989; Molta, 1997; Murphy, 1997; Payne, 1992; Ruocchio, 1989; Stainsby, 1992; Turner, 1993; Wagner, 1996).

The process of thematic analysis began with reading the personal accounts and making abbreviated notes around the emergent themes. Repeated readings of these accounts added clarity to the emerging themes.

It was also interesting to note that nine of the authors of autobiographical accounts chose not to identify themselves. Perhaps their anonymity was another reflection of the stigma of mental illness and personal experiences of the authors.

3.17.4. Qualitative Studies About Life Experiences

The qualitative studies about the life experiences of people with mental illness were differentiated from the personal narratives because the individual stories were synthesised by the authors of these studies and the raw data was not available. The qualitative studies reviewed were categorised into two groups. First, there were autobiographical reports about experiences of schizophrenia (Brekke et al., 1993; Corin & Lauzon, 1994; Cutting & Dunne, 1989; Davidson, 1992; Estroff, 1989; Gara et al., 1989; Gilmartin, 1997; Hooks & Levin, 1986; Kim et al., 1994; Mueser et al., 1997; Muller & Gunther, 1984; Strauss, 1989; Strauss, 1994; Wciorka, 1988; Windgassen, 1992).

Secondly, there were biographical reports of experiences of individuals with a mental illness (Gardner, 1991; Goldin, 1990; Hayne & Yonge, 1997; Herman, 1987; Herman, 1993; Lally, 1989; Letendre, 1997; MacDonald & Sheldon, 1997; Lorencz, 1988; Manos, 1992; Okin & Pearsall, 1993; Pugh et al., 1994; Vellenga & Christenson, 1994).

3.17.5 <u>Themes</u>

Three themes identified from the analysis of the literature were supported by previously reviewed theoretical and empirical studies. The first theme was about prejudice related to people's discomfort in associating with someone who had a mental illness. The second theme was about discrimination and the negative actions towards individuals with mental illness. The third theme was about coping and mechanisms used to prevent rejection and discrimination. These three themes are seen in the following table 3.2.

Table 3.2 Themes Identified

People who might stigmatise	Situations in which stigma might be experienced	Attributes to the mentally ill via stigma and self-stigma
Family or relative Friend Individual with mental illness Acquaintance Community Landlord Teacher Supervisor or employer Charity worker Co-worker Police officer Religious leader Health care provider Media personnel	Socialising: existing relationship developing relationship marriage Getting housing Sharing housing Seeking employment Volunteering Working Access to education Dealing with legal issues Non-criminal proceedings Being in hospital	Dangerous Untrustworthy Shameful Discredited Devalued Unintelligent Alienated or avoided

3.17.6. Stigma As A Construct

The framework used in the development of this questionnaire was based on the notion that socialisation led individuals to develop a set of beliefs about how people treated individuals with a mental illness. When individuals received a diagnosis of mental illness, these beliefs took on a new meaning. The more patients believed that they would be devalued and discriminated against, the more they feelt threatened about the possibility of interacting with others (Link and Phelan, 1999). They may keep their treatment a secret, try to educate others about their situation, or withdraw from social contacts that they perceived as potentially rejecting. Such strategies had negative consequences for social support networks, jobs, and self-esteem.

Items relating to secrecy, withdrawal, and education were used to focus on coping orientations that individuals with mental illness used to deal with stigmatisation. The levels at which these strategies were endorsed reflected the threat that was perceived and were applicable to individuals who had been diagnosed with mental illness, through contact with services (Link et al., 1989).

Therefore, in this conceptualisation, stigma is a combination of the perception of being devalued and discriminated against, and the use of coping mechanisms to prevent rejection and discrimination.

3.17.7 Items From Existing Scales

Although there were a number of attitude scales already in existence, these did not meet the specific needs of this research, or match the conceptual framework, which had been developed. It was not possible to combine these

scales into a single inventory to assess aspects of stigma that related to the public and service users.

The initial process used to devise the scale included an examination of what other researchers did in existing scales. It was also valuable to identify what other researchers deemed to be relevant, important, and discriminating within the topic of stigma and discrimination. Three instruments were used as a guide to items for the stigma scale. The first instrument was developed by Link, (1987) and consisted of 12 items that were written to assess the extent to which an individual believed most people would devalue or discriminate against a psychiatric patient. The items were presented in a six-point Likert scale format.

The second instrument was designed to measure the endorsement of the coping strategies of secrecy, withdrawal, and education (Link et al, 1989). Three multiple-item measures were written to explore the coping orientations that people with mental illness used to deal with stigmatisation. The items in this scale were answered with the same six-point Likert format used for the devaluation-discrimination measure. The third instrument was a measure of discrimination against people with severe mental illness designed by Wahl (1997) as part of the National Alliance for the Mentally III's (NAMI) 'Campaign to End Discrimination Against People with Severe Mental Illness'. This scale was developed to determine how people with diagnosed mental illnesses were treated by their community.

3.17.8 Other Scale Items

Existing scales did not include the following themes that were identified from the literature:-

- The community's acceptance for a group home for the mentally ill in their neighbourhood.
- The belief that people with a mental illness were a danger to themselves or to others.
- The supportiveness of religious leaders to individuals with a mental illness.
- Being treated compassionately when using Accident and Emergency.
- Being socialised about stigma by mental health care professionals.
- Service users claiming to have a less stigmatized diagnosis to protect themselves from possible rejection.
- Reluctance to develop new friendships for fear of being rejected because of a mental illness.
- The ability of people with a mental illness to fit into society.

These ten new items were included to reflect the experiences of people with schizophrenia or other mental illnesses.

3.17.9 Scale Items

In summary, scale items were developed to elicit information about each theme identified. When available, items were adapted from existing instruments measuring related constructs. New items were generated where necessary and based on the subjective experiences of people with schizophrenia or other mental

illness and from research or theory. The compilation of items allowed for the assessment of different versions of a theme and subsequent refinement. The following tables illustrate items from the three existing scales and items which emerged from analysis of biographical and autobiographical accounts.

Table 3.3a: Themes and Associated Items Regarding Prejudice

Theme: Prejudice - C	Others' discomfort in associating with someone who has a mental illness
Situation or attribute	ltem
Conversation	1. I believe most people feel afraid to have a conversation with someone who had a mental illness (WPA, Community survey).
Working	2. I think most people would be uncomfortable about working on the same job with someone who had a mental illness (WPA, Community survey).
Friendship	3. I believe most people would maintain a friendship with someone who had a mental illness (WPA, Community survey).
Living together	4. I think most people would feel uncomfortable about living with someone who has a mental illness (WPA, Community survey).
Friendship	5. I believe most people would accept someone who has a mental illness as a close friend (Link, 1987).
Dating	6. I think most people would be reluctant to date someone who has a mental illness (Link, 1987).
Marriage	7. I believe most people would marry someone with a mental illness just as they would anyone (WPA, Community survey).
Shame	8. I think most people would feel ashamed if others knew that someone in their family had been diagnosed with a mental illness (WPA, Community survey).
Community	9. I believe most people in my community, if they knew, would treat someone who has a mental illness just as they would anyone (Link, 1987).
Housing in neighbourhood	10. I think most people would be opposed to having a group home for people with a mental illness in their neighbourhood.
Developing housing next door	11. I believe most people would be opposed to having a group home for people with a mental illness next door.
Being in hospital Discredited	12. I believe most people think unfavourably of a person who has been in hospital for psychiatric treatment (Link, 1987).

Table 3.3b: Themes and Associated Items Regarding Prejudice (Continued)

Situation or attribute	ltem
Dangerous to self	13. I believe most people think that a person who has a mental illness is a danger to himself or herself.
Dangerous to others	14. I believe most people think that a person who has a mental illness is dangerous to others.
Unintelligent	15. I think most people believe that a person who has a mental illness is as intelligent as the average person (Link, 1987).
Untrustworthy	16. I think most people believe that someone with a mental illness is as trustworthy as the average citizen (Link, 1987).
Discredited or devalued	17. I believe most people would take the opinions of someone who has a mental illness less seriously (Link, 1987).
Being in hospital Shameful	18. I think most people believe that if they entered a hospital for psychiatric care it would be a sign of personal failure (Link, 1987).
Getting work - qualified	19. I believe most employers would hire an individual who has a mental illness if he or she was qualified for the job (Link, 1987).
Getting work - trustworthiness	20. I believe most people would not hire someone who has had mental illness to take care of a family member (e.g., child, person with disability, elderly parent) even if he or she had been well for some time (Link, 1987).
Getting work - passed over	21. I think most employers would pass over the application of someone who has a mental illness in favour of another applicant (Link, 1987).

Table 3.3c: Themes and Associated Items Regarding Discrimination

Theme: Discrimin	ation - Negative actions taken towards individuals with mental illness
Situation or attribute	Item
Recognizing stigma identity - media	22. I have seen or read things in the mass media (e.g., television, movies, and books) about people with mental illness, which I found hurtful or offensive (Wahl, 1997).
Recognizing stigma identity - others	23. I have been in situations where I have heard others say unfavourable or offensive things about people who have a mental illness (Wahl, 1997).
Discredited	24. I have worried that others will view me unfavourably because I have a mental illness (Wahl, 1997).
Socializing	25. I have been treated fairly by others who know I have a mental illness (Wahl, 1997).
Devalued	26. I have been advised to lower my expectations for accomplishments in life because I have a mental illness (Wahl, 1997).
Friends	27. Friends who learned I have a mental illness have been supportive (Wahl, 1997).
Discredited	28. I believe I have been treated as less competent by others when they learned I have a mental illness (Wahl, 1997).
Family	29. Family members who learned I have a mental illness have been supportive (Wahl, 1997).
Shunned	30. I have been shunned or avoided by others when it was revealed that I have a mental illness (Wahl, 1997).
Employer Getting a job	31. I believe I have been turned down for employment, for which I was qualified, when it was revealed that I have a mental illness (Wahl, 1997).
Co-worker or supervisor	32. Co-workers and/or supervisors at work were supportive when they learned I have a mental illness (Wahl, 1997).
Getting housing	33. I have had difficulty renting other housing when it was known that I have a mental illness (Wahl, 1997).
Volunteering -outside mental health	34. I have been excluded from volunteer activities outside the mental health field when it was known that I have a mental illness (Wahl, 1997).

Table 3.3d: Themes and Associated Items Regarding Discrimination Continued

Situation or attribute	Item								
Volunteering Within mental health services	35. I have been excluded from volunteer activities within the mental health field when it was known that I have a mental illness (Wahl, 1997).								
Religious leaders Getting care	36. Leaders within my religious community have been helpful when they learned of my mental illness.								
Legal issues -non-criminal proceedings	37. The fact that I have a mental illness has been used against me in non-criminal legal proceedings (such as child custody or divorce disputes) (Wahl, 1997).								
Legal issues - ordinance	38. I have been treated fairly by police officers when they learned I have a mental illness (Wahl, 1997).								
Health care provider	39. I have been treated fairly when I have used hospital emergency services for my mental illness.								

Table 3.3e: Themes and Associated Items Regarding Coping Mechanisms

Theme: Coping m	echanisms to prevent rejection and discrimination
Situation or attribute	Item
Medical advise	40.1 have been advised by health professionals to conceal my mental illness to avoid rejection and discrimination.
Secrecy -lying	41. I have lied on written applications (for job, licenses, housing, school, etc.) that I had a mental illness for fear that information would be used against me (Wahl, 1997).
Secrecy -diagnosis	42. The best thing to do is to keep my diagnosis of a mental illness a secret (Link et al., 1989).
Secrecy -diagnosis	43. There is no reason for a person to hide the fact that he or she had a mental illness (Link et al., 1989).
Secrecy -treatment	44. I often feel the need to hide the fact that I have had psychiatric treatment (Link et al., 1989).
Secrecy -telling	45. I have avoided telling others outside my immediate family that I have a mental illness (Wahl, 1997).
Advise for relative	46. "If I had a close relative who had been treated for a mental illness, I would advise him or her not to tell anyone about it" (Link et al., 1989, p. 414)
Getting work	47. In order to get employment I believe that I will have to hide my history of treatment for a mental illness (Link et al., 1989).
Educate others	48. "I've found that it's best to help the people close to me understand what psychiatric treatment is like" (Link et al., 1989, p. 414).
Educate friends	49. If I thought a friend was uncomfortable with me because I had a mental illness, I would try to educate him or her about my illness (Link et al., 1989).
Educate employer	50. If I thought an employer felt reluctant hiring a person who had a mental illness, I would try to explain to him or her that most people with a mental illness are good workers (Link et al., 1989).
Educate public	51. I would participate in an organized effort to teach the public more about mental illness (Link et al., 1989).

Table 3.3f: Themes and Associated Items Regarding Coping Mechanisms Continued

Situation or attribute	Item
Educate others	52. After I started treatment for my mental illness, I often found myself educating others about my illness (Link et al., 1989).
Friendship	53. It is easier for me to be friendly with people who have or had a mental illness (Link et al., 1989).
Withdrawal	54. If I thought that someone I knew held negative opinions about people with a mental illness, I would try to avoid them (Link et al., 1989).
Getting work -withdrawal Form	55. If I was looking for a job and received an application, which asked about a history of psychiatric treatment, I would complete it (Link et al., 1989).
Getting work -withdrawal of Application	56. If I thought an employer was reluctant to hire a person with a history of a mental illness, I wouldn't apply for the job (Link et al., 1989).
Avoidance	57. If I believed that a person I knew thought unfavourably about me because I have a mental illness, I would try to avoid him or her (Link et al., 1989).
Conversion	58. I have claimed to have a different diagnosis to protect myself from possible rejection.
Covering	59. "When I meet people for the first time, I make a special effort to keep the fact that I have been in psychiatric treatment to myself" (Link et al., 1989, p. 414).
Developing relationship	60. I am reluctant to develop new friendships in fear of being rejected because I have a mental illness.
Socialization	61. Individuals who have had a mental illness are not able to fit into society.

3.18. Instrument Formation

Discussions and review of the questionnaire was undertaken with a group consisting of two clinical psychologists, three nurses who worked in in-patient and community settings and a psychiatrist who all had extensive research and clinical experience. It was agreed that the scale should take the form of a simple, paper-and-pencil questionnaire that was brief and easy for everyone to complete and potentially amenable to computer administration and scoring. In addition, an attempt was made to keep the questionnaire simple, interesting, and non-threatening. The panel was also helpful in spotting overlaps and provided further scrutiny of attitude statements.

Thirty five items were identified for the attitude scale. This was based on having easy to understand statements which did not overlap, nor elicit similar aspects of stigmatisation.

3.18.1. Scaling Responses

A technique called direct estimation was used to quantify the judgements of the subjects on scale items. Direct estimation methods were designed to elicit a direct quantitative estimate of the magnitude of an attribute (Streiner & Norman, 1995). The approach involved asking respondents to express an opinion on a five-point Likert-type scale (DeVillis, 1991) composed of four response options: strongly agree, agree, disagree, and strongly disagree. The use of a 'not sure' or neutral position between disagree and agree was considered but not employed so as to eliminate neutral responses. This was considered essential because this

scale was designed to elicit emotive responses to statements which were usually biased (Oppenheim, 1996).

3.18.2 Pilot testing of research tools

The pilot test evaluated the content, feasibility of administration, including acceptability, clarity and the interpretability of the data, in a small and selected sample of individuals who were service users or members of the public.

Subjects in the pilot of the questionnaire were eighteen to sixty-five years of age. Each subject was required to understand the nature of the study and voluntarily signed a consent form. Service users had a clinical diagnosis of mental illness. Subjects were excluded if they were acutely ill or unable to provide informed consent. Members of the public were randomly selected from the Harrow Telephone directory.

The aim was to have the scale completed by about fifteen subjects. There is no consensus on sample size for instrument development and testing (Goering & Streiner, 1996; Kuzel, 1992), but it was expected that this number of subjects would be sufficient to highlight any problems and deficiencies with the questionnaire.

Sixteen subjects participated in the pilot study. Eight were people with a clinical diagnosis of mental illness and were either an in-patient or attended a day hospital or community mental health facility. The other subjects were members of the public.

A two-step procedure was used to obtain informed consent (see appendix i). In this first step, potential subjects were advised of the study either in a group

forum or personally. Interested subjects completed the preliminary consent form, which were reviewed for inclusion and exclusion criteria. The involvement of lead clinicians ensured that vulnerable subjects were not approached to be part of this research, and that subjects had given permission to be approached.

During the second step, the formal consent form was reviewed with the potential subjects. This review outlined the nature of the study, their participation, how data would be handled and protected, study risks, and study benefits. Interested subjects were asked to read the formal consent form before signing. A similar procedure for acquiring consent was also used for the main study.

Once informed consent was obtained, the questionnaire and other relevant information were provided to each subject. Subjects completed the questionnaires individually and also gave verbal comments about the use of the questionnaire.

3.18.3. Scale Interpretation

Psychometric scaling techniques typically assume interval level data for ordinal categories if they are normally distributed (Brace et al., 2000). Based on the earlier analyses, the responses for each subscale were well distributed except for one aspect. Responses for items regarding coping mechanisms had a strong central tendency, which reduced the ability of the scale to distinguish change, but still permitted the responses to be treated as interval data. Therefore, it was possible to assume interval level data for ordinal categories and aggregate the subscale (MacDowel & Newell, 1996; Streiner & Norman, 1995).

3.18.4 Scoring Procedure

The scoring approach chosen made no assumptions about the individual items. The only implicit assumption was that the items were equally important in contributing to the overall score.

All items were scored so that accumulative higher scores indicated a more positive attitude. A total of the individual item scores resulted in the overall stigma score.

3.18.5. Missing Items

When calculating scores from items that have missing data the researcher is faced with four options. The options are (a) ignore the missing data, (b) omit persons with missing data from the study (c) omit the persons from the particular analysis of a subscale that contains the missing data, or (d) find a way to replace the missing data with an estimate of what the missing item might be.

If missing items were ignored the resulting summing over of the remaining items could lead to an underestimation of the individual's score. On the other hand, dropping the participants with missing data from the analyses could reduce the power and accuracy of the analyses, particularly where missing data is extensive. Substituting a neutral value, for example, the mean of all of a subject's completed items for those items they have not completed, has been found to result in a good representation of the original data when the number of items missing was 20% or less. This replacement method was called the 'person mean substitution approach' and could be applied to preserve data (Downey & King, 1998). The completed questionnaires were fully completed, so there was no

need to use this approach.

3.18.6 Results Of Pilot Test Of Questionnaire

The individual scores for each theme category or subscale are summarized in Table 3.4.

Table 3.4: Individual Scores for Each Theme Category

Theme Category or Subscale	Subject Number (n=16)															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Prejudice	54	38	42	44	46	38	43	41	45	48	37	38	46	44	27	30
Stigma socialization	12	12	6	14	10	11	21	21	10	11	10	9	20	20	24	26
Coping mechanisms	20	16	23	19	20	23	24	15	19	16	16	15	17	23	25	19
Overall Stigma Score	86	66	71	77	76	72	88	77	74	75	63	62	83	87	76	75

Results indicated that the stigma scale was able to discriminate between different levels of stigma, which was evident in the wide range of scores. Results showed a statistically significant negative correlation between attitude to mental illness and perceived stigma.

3.18.7. Validity And Reliability Of The Stigma Scale

The scale consisted of groups of statements that elicited certain aspects of stigma. Groups of statements were more reliable than single items because they gave more consistent results (Oppenheim, 1996). This comes about because vagaries of questionnaire wording will probably apply only to certain items, and bias may be cancelled out, whereas the underlying attitude will be common to all the items in the group of statements (Oppenheim, 1996).

The main difficulty in assessing the validity of this scale was the lack of criteria group. It would have been ideal to have groups of people with known attitude characteristics to examine whether the attitude scale can discriminate among such groups. There was no reason to suggest that group membership as a reflection of an attitude was any more valid than an attitude scale. The links between attitude and behaviour are complex and an attitude score may not be a valid criterion of a specific attitude.

An ideal test of external reliability would be to test a group of subjects, then retest the same group some time later. The two sets of scores could then be correlated to see if subjects had similar scores on retest. Correlations would be expected to be between 0.75 and 0.89 (Oppenheim, 1996).

There could be a number of difficulties if this test-re-test reliability method was applied to this attitude scale, particularly on an emotive topic such as attitudes to mental illness and stigma. Subjects may answer

differently on re-test because they may wish to alter the image that was made initially, or later on, may attempt to give more socially desirable responses. Subjects might also be able to recall their responses from the first test and answer differently to their current perception. There is also the possibility that some event may have occurred, during test and retest, which could have a significant impact on their attitudes. For example, in the interim period, there could be a homicide involving a person with mental illness, which could impact attitudes.

Reliability of the stigma scale was measured using the internal consistency method associated with the Cronbach Alpha coefficient. This method gave a reliability measure in the form of a correlation coefficient. The internal consistency method was underpinned by scaling theory (Oppenheim, 1996). The scale was designed to measure a single factor (stigma) so the items should have strong correlations with the factor stigma and with each other. The resulting correlation suggested that the scale items were more likely to be a valid measure of stigma. The Cronbach alpha score of 0.83 gave an estimation of the proportion of the total variance that was not due to error, representing the reliability of the scale.

The following tables (3.5 and 3.6) show the results of the Cronbach Alpha correlations.

Table 3.5. Correlation Between Prejudice And Stigma Score

Correlations

		PREJUDIC	STIGSCOR
PREJUDIC	Pearson Correlation	1	.934**
	Sig. (2-tailed)		.000
	N	16	16
STIGSCOR	Pearson Correlation	.934**	1
	Sig. (2-tailed)	.000	
	N	16	16

^{**.} Correlation is significant at the 0.01 level (2-tailed).

Table 3.5 shows a significant correlation between prejudice and stigma score

Table 3.6 Correlation Between Stigma Score And Coping Mechanism

Correlations

		STIGSCOR	COPEMECH
STIGSCOR	Pearson Correlation	1	.731**
	Sig. (2-tailed)		.001
	N	16	16
COPEMECH	Pearson Correlation	.731**	1
	Sig. (2-tailed)	.001	
	N	16	16

^{**.} Correlation is significant at the 0.01 level (2-tailed).

Table 3.6 shows a significant correlation between stigma score and coping mechanism. The average of the correlation coefficients (0.93 and 0.73) gave a Cronbach Alpha score of 0.83.

3.18.8. Response Bias

The ease of design and administration of this scale was both an asset and a liability. This was the case because the intent of questions framed on a rating scale was often obvious to both the researcher and respondent and as a result, there could have been a response bias.

Acquiescence bias was the tendency to give positive responses. At the extreme, the subject responds positively irrespective of the content of the item. At the opposite end of the spectrum the person disagrees with the items. It is believed that this tendency was normally distributed (Oppenheim, 1996) so that relatively few people are at the extremes, but many people exhibited this trait to lesser degrees. In this study acquiescence was accounted for by having an equal number of items keyed in the positive and negative directions. This meant that some items that were eliciting a positive response was scored 5,4,3,2,1, on the Likert scale from strongly disagree to agree and for items that were eliciting a negative response 1,2,3,4,5 from strongly disagree to agree.

The scale items were set out in an unpredictable mixture of positive and negative statements about the attitude object. This aimed at keeping the respondent thinking about each item or gave the respondent that tended to agree with all items, a central rather than an extreme score.

3.18.9. Demographic Variables

The collection of descriptive information about respondents was common in surveys. Variables such as age, sex, marital status, employment status and education, were used to evaluate the degree of representation of the study sample and to correlate responses of survey items. These variables were used in this study, as well as questions about social contacts, frequency and duration of hospitalisation, and detention under the Mental Health Act (1983).

CHAPTER FOUR RESULTS

This chapter gives a detailed account of characteristics and demography of the study sample, results from correlations, regression analyses, interpretative phenomenological analysis of the interview data and principal factor analysis of the personal constructs of stigma. Descriptive and inferential statistics in the study data were subjected to analyses using the Statistical Package for the Social Sciences (SPSS version 15.0).

This study employed methodological triangulation, which involved the use of mixed methods for the collection of data. Quantitative data was collected via the attitude scale and qualitative data through the use of semi-structured interviews. The repertory grid technique which was used for personal construct of stigma, yielded both quantitative and qualitative data. More robust inferences and conclusions were drawn as a result of the methodological triangulation and convergence of findings.

4.1. Sample Characteristics

4.1.1. Public Sample

Three hundred postal questionnaires were sent out and 153 were returned. This gave a response rate of 51%. From the returns, one hundred and thirty-six questionnaires were usable, from which the first 132 to be returned, was selected. The mean age for the sample was 40 years with 60 males and 72 females. The white British, Scottish and Welsh ethnic groups had 71 subjects and the other ethnic groups totalled 61 subjects. The average education level was diploma and degree levels. The mean attitude score was 93.0.

4.1.2. Mental Health Service User Sample

The average age in the service user sample was 40-44 years. There were 85 males and 47 females, which also reflected the higher number of male service users. The white British, Scottish and Welsh group had 50 and the other ethnic groups totalled 82.

The mean period of contact with mental health services [carespan] was six to ten years, with 36.4% of the sample over ten years. The main clinical area of contact with mental health services was the mental health in-patient unit with 46.2%, while 22.7% of clients had contact with forensic services. 78% of the sample, at some time, was detained under the Mental Health Act (1983). 61% were single, 13% divorced and 8% were separated from their spouse.

51% lived alone, 23% lived in the forensic unit, group home or were homeless. The average education level was 'O' and 'A' level. 78% did not work or were unemployed in the last year. 53% had friends with and without mental illness, 25% interacted only with other people with a mental illness and 22% did not interact with people with a mental illness. For service users, the average perception of stigma score was 82.80.

Table 4.1 Statistics For Stigma

N	264
Mean	88.2273
Mode	90.00
Std. Deviation	10.21189
Skewness	-0.306
Std. Error of Skewness	0.150
Kurtosis	0.031
Std. Error of Kurtosis	0.299
Minimum	55.00
Maximum	115.00

Table 4.1 shows the central tendencies, skewness, kurtosis, standard deviation and standard errors of skewness and kurtosis of stigma.

Mean stigma score is 88.23

Mode of stigma is 90.00

Standard deviation is 10.21

Minimum score is 55

Maximum score is 115

Skewness -0.306

Standard error of skewness 0.150

Kurtosis 0.031

Standard error of kurtosis 0.299

4.2 Test For Normality Of Distribution For Stigma.

264

Table 4.2

Test of Normality for Stigma

0.065

Kolmogorov-Smirnov		Shapi	ro-Wilk		
Statistic	df	Sig.	Statistic	df	Sig.

0.991

264

0.12

0.010

Table 4.2 shows the Kolmogorov-Smirnoff statistic, the degrees of freedom and the Shapiro-Wilkinson statistic. The Kolmogorov-Smirnoff statistics should be greater than 0.05 to illustrate normality of distribution.

Kolmogorov-Smirnov score of 0.010

Degrees of freedom (df) 264

stigma

Shapiro-Wilkinson statistic 0.991

The result of the test for normality of distribution illustrated that the statistic was too high to be a normal distribution, but this is usual for large samples, as in this study. The following histogram and Q-plot further illustrated the normal distribution pattern of stigma.

Figure 4.1

Histogram Of Stigma

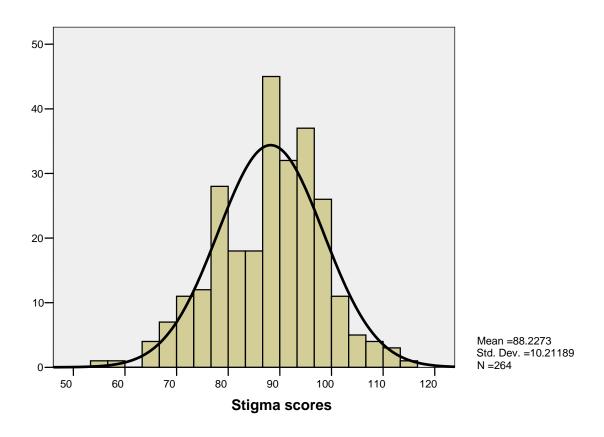
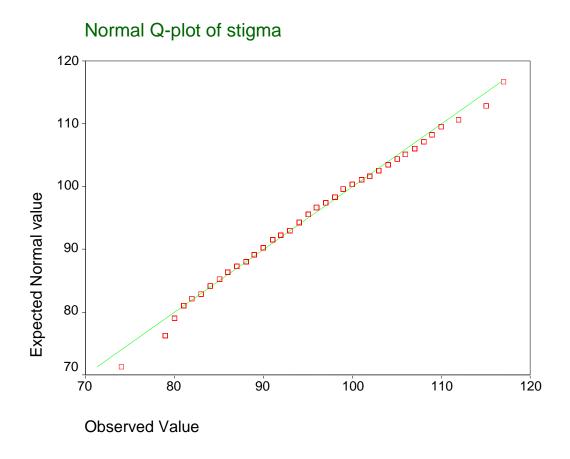


Figure 4.1 shows stigma scores and frequencies which follow the normal distribution.

Figure 4.2



In figure 4.2 the Q-plot of stigma shows the observed value plotted against the expected value from a normal distribution. Because the scores aligned in a reasonably straight line, they indicated a normal distribution.

Figure 4.3

Distribution Of Stigma Scores

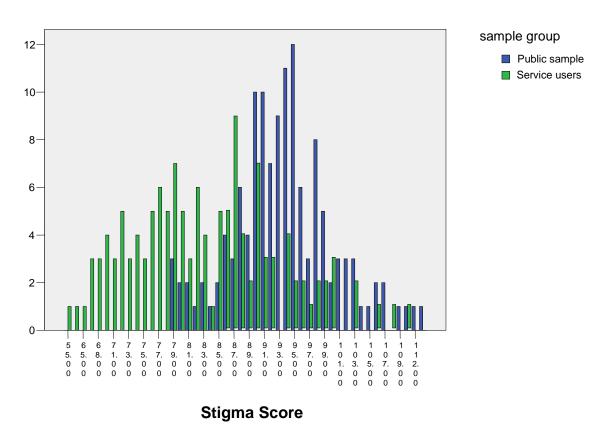


Figure 4.3 <u>Distribution of Stigma Scores</u>.

Figure 4.3 shows the distribution and frequency of stigma scores for group one (public sample in blue) and group two (service users in green). This figure illustrates that public scores (blue) were higher than service-user scores (green). The range of stigma scores is shown along the y axis and the frequency of scores on the x axis.

Stigma Scores by sex

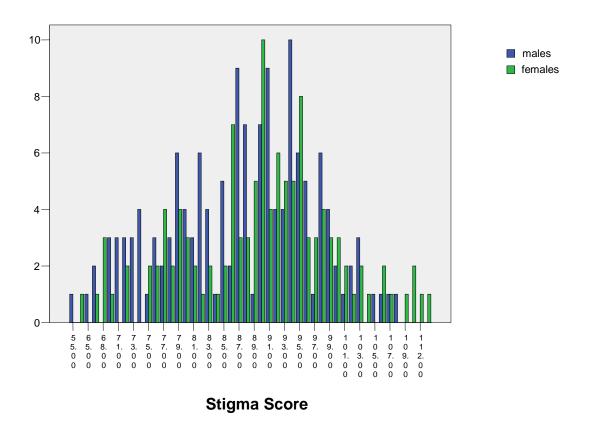


Figure 6.4. Distribution of Stigma Scores By Sex

Figure 4.4 shows the distribution and frequency of stigma sores by sex. The blue bars represented males and green represented females. The frequency of blue bars versus green bars illustrate that males scored lower (higher level of stigma) than females. The stigma scores are along the y axis and the frequency of scores along the x axis.

4.3 <u>Age</u>

The legend of age in the sample from level 1 to level 12 were as follows.

1= 18-19 yrs	2= 20-24 yrs	3=25-29 yrs	4= 30-34 yrs
5= 35-39 yrs	6= 40-44 yrs	7=45-49 yrs	8= 50-54 yrs
9= 55-59 yrs	10=60-64yrs	11=65-69 yrs	12= 70 ⁺ yrs

Table 4.3 Statistics For Age

Mean	5.6439
Minimum	1.00
Maximum	12.00

Table 4.3 displays the mean age, minimum and maximum age of the sample.

Average age (5.6) = 40 yrs

Minimum age (1) =18-19 yrs

Maximum age (12) 70+ yrs

Histogram of age

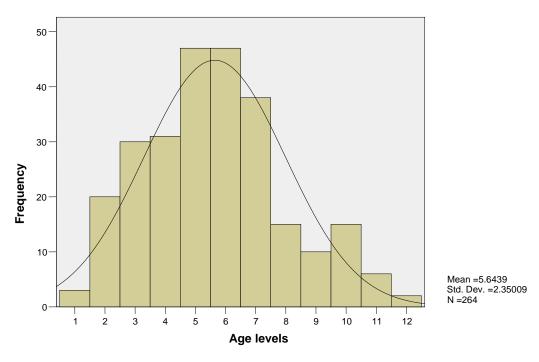


Figure 4.5 <u>Distribution Of Age With Normal Distribution Curve.</u>

Figure 4.5 shows the frequency and distribution of age in the sample. The mean age was 40yrs. This histogram also illustrates the normal distribution curve, indicating that age was normally distributed.

The distribution of age in the sample was as follows.

1.1 % (3) of subjects were 18-19 years old

7.6 % (20) of subjects were 20-24 years old

11.4 % (30) of subjects were 25-29 years old

11.7 % (31) of subjects were 30 -34 years old

17.8 % (47) of subjects were 35-39 years old

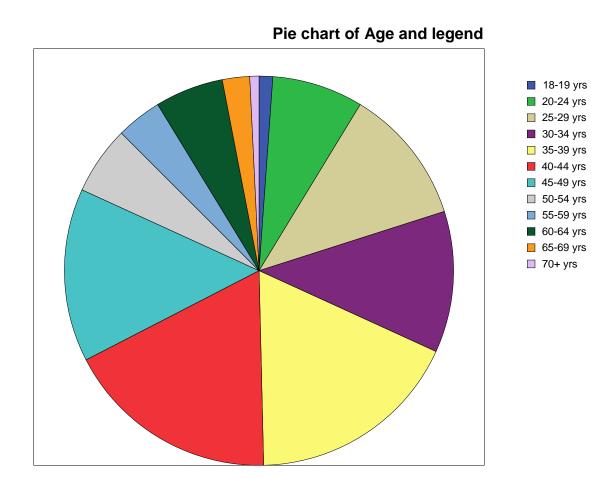
17.8 % (47) of subjects were 40-44 years old

14.4 % (38) of subjects were 45-49 years old

5.7 % (15) of subjects were 50-54 years old

3.8 % (10) of subjects were 55-59 years old 5.7 % (15) of subjects were 60-64 years old 2.3 % (6) of subjects were 65-69 years old 0.8 % (2) of subjects were 70 plus years old

Figure 4.6 Pie Chart Representation Of Age Levels With Colour Coding



The frequencies in the age distribution were scattered and some groups had very small numbers. To strengthen inferences the age clusters were regrouped to six age clusters. This regrouped variable is illustrated in the following table (4.4). Groups 1, 2 and 3 became group 1; group 4 became group 2; group five became group 3; group six became group 4; group 7 became group 5; and groups 8, 9, 10, 11 and 12 became group six. This

regrouping was primarily for statistical calculations and did not change the values.

Table 4.4. Distribution of Age (regrouped variable).

Age Level	Frequency	Percent
Level 1 (18-29 yrs)	53	20.1
Level2 (30-34 yrs)	31	11.7
Level 3 (35-39 yrs)	47	17.8
Level 4 (40-44 yrs)	47	17.8
Level 5 (45-49 yrs)	38	14.4
Level 6 (50-70+ yrs)	48	18.2
Total	264	100

Table 4.4 shows the six levels in the regrouped variable with frequency, and percentage.

Table 4.5 Statistics For The Regrouped Variable Of Age

Age

Mean	5.6439
Minimum	1.00
Maximum	12.00

Table 4.5 show statistics for age as follows

Average age (3.49) = 40-44 years

Minimum age (1) =18-29 years

Maximum age (6) = 50-70+ years

4.4 Ethnicity

Table 4.6 <u>Legend of Ethnicity</u>

White English/ Scottish/ Welsh	1	Indian	6
White Irish	2 Pakistani		7
White Other(Please describe)	3	Bangladeshi	
Black African	4	4 Chinese	
Black Caribbean	5	Any other Ethnic group (please describe)	10

Table 4.6 shows the ethnic groups and the level assigned to each group.

Table 4.7 Ethnic Distribution And Percentages In The Sample

	Frequency	Percent
Level 1 (White British)	121	45.8
Level 2 (Irish)	16	6.1
Level 3 (White other)	18	6.8
Level 4 (Black African)	17	6.4
Level 5 (Black Caribbean)	37	14.0
Level 6 (Indian)	25	9.5
Level 7 (Pakistani)	2	0.8
Level 8 (Bangladeshi)	2	0.8
Level 9 (Chinese)	2	8.0
Level 10 (Other self-description)	24	9.0
Total	264	100

Table 4.7 shows ethnicity frequencies and percentages in the sample.

Figure 4.7 <u>Histogram Of Ethnic Groups</u>

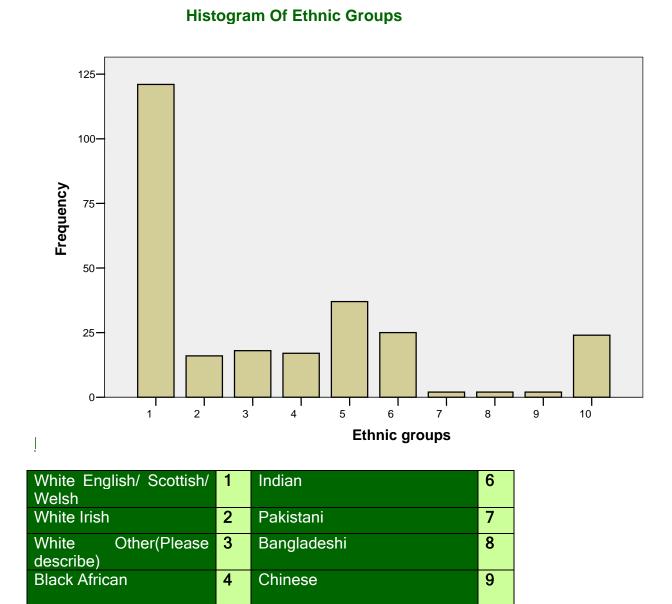


Figure 4.7 illustrated the ethnic distribution in the sample. There were 121 subjects in ethnic group one, which did not balance, in terms of sufficient numbers for analysis, with the other ethnic groups.

other

(please describe)

Ethnic

group

10

5

Black Caribbean

Any

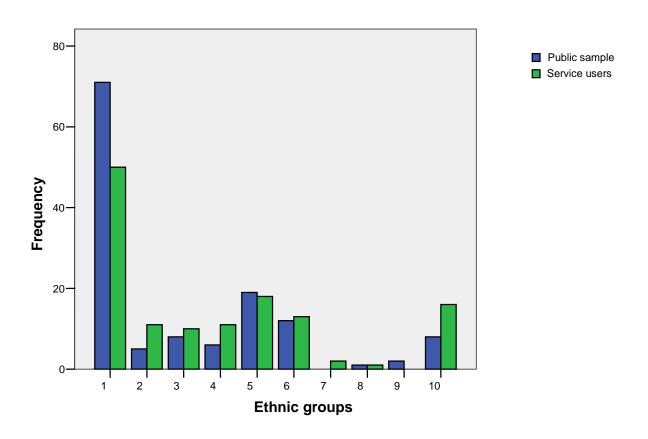
Table 4.8 Breakdown Of Ethnicity In The Public And Service Users' Group

Ethnic groups	Public sample	Service users	Percent
1 White British	71	50	45.8
2 White Irish	5	11	6.1
3 White European	8	10	6.8
4 Black African	6	11	6.4
5 Black Caribbean	19	16	14.0
6 East Indian	12	13	9.5
7 Pakistani	0	2	0.8
8 Bangladeshi	1	1	0.8
9 Chinese	2	0	0.8
10 Other (self-defined)	8	16	9.1

Table 4.8 illustrates the breakdown in ethnicity of the sample.

Figure 4.8

Histogram Of Ethnic Groups



Legend of ethnicity:- 1 White British 2 White Irish 3 White European 4 Black African 5 Black Caribbean 6 East Indian 7 Pakistani 8 Bangladeshi 9 Chinese 10 (self-defined).

Figure 4.8 shows the number of members of the public (blue) compared to service users (green) for each ethnic group. The figure shows that there were more service users in the non-white ethnic groups.

The spread of subjects in some ethnic groups was sparse and had too few numbers for meaningful statistical analyses. To give better meaning to this variable, subjects were clustered into one of two groups, Whites and non-Whites, and is illustrated in table 4.9

Table 4.9 The Number And Percentages In Ethnic Groups

	Frequency	Percent
Whites	121	45.80
Non-Whites	143	54.20

Table 4.9 shows numbers, percentages and cumulative percentages of the two ethnic groupings.

4.5 <u>Sex</u>

Table 4.10. Sex Distribution In The Total Sample

	Public Sample	Service Users	Total	Percent
Male	60	85	145	54.9
Female	72	47	119	45.1
Total	132	132	264	100

This table 4.10 shows the frequency, total, and percentage of males and females in the sample.

54.9 % (145) of subjects were male

45.1 % (119) of subjects were female

4.6. Education Level

Table 4.11. Frequency And Percentages For Education Level

Education level	Frequency	Percentage
Level1 (Primary to GCSE)	113	42.8
Level 2 (Advanced level)	65	13.3
Level 3 (Diploma to degree)	26	9.8
Level 4 (Higher degree)	65	24.6
Level 5 (Skills-based)	25	9.5
Total	264	100

Figure 4.9

Histogram Of Education

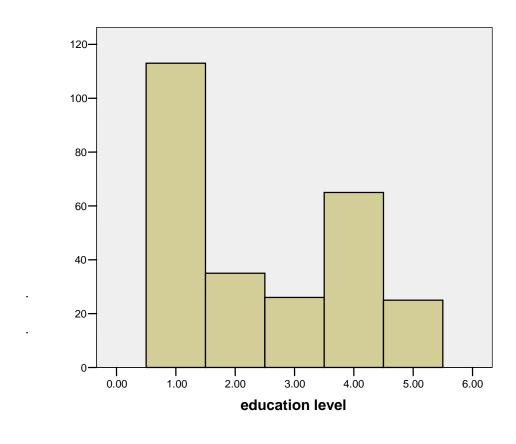


Figure 4.9 shows the distribution and frequency of education level in the sample

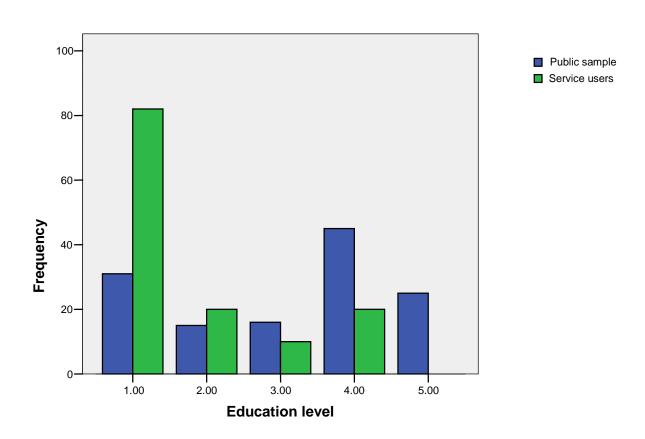
Table 4.12 Percentage And Frequency In Education Level Within Groups

Education level	Public sample N / %	Service users N / %
1 (primary to GCSE)	31 / 23.5	82 / 62.1
2 (Advanced level)	15 / 11.4	20 / 15.2
3 (Diploma to degree)	16 / 12.1	10 / 7.6
4 (Higher degree)	45 / 34.1	20 / 15.2
5 (Skills based)	25 / 18.9	0 / 0.0

This table 4.12 shows legend of education, percentage and frequencies in education level within the two groups of the sample.

Figure 4.10

Histogram Of Education



Legend of Education

Education level
1 (primary to GCSE)
2 (Advanced level)
3 (Diploma to degree)
4 (Higher degree)
5 (Skills based)

Figure 4.10 Histogram Of Education Levels Between Sample Groups

This figure 4.10 illustrates the frequency for education levels between the public sample and service users. It illustrates that 62.1% of service users were at level one and none had skills-based qualifications. There were fewer service users with diplomas and higher degrees than members of the public.

4.7 Carespan

Carespan was the period over which service users had contact with mental health services.

Table 4.13. Carespan Of Service Users With Legend

Level of Carespan	Frequency	Percent
Level 1 (up to one year)	24	18.1
Level 2 (two to five years)	44	33.4
Level 3 (five to ten years)	16	12.1
Level 4 (ten years plus)	48	36.4

Table 4.13 shows the carespan of service users. More service users were in levels two and four, two to five years, or more than ten years of contact with mental health services.

Figure 4.11

Histogram Of Care Span

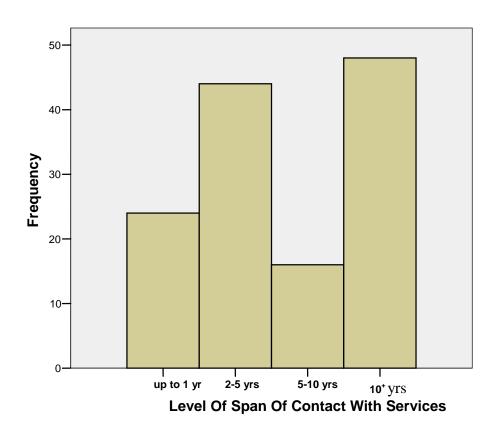


Figure 4.11 <u>Histogram Of Service-Users' Contact With Services</u>

The distribution of carespan was small for level one (24 subjects) and level three (16 subjects) so the total sample was regrouped. Levels one and two became level one and levels three and four became level two. This regrouping meant that values were not affected, but this facilitated stronger statistical analyses. Level one represented up to five years of contact with services and level two indicated more than five years. Results from the regrouped carespan variable were as follows.

51.5 % (68) service users were receiving care for up to five years 48.5 % (64) service users were receiving care for more than five years

This result provided more even numbers in each group, which meant better statistics for comparison. This is illustrated in figure 4.12.

Figure 4.12 Histogram Of Regrouped Carespan

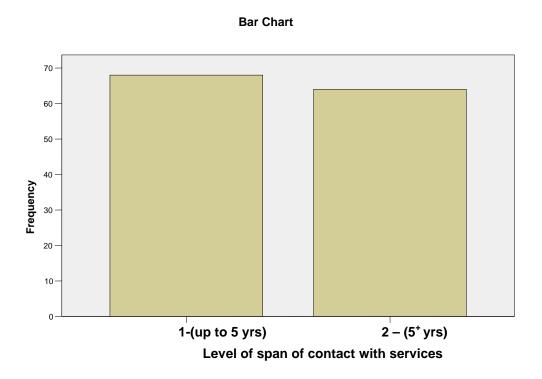


Figure 4.12. <u>Histogram Of Regrouped Carespan</u>

Figure 4.12 illustrates that there is a more even balance in frequency between level one (up to 5 yrs contact) and level two (more than 5yrs contact).

Table 4.14. Sex Differences In Carespan

	Level 1 up to 5-yrs	Level 2 5 yrs plus	Total / Percent
Male	44	41	85/ 64.4
Female	24	23	47 / 35.6
Total	68	64	132 / 100

Table 4.14 shows the frequency and percentages in gender differences in carespan.

51.8 % (44) male service users had contact for up to five years

51.1 % (24) female service users had contact for up to five years

48.2 % (41) male service users had contact for more than five years

48.9 % (23) female service users had contact for more than five years

4.8. Care Setting

Table 4.15 <u>Care Settings Of Service-Users</u>

Care setting	Number	Percent
Level 1 Mental health Unit	88	66.7
Level 2 Secure / Forensic	44	33.3

Table 4.15 shows the frequency and percentage of care settings.

Level one was an in-patient stay in a mental health unit or mental health unit within a general hospital.

Level two was an in patient stay in a secure forensic mental health unit.

Table 4.16. Sex Differences In Care Settings

	Males Number / Percent	Females Number / Percent	Total
Level 1 Mental health Unit	60 / 68.2	28 / 31.8	88
Level 2 Secure / Forensic	25 / 56.8	19 / 43.2	44
Total	85/ 100	47 / 100	132

Table 4.16 shows sex differences in care settings. These results were better illustrated in the following figure 4.13

Figure 4.13 <u>Sex Differences In Care Settings</u>

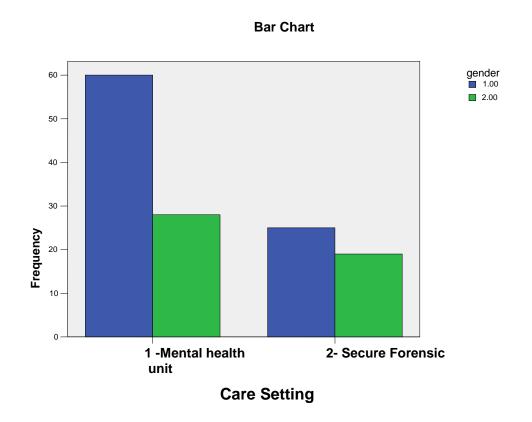


Figure 4.13 <u>Sex Differences In Care Settings</u>

This figure 4.13 illustrates sex differences in care settings. It shows that males (blue) were more frequent than females (green) in both care settings. There were more than twice the number of males than females, in a mental health unit (Level 1).

4.9 Living Arrangements

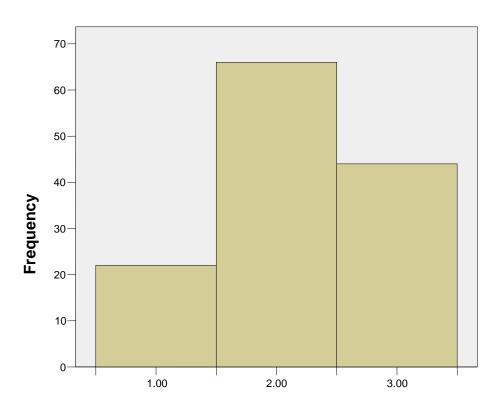
Table 4.17 <u>Living Arrangements Of Service Users</u>

Legend / Level of living arrangement	Frequency	Percent
Level 1 Living alone	22	16.7
Level 2 living with partner parents or siblings	66	50.0
Level 3 Living in group home or homeless	44	33.3

Table 4.17 shows the frequency and percent of living arrangement of service users. These results are illustrated in the following Figure 4.14.

Figure 4.14

Histogram Of Living Arrangement



Living Arrangement Level

Figure 4.14 Living Arrangements Of Service Users

Legend Of Living Arrangement

Level Of Living Arrangement
Level 1 Living alone
Level 2 living with partner parents or siblings
Level 3 Living in group home or homeless

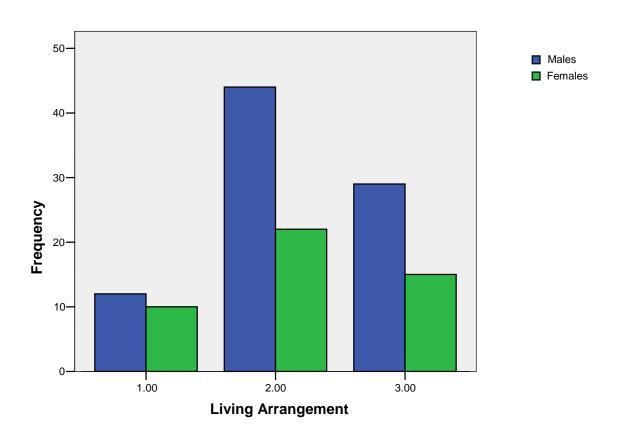
This figure 4.14 illustrates the frequency of service users and their different living arrangements. Half of the service users sample lived with a significant other.

Table 4.18 Sex Differences In Living Arrangement

Level of living arrangement	Males Frequency / Percent	Females Frequency / Percent	Total
Level 1 living alone	12 / 55.5	10 / 45.5	22
Level 2 living with partner parents or siblings	44 / 66.7	22 / 33.3	66
Level 3 living in group home or homeless	29 / 65.9	15 / 34.1	44
Total	85 / 64.5	47 / 35.6	132

Table 4.18 shows the percentage, and frequency distribution between the living arrangements of male and female service users.

Figure 4.15 <u>Sex Differences In Living Arrangements</u>



Level Of Living Arrangement
Level 1 Living alone
Level 2 living with partner parents or siblings
Level 3 Living in group home or homeless

Figure 4.15 illustrates sex differences in living arrangement. More males (blue) lived with a significant other than females. Compared to females, about twice as many males were single and lived in a group home, hostel, hospital or were homeless.

4.10. Marital Status Of Service Users

Table 4.19. Marital Status Of Service Users

Level of marital status	Frequency	Percent
Level 1 single	80	60.6
Level 2 with partner	10	7.6
Level 3 married	13	9.8
Level 4 separated	10	7.6
Level 5 divorced	18	13.6
Level 6 widowed	1	0.8

Table 4.19 shows the legend, frequency and percentages in the marital status of service users.

Figure 4.16

<u>Histogram Of Sex Differences In Marital Status</u>

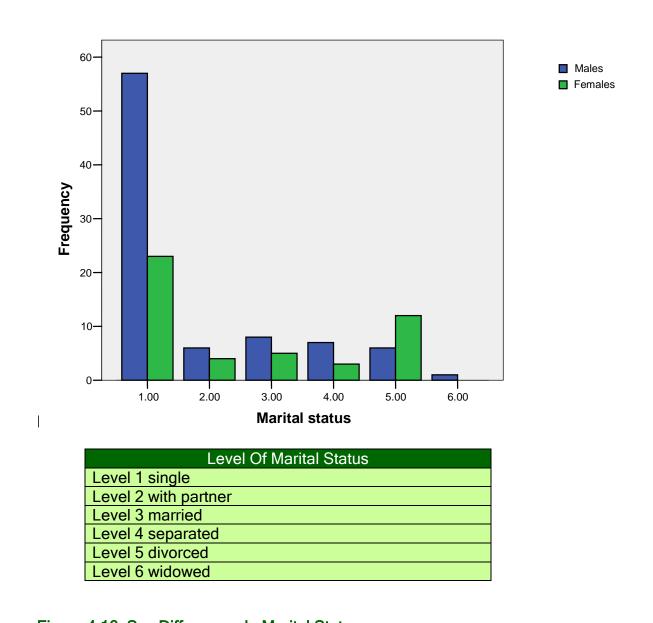


Figure 4.16. <u>Sex Differences In Marital Status.</u>

Figure 4.16 shows that male service users (blue) were over-represented in being single and more males were separated from their partners.

67.1 % (57) males were single 48.9 % (23) females were single

7.1 % (6) males lived with a partner 8.5 % (4) females lived with a partner

8.2 % (7) males were married	10.6 % (5) females were married	
8.2 % (7) males were separated	6.4 % (3) females were separated	
7.1 % (6) males were divorced	25.5 % (12) females were divorced	
1.2 % (1) male was widowed	0.0 % (0) females were widowed	

The variable marital status was regrouped because there were insufficient numbers to provide a meaningful analysis. The two groups comprised of those who were single and those who lived with a partner, and is indicated as follows: 60.6 % (80) service users were single and 39.4 % (52) lived with a partner.

4.11. Compulsory Detention Under The Mental Health Act (1983)

Table 4.20 <u>Legend</u>, <u>Frequency And Percentages Of Compulsory Detention</u>

Mental Health Act (1983) [MHA] Status	Frequency	Percent
Level 1 (Informal)	28	21.2
Level 2 (Detained)	104	78.8

Table 4.20 shows the frequency and percentages of service users who were detained under the Mental Health Act (1983).

Figure 4.17

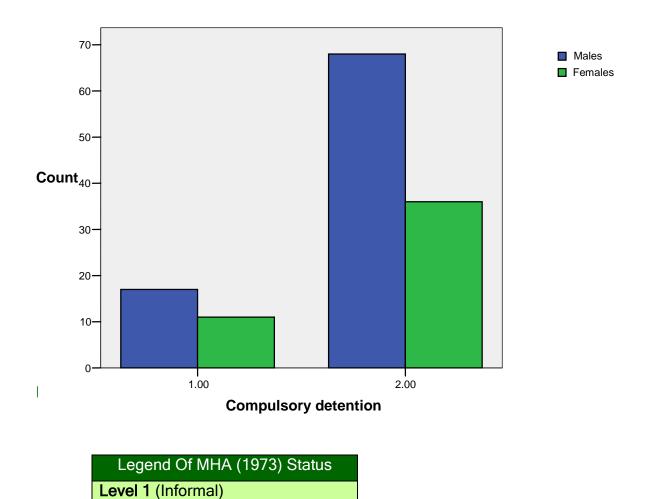


Figure 4.17 shows sex differences in compulsory detention. Males were twice as likely to be detained, compared to females.

20.0 % (17) males were informal

Level 2 (Detained)

23.4% (11) females were informal

80 % (68) males were detained

76.6 % (36) females were detained

4.12 Employment

Table 4.21 Employment History of Service Users

Employment level	Frequency	Percent
Level 1 employed over past year	29	22
Level 2 not employed over past year	103	78

Table 4.21 shows the frequency and percentages of service users who were employed or worked regularly over the past year.

22.0 % (29) were employed over the past year

78.0 % (103) were not employed over the past year

Figure 4.18



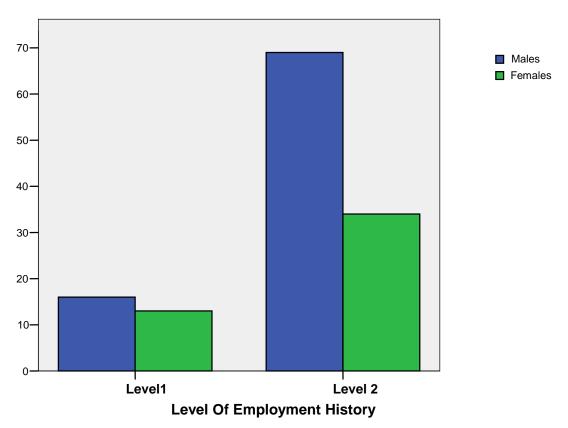


Figure 4.18 Sex Differences in Employment History

Legend	
Level 1 employed over past year	
Level 2 not employed over past year	

Figure 4.18 shows the frequency and sex differences in employment history. Slightly more males than females were employed over the past year. More males than females were also unemployed over the past year.

18.8 % (16) male service users were employed over the past year

27.7 % (13) female service users were employed over the past year

81.2 % (69) male service users were not employed over the past year

72.3%(34) female service users were not employed over the past year.

4.13 Social Interaction

Table 4.22 Distribution Of Social Interaction.

	Frequency	Percent
Level 1 other service users	34	25.8
Level 2 people without mental illness	28	21.2
Level 3 mix of people with and without mental illness	70	53.0

Table 4.22 shows the legend, frequency and percentage of distribution of 'interaction'. Over half of service users interacted with a fair mixture of people with and without a mental illness.

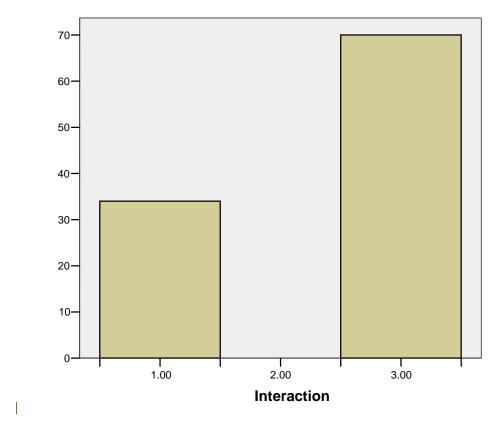
25.8 % (34) interacted mainly with service users

21.2 % (28) interacted mainly with people without a mental illness

53.0 % (70) interacted with a fair mixture of people with and without a mental illness.

Figure 4.19 <u>Histogram Of The Distribution Of Social Interaction</u>

Histogram Of Interaction



Level 1 other service users

Level 2 people without mental illness

Level 3 mix of people with and without mental illness

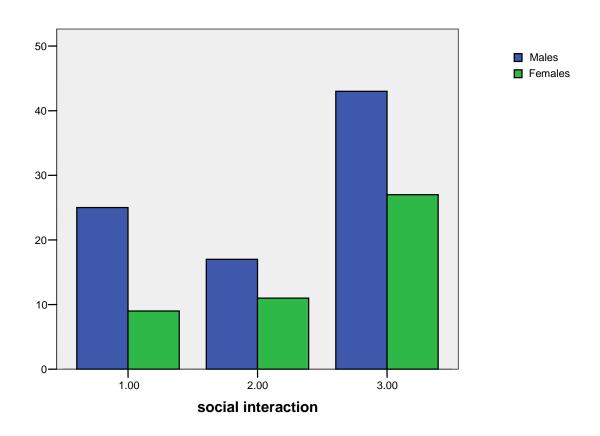
Figure 4.19 shows the frequency and distribution of social interaction. It illustrates the frequency of users at each level of social interaction.

Table 4.23. Sex Differences in Social Interaction

	Males Frequency / Percent	Females Frequency / Percent
Level1 other service users	25 / 29.4	9 / 19.1
Level 2 people without mental illness	14 / 16.5	11 / 23.4
Level 3 mix of people with and without	46 / 54.1	27 / 57.5
mental illness		

Table 4.23 shows the frequency and percentages in social interaction within and between male and female service users.

Figure 4.20 Sex Difference In Social Interaction



Legend				
Level 1 other service users				
Level 2 people without mental illness				
Level 3 mix of people with and without mental illness				

Figure 4.20 illustrates sex differences in social interaction. In level one, twice as many males (Blue) interacted mainly with other service users than females (Green).

4.14 Analysis Of Data

Table 4.24 (Quantitative Test Of Hypothesis) T-Test- Public Stigma Vs Service Users' Perception Of Stigma

Eta squared statistic	Public Mean SD [*]	Service users Mean SD	Difference in means	95% confidence interval Lower Upper	P value
0.28	93.64	82.82	10.82	8.72	p < .01
	6.83	10.19		12.92	

^{*} SD standard deviation

Table 4.24 shows the results of the T-test. Means and difference in stigma scores, the results of the T-test between the public sample and service users' perception of stigma, the magnitude of the difference (eta squared statistic) confidence intervals and significance level.

4.14.1 Interpretation Of Statistics From T-Tests

There was a very high statistically significant difference between stigma scores for the public and service users, p < .01.

The magnitude of the difference in the perception of stigma between the public and service users was large (eta squared = 0.28). This is equivalent to a twenty-eight (28%) percent difference.

Table 4.25 <u>T-Test Ethnic Groups And Stigma Scores</u>

Eta squared statistic	Public Mean SD [*]	Service users Mean	SD	Difference in means	95% confider interval Lower	ice Upper	P value
0.031	90.19	86.56 10.39		3.62	1.12	6.07	p <0 .04

^{*} SD standard deviation

Table 4.25 shows the results of the T-test between stigma scores of the two ethnic groups, including means, difference in means, confidence level, significance level and eta squared statistic.

The statistics showed that there was a statistically significant difference between scores of Whites and non-Whites. The eta squared statistic showed that the magnitude of this difference was 3.1%.

Table 4.26 T-Test Of Stigma Scores And Sex (Service Users)

Eta squared statistic	Males Mean SE	Females Mean SD	Difference in means	95% confidence interval Lower Upper	P value
0.015	87.06	89.64	3.62	-5.0 -	p <
	9.99	10.34		.11	0.04

^{*} SD standard deviation

Table 4.26 shows the results of the t-test between stigma scores and sex.

Results indicated that there was a statistically significant difference between the stigma scores of males and females. However, the magnitude of this difference was small, 1.5%.

4.14.2 Correlations

Service users' variables were subjected to correlation analyses to assess the degrees of inter-relationship. The result of parametric and non-parametric correlation analyses are illustrated in the following table 4.27.

Table 4.27 Non-Parametric Correlations Of Service User Variables

	Employment History	Care Setting	Compulsory Detention	Span Of Contact	Marital Status	Stigma Score (PC)	Social Interaction
Employment History	1.00						
Care Setting	.220 [*]	1.00					
Compulsory Detention	0.172*	0.328**	1.00				
Span of contact	0.222*	0.182 [*]	0.244**	1.00			
Marital status	0.053	-0.175 [*]	-0.151	0.086	1.00		
Stigma score (PC)	0.001	-0.084	-0.009	0.137	-0.002	1.00	
Social interaction	-0.115	-0.098	-0.126	-0.129	0.015	0.119	1.00

^{*}correlation was significant at the 0.05 level (two tailed)

PC- Pearson parametric correlations

Results indicated correlations as follows

Employment history and care setting p < 0.05

Employment history with compulsory detention p < 0.05

Care setting and compulsory detention p < 0.01

^{**}correlation was significant at the 0.01 level (two-tailed)

Span of contact with services with employment history p < 0.05Marital status and care setting p < 0.05

Table 4.28 Regression Analysis Of Service User Variables

Variable	Beta Coefficient	Standard Error	P Value
Age level 2 (30-34 yrs)	-4.088	3.245	0.210
Age level 3 (35-39 yrs)	-1.908	2.987	0.524
Age level 4 (40-44 yrs)	-0.793	3.136	0.801
Age level 5 (45-49 yrs)	-3.591	3.349	0.286
Age level 6 (50-70 yrs)	-0.486	3.274	0.882
Education 2 (Advanced level)	.0823	3.284	0.803
Education 3 (Diploma / degree)	2.794	2.880	0.334
Education 4 (Higher degree)	0.785	3.184	0.837
Education five (Skills based)	0.423	2.883	0.883
Sex	0.123	1.997	0.951
Ethnicity	-0.241	0.329	0.465
Interaction 2 (people without mental	-1.462	2.881	0.613
illness)			
Interaction 3 (mix of people with and	2.244	2.399	0.352
without mental illness)			
Care setting	-1.782	2.233	0.427
Carespan	3.634	2.161	0.095
Detention (MHA status)	0.019	2.534	0.994
Employment	-0.722	2.396	0.764

As seen in table 4.28, none of the correlated service user variables achieved statistical significance. However, observed trends in the data showed higher stigma scores (thus less stigmatising) for higher levels of social interactions. Level three of education (degree level) scored higher on stigma, and stigma score increased with lower spans of care i.e. people with less than five years contact with services scored higher, meaning these were less stigmatising.

4.14.3 Public Demographic Variables And Stigma

Correlation and regression analyses of demographic variables were carried out to measure their relationship with stigma and to extract the variables that were the strongest predictors of stigma.

Table 4.29 Correlations Of Public Demographic Variables

	Age	Gender	Education Level	Stigma Score (Parametric)	Ethnic Group
Age	1.00				
Gender	-1.63	1.0			
Education level	097	.104	1.0		
Stigma score (Parametric)	.016**	.126	.274	1.0	
Ethnic group	258	.008**	026**	177	1.0

^{**}correlation was significant at the 0.01 level (two-tailed)

Table 4.29 shows parametric and non-parametric correlations of demographic variables.

^{*}correlation was significant at the 0.05 level (two-tailed)

Gender and ethnicity, rho value - .008. This correlation was statistically significant at the 1% level. Age and stigma rho value -.016, was statistically significant at 1% level. Education and ethnic group rho value -.026 this correlation was statistically significant at the 5 % level.

4.14.4 Multiple Regression

Table 4.30. <u>Multiple Regression Of Public Demographic Variables</u>

Variable	Beta Coefficient	Standard Error	Significance
Age 2 (30-34 yrs)	-4.582	2.226	0.042
Age 3 (35-39 yrs)	-4.401	1.896	0.022
Age 4 (40-44 yrs)	-2.647	1.195	0.170
Age 5 24-49 yrs)	-3.702	2.173	0.091
Age 6 (50-70+ yrs))	-3.790	2.008	0.061
Education (Advanced level)	0497	2.251	0.826
Education (Diploma/ degree)	-0.509	2.143	0.813
Education (higher degree)	0.106	1.600	0.947
Education (skills based)	2.097	1.879	0.266
Ethnicity	-2.605	1.228	0.036
Sex	0.433	1.356	0.750

Table 4.30 shows the results of regression analysis of public demographic variables.

In the public demographic variables the predictors of stigma which achieved statistical significance were Ethnicity p < .05 and Age groups two and three p < .05

4.14.4.1 Public And Service Users' Demographic Variables And Stigma

Correlations and regression analysis were carried out on the demographic variables of the total sample in order to compare predictors of stigma for both service users and the public. There were statistically significant correlations between sex and stigma (p < .05) ethnicity and stigma (p < .05) and education and stigma (P < .01).

The more sophisticated stepwise method of regression analysis was employed to establish a more robust model of predictors for stigma. The results indicated two models, 1) education on its own (p < .01) and 2) education with ethnicity (p < .01). These two models were statistically significant at the one percent level and accounted for ten percent of the variance in stigma scores.

4.14.5 Summary Of Quantitative Results

There was a very high statistically significant difference between the stigma scores of the public and service users (p < .01). The magnitude of the difference between public and service users' scores was twenty-eight-percent (eta squared statistic 0.28). The very high statistically significant difference suggests that the levels of reported public attitudes are significantly 'higher' than the 'lower' perception of positive attitudes amongst service users.

There was a statistically significant difference in stigmatising attitudes and the perception of stigma between white British and other ethnic groups in the sample. The magnitude of the difference in the means of White British and other ethnic groups was very small (eta squared .018) at 1.8%. There was a statistically significant difference in the stigma scores between males and females in the sample p < .05.

There were non parametric correlations between in-patient stay, employment history, being sectioned under the Mental Health Act (1983), care-span and interaction. All of these variables were statistically significant predictors of stigma.

4.14.5.1 Correlations of Service User Variables

Employment history and care setting (p < .05)

Employment history and compulsory detention (p < .05)

Employment history and span of care (p < .05)

Employment history and care setting (p < .01)

4.14.5.2 Regression Analysis of Service Users' Variables

The regression model tested involved the variables care setting, span of care, compulsory detention, employment history and social interaction. However, this model did not attain statistical significance (p > .05).

In the regression analysis of service user variables, there was no statistical significance. However, observed trends in the data showed higher stigma scores, thus less stigmatising attitudes, for higher levels of social interactions. Subjects on level three of the education variable scored higher on stigma, and the stigma score increased with lower spans of care. Again,

service users with less than five years contact with mental health services scored higher, suggesting more positive attitudes.

4.14.5.3 Demographic Variables Of Public Sample Correlations

There were statistically significant correlations between age and gender, age and ethnicity, education and gender and education and stigma.

Age and gender p < .05

Age and ethnicity p < .01

Education and stigma p < .01

Stigma and education p < .01

Ethnicity and stigma p < .05

4.14.5.4 Regression Analysis Of Public Variables

The variables of age, at level two 30-34yrs and level three at 35-39 yrs and ethnicity, achieved statistical significance and on average, scores were four and a half points (4.5) lower for these groups. The results showed a trend, whereby the average age in the sample (40-44yrs) had the least impact on lower stigma scores, whereas in other age groups stigma scores decreased on average four to four point five (4.0 - 4.5) points.

For the education variable, there was a trend of lower scores of about five points, for education at levels two and three. On average, subjects at level five of the education variables scored two points above the average stigma score.

4.14.5.5 Public And Service Users' Demographics (combined)

Stepwise regression revealed that education on its own, and education in combination with ethnicity, were the best predictors of stigma.

4.15 Interpretative Phenomenological Analysis [IPA] Of Interview Data

The results of the analysis of the interview data were presented so that a trail was evident from data to interpretation. The format of presentation will be data by subject and themes extracted, clustered themes and interpretation of data. The interpretation of the data will be presented in tabular format with supporting references to original themes.

Table 4.31a Interview Data By Subject and Themes Extracted

Subject 1

I think there should be (1) more activities and treatments for the mentally ill to make them calmer, throughout the system otherwise people with mental illness will be more stressed and uplifted. (2) It is better to do more than less for everyone, so they remain calm. (3)You cannot send us all off to day centres and expect us to get better from that. (4) We each need different therapy, even if we are all schizophrenics. (5) I try not to listen to what the public say about people who have schizophrenia. (6)They all think we will kill or do something to upset everybody, so they are afraid to talk to us.

THEMES EXTRACTED

- 1.1 Need more activities and treatment
- 1.2 Do more therapies for everyone
- 1.3 Everyone needs a unique therapeutic approach
- 1.4 Should not treat all the same
- 1.5 Try to ignore public stigma
- 1.6 Public fear that the mentally ill are dangerous

Subject 2

I was ill in 82 and 86 (1) but was over-medicated to get me out of hospital. (2) Had they taken their time with me, I would probably have worked for the past 20 years, (3) so it was false economy. Twenty years ago (4) my friends disowned me, but now mental illness has been on Eastenders etc. (5) They still do not show you the reality of mental illness on TV, (6) only that we are all dangerous. (7) I still do not have friends, and that's why I come here (Day centre). It is best to be honest and accept your illness,(8) keep it secret and (9) prove to people that you have your act together.

- 2.1 Given too much medication
- 2.2 Root cause not addressed
- 2.3 Overdependence on medication is false economy
- 2.4 Disowned by friends
- 2.5 Reality of mental illness not portrayed by the media
- 2.6 Portrayal of mentally ill as dangerous
- 2.7 Do not have friends
- 2.8 Employ secrecy to cope
- 2.9 Try to be like people who are not mentally ill

Table 4.31b Interview Data By Subject and Themes Extracted

Subject 3

The problem with (1) others is that they do not trust me. Even my family are (2) wary of me. I have never been in trouble with the police or even in a fight. (3) I remember life being normal, that was a long time ago and (4) often wonder what life would be like, without schizophrenia,(5) being like everyone else. I just (6) keep it to my self and do not tell anyone. (7) You have to keep it a secret if you are to be (8) accepted by society.

THEMES EXTRACTED

- 3.1 Public do not trust people with mental illness
- 3.2 Family wary of people with mental illness
- 3.3 Remember life being normal
- 3.4 Think of times before mental illness
- 3.5 Desire to be like normal people
- 3.6 Keep mental illness secret
- 3.7 Public rejection because of mental illness

Subject 4

I have been in treatment since I was ten, I am now 60 years old, and I am very happy with the (1) improvement in medication over the years. However, I find the new way of nursing, with (2) virtually no patient contact by nursing staff is unproductive and (3) does not help speedy improvement on the part of the patients.

(4) They give you medication, but not much else. (5) They do not listen to what I have to say about my mental illness. (6) I feel like an item on a production line, get out as soon as possible. (7) Why not take time to find out what causes me to get ill and treat that so I (8) do not have to come back every few months into hospital.

- 4.1 Medication has improved
- 4.2 No contact with nursing staff
- 4.3 Lack of contact with staff inhibits improvement
- 4.4 Only medication therapy given
- 4.5 Unable to engage therapeutically
- 4.6 Lack of involvement in treatment
- 4.7 Not enough time to find root cause of illness
- 4.8 Addressing causes will minimise admissions

Table 4.31c Interview Data By Subject And Theme Extracted

Subject 5

I (1) have negative experiences from mental health units. Wrong diagnosis, (2) <u>bad</u>, negative staff attitudes. (3) <u>Staff indifference to your situation</u>, especially Approved Social Workers. (4) <u>Medication is unsafe with horrible side-effects</u>. We (5) <u>see the revolving-door here</u> (6) no one has benefited from treatment. (7) <u>They do not treat people like humans</u>. The police also drag you into hospital and treat you badly, as a matter of fact, it is (8) <u>all of society that gives you the elbow</u>.

I was told by the doctor to (9) <u>lower my</u> <u>expectations for accomplishments in life</u> and have always disagreed. We have nothing to fear but fear itself. (10) <u>I get angry at the thought that for my mental illness, I am treated differently.</u>

THEMES EXTRACTED

- 5.1 Negative experiences in mental health units
- 5.2 Negative staff attitudes
- 5.3 Staff indifference to your situation
- 5.4 Medication is unsafe
- 5.5 Revolving door evident
- 5.6 No one benefits from treatment
- 5.7 Not treated like a human
- 5.8 Stigma from all of society
- 5.9 Stigmatised information given
- 5.10 Angry because of the discrimination

Subject 6

Due to (1) lack of resources, doctors will put patients on (2) medication rather than explore reasons for the illness. The patient then becomes dependent on the medication which can be difficult to come off. There needs to be a (3) more planned approach to mental health recovery also the (4) options for recovery needs to be (5) explored with patients. Religion plays an important part and patients need to be given hope, more often than not the patient is (6) left to take the medication and get on the best they can. There are too many demands on one person, so they break down. Schools need to be targeted to educate people about mental illness. Stress can cause mental illness which (7) can leave you isolated and labelled a schizophrenic.

- 6.1 Lack of resources for treatment
- 6.2 Emphasis on medication therapy
- 6.3 Need for planned recovery approaches
- 6.4 Need for involvement in treatment
- 6.5 Need for choice in treatment
- 6.6 Reliance on medication
- 6.7 Mental illness leads to labelling and isolation

Table 4.31d Interview Data By Subject And Themes Extracted

Subject 7

Since my experience of schizophrenia, I discovered that the people I thought were my

- (1) <u>friends are not really my friends</u>, because they showed (2) <u>prejudice and stigmatised me</u>.
- (3) They disrespected me and no longer look into my eyes when they speak to me. They look at my head. Some people I know just (4) ignore me. I know what they think of me now. (5) The nurses treat me like an animal, holding me down and injecting me with 'shit', all because they(6) do not want to listen to what I have to say about my madness. Look at how (7) this 'shit' has turned me into a wreck (showing shaking limbs).

THEMES EXTRACTED

- 7.1 Loss of friends
- 7.2 Prejudice and stigma from friends
- 7.3 Not respected by friends
- 7.4 Ignored by friends
- 7.5 Nurses rely on medication instead of talk therapy
- 7.6 Improper treatment from nurses
- 7.7 Medication giving negative side-effects

Subject 8

I applied for a job in management. I worked as manager of a jewellery shop. I was very honest about my illness and (1) was very surprised when I got the job. As long as you (2) can do your job and appear well no one will treat you different. (3) I only told close friends of my illness. I have not worked for a few years and would find it difficult to get a job.

I guess people get (4) scared because they don't know about it. (5) No one explained things to them. The different kinds of mental illness that are around, I guess(6) if you do not understand something you always stay one step behind and (7) use stigma as your defence against patients.

- 8.1 Surprise at reaction to disclosure of mental illness
- 8.2 Need to perform like everyone else for acceptance
- 8.3 Employ secrecy
- 8.4 Public fear due to ignorance about mental illness
- 8.5 Public not given information on mental illness
- 8.6 Public misunderstanding re mental illness
- 8.7 Stigma employed as a defence against people with mental illness

Table 4.31e Interview Data By Subject And Themes Extracted

INTERVIEW DATA Subject 9 I have severe schizophrenia which has rendered me unable to continue teaching after 1976. However, (1) I have since adjusted to this condition and have lived a largely healthy and profitable life. Living at home and caring for my husband's parents and their various degrees of disability as they grew older. My husband and both our (2) families have been very supportive throughout and there has been (3) no sense of diminishing the value of my life after schizophrenia which manifested itself in 1976. (4) Only close family know of my illness.

THEMES EXTRACTED

- 9.1 Adjusted to schizophrenia
- 9.2 Family support helpful
- 9.3 No sense of being devalued
- 9.4 Employ secrecy

Subject 10

For me my mental health state (1) I have kept very private, and I am sick of hearing that condescending statement (lower life expectations). If you had a broken leg you would get it fixed? Mental health is the same. (2) I am prejudiced against ever being able to do jury service because of my past medical status, not that I would want to but (3) the stigma is rife in the system and within families and of course in society, you did ask.

- 10.1 Employ secrecy
- 10.2 Prejudiced by legislation
- 10.3 Stigma is rife in mental health care, within families and society

Table 4.31f Interview Data By Subject And Theme Extracted

A THEMES EXTRACTED

Subject 11

I have bi-polar myself and (1) only tell close friends and family, sometimes I just (2) tell people I suffer from depression. Your ability to care for your child is important, not your mental illness. If one's mental illness affects the ability to care for a child, you can get help from the state, friend or family.

state, friend or family.

Friend developed schizophrenia and she was terrified, but now she handles it brilliantly. (3)

There is too much stigma attached to mental illness because (4) people don't have enough

information and it scares them.

- 11.1 Employ secrecy as coping mechanism
- 11.2 Minimise severity of illness to cope
- 11.3 Too much stigma attached to mental illness
- 11.4 People lack information regarding mental illness

Subject 12

I had a friend, who like me had depression. I had to lose contact with her because she would physically and mentally drain me. (1) I think you have to be a very patient friend to cope with people who are mentally ill. They (2) give you the same tablets every time you go into hospital and get you (3) back out too quickly, only to go back in another time. (4) I would like to have better treatment at home. Why take me into hospital when I (5) can be given the same thing at home.

- 12.1 Much patience needed to cope with the mentally ill
- 12.2 Same medication therapy repeated
- 12.3 Insufficient time addressing illness
- 12.4 Treatments need improving
- 12.5 In-patient treatment is not different to home treatment

Table 4.31g Interview Data By Subject And Theme Extracted

Subject 13

I have a long experience of mental illness and my perception of most people was one of empathy, sympathy and favourable. There is also the (1) typical, rubbish newspaper lurid headline reading and believing bigots! I do remember (2) feeling shame and failure as a parent and to be honest I (3) probably had negative reactions, but I now am (4) visually blissfully unaware of unpleasantness, so maybe I (5) experienced prejudice and did not realise it. One thing I know is that to (6) encourage openness and honesty about mental illness is really important to realise how prevalent it is; to be honest, in this world how anybody escapes basic depression is beyond me! (7) I just ignore what they say.

THEMES EXTRACTED

- 13.1 Negative portrayal of mental illness in newspapers
- 13.2 Felt was a failure and ashamed as a parent
- 13.3 Experienced negative reactions
- 13.4 Current no visible experience
- 13.5 Did not perceive stigma
- 13.6 Openness and honesty needed re mental illness
- 13.7 Ignore what is said about mental illness

Subject 14

I think that the more serious the mental illness is, the more likely it is to be stigmatised. Sadly, although I have suffered from anxiety and depression and continue to on-and-off, I am (1) mindful of the prevalence of stigma and do (2) feel mental illness negatively affected the way I am perceived i.e. not coping or as weak. Therefore, although objectively I think people with mental illness can achieve a lot in life, sometimes their illness will be disabling and (3) stigma by others or by (4) themselves will be a barrier. I think people would be (5) more tolerant / understanding with better education and awareness of mental illness. But do they have the time in modern society?

- 14.1 Mindful of the prevalence of stigma
- 14.2 Negative public attitudes impacts perception of self
- 14.3 Stigma from others can be disenabling
- 14.4 Self-stigma can be a barrier
- 14.5 Education and awareness will increase tolerance

Table 4.31h Interview Data By Subject And Themes Extracted

INTERVIEW DATA	THEMES EXTRACTED
Subject 15	
I keep to myself and do not worry about	15.1 Lost friends because of mental illness
the public and what they think about mental	15.2 Society is in hospital
illness. Since I became mentally ill as a	15.3 Cannot return to time before illness
teenager, (1) <u>I have lost friends, refused jobs,</u>	15.4 Pre-illness was treated as a real person
rejected from getting a flat from the council. I	
had a flat but lost it when I came into hospital	15.5 Society does not care about people with mental illness
two years ago. (2) My society is the hospital	
and I do not feel that I am part of normal	15.6 Societal stigmatisation in labels
society. I get everything here. I (3) cannot go	
back to when I (4) was treated as a real person.	
(5) Society does not give a f***! about people	
with mental illness, (6) calling me psycho and	
<u>nutter</u> .	

Following the extraction of themes from the data, the themes were clustered under a super-ordinate theme as follows

Table 4.32a Super-Ordinate Themes And Subordinate Clustered Themes

Super-ordinate Theme	Clustered themes	
	1.1 Need more activities and treatment	
	1.2 Do more therapies for everyone	
	1.3 Everyone needs a unique therapeutic approach	
Activities and Therapies	1.4 Should not treat all the same	
	4.5 Unable to engage therapeutically	
	4.6 Lack of involvement in treatment	
	6.1 Lack of resources for treatment	
	6.3 Need for planned recovery approaches	
	6.4 Need for involvement in treatment	
	6.5 Need for choice in treatment	
	7.5 Nurses rely on medication instead of talk therapy	
	12.4 Treatments need improving	
	12.5 In-patient treatment is not different to home treatment	
	1.5 Try to ignore public stigma	
	1.6 Public fear that the mentally ill are dangerous	
	3.1 Public do not trust people with mental illness	
	3.7 Public rejection because of mental illness	
	5.8 Stigma from all of society	
	8.5 Public not given information on mental illness	
	8.6 Public misunderstanding re mental illness	
	8.7 Stigma used as a defence	
	10.3 Stigma is rife in mental health care, within families and society	
	11.3 Too much stigma attached to mental illness	
	11.4 People lack information regarding mental illness	
Public Stigma	12.1 Much patience needed to cope with the mentally ill	
 _	13.3 Experienced negative reactions	
	13.6 Openness and honesty needed re mental illness	
	14.1 Mindful of the prevalence of stigma	
	14.2 Negative public attitudes impacts perception of self14.3 Stigma from others can be disenabling	
	14.5 Education and awareness will increase tolerance	
	15.2 Society is in hospital	
	15.5 Society does not care about people with mental illness	
	15.6 Societal stigmatisation in labels	

Table 4.32b Super Ordinate Themes And Subordinate Clustered Themes

<u>Medication</u>	2.1 Given too much medication 2.3 Overdependence on medication is false economy 4.1 Medication has improved 4.4 Only medication therapy given 5.4 Medication is unsafe 6.2 Emphasis on medication therapy 6.6 Reliance on medication 7.5 Nurses rely on medication instead of talk therapy 7.7 Medication giving negative side-effects 12.2 Same medication therapy repeated		
<u>Limited Therapeutic</u> <u>Engagement</u>	4.2 No contact with nursing staff 4.3 Lack of contact with staff inhibits improvement		
Not Addressing Cause	2.2 Root cause not addressed 4.7 Not enough time to find root cause of illness 12.3 Insufficient time addressing illness		
Impact On Social Contacts	2.4 Disowned by friends 2.7 Do not have friends 7.1 Loss of friends 7.2 Prejudice and stigma from friends 7.3 Not respected by friends 7.4 Ignored by friends 15.1 Lost friends because of mental illness		
Negative Media Portrayal	2.5 Reality of mental illness not portrayed by the media 2.6 Portrayal of mentally ill as dangerous 13.1 Negative portrayal of mental illness in newspapers		

Table 4.32c Super-Ordinate Themes And Subordinate Clustered Themes

	2.8 Employ secrecy to cope	
	3.6 Keep mental illness secret	
	8.3 Employ secrecy	
	9.4 Employ secrecy	
5 1 0	10.1 Employ secrecy	
Employ Secrecy	11.1 Employ secrecy as coping mechanism	
	11.2 Minimise severity of illness to cope	
	13.6 Openness and honesty needed re	
	mental illness	
	2.9 Try to be like people who are not mentally	
	3.3 Remember life being normal	
	3.4 Think of times before mental illness	
	3.5 Desire to be like normal people	
Endeavour For Normalcy / Acceptance	5.10 Angry because of the discrimination	
Acceptance	6.7 Mental illness lead to labelling and isolation	
	8.1 Surprise at reaction to disclosure	
	8.2 Need to perform like everyone else for acceptance	
	9.1 Adjusted to schizophrenia	
	9.3 No sense of being devalued	
	15.3 Cannot return to time before illness	
	15.4 Pre-illness was treated as a real person	
	3.2 Family wary of mental illness	
	9.2 Family support helpful	
Familial Stigma	10.3 Stigma is rife in mental health care,	
	within families and society	
Prejudiced Legislation	10.05	
i rejudiced Legislation	10.2 Prejudiced by jury legislation	

Table 4.32d <u>Super- Ordinate Themes And Subordinate Clustered Themes</u>

	13.2 Felt was a failure and ashamed as a parent
Self-Stigmatisation	13.6 Openness and honesty needed re mental illness
	14.1 Mindful of the prevalence of stigma
	14.2 Negative public attitudes impacts perception of self
	14.3 Stigma from others can be disabling
	14.4 Self-stigma can be a barrier
	E 1 Negative comparisoners in magnetal health
	5.1 Negative experiences in mental health units
	5.2 Negative staff attitudes
	5.3 Staff indifference to your situation
Professional Stigmatisation	5.7 Not treated like a human
r rolessional etigmatisation	5.9 Stigmatised information given
	7.5 Nurses rely on medication instead of talk therapy
	7.6 Improper treatment from nurses
	10.3 Stigma is rife in mental health care, within families and society
	4.8 Addressing causes will minimise admissions
Frequent Admissions	5.5 Revolving door evident
	5.6 No one benefits from treatment

The interpretation of the interview data, super-ordinate themes and subordinate clusters is presented in the following table 4.33.

Table 4.33 Results From IPA Of Interview Data, Showing Emergent Themes Interpreted As Three Super-Ordinate Categories With Sub-Ordinate Themes And Supporting References

1 Stigma from professionals	2 Self stigma	3 Public stigma
Limited therapies (1.1, 1.4, 4.5, 4.6, 6.1, 6.3, 6.4, 6.5, 7.5, 12.4, 12.5.)	Social identity issue (1.5, 8.1, 8.2, 9.1, 14.2, 15.3, 15.4)	Low literacy re mental illness (8.6, 11.4, 11.4)
Staff indifference (4.2, 4.3, 5.2, 5.3, 10.3)	Feeling devalued (2.4, 2.7, 9.3, 13.2, 142, 15.1)	Ignorance (driving stigma) (8.5, 11.4, 11.5)
Revolving-door syndrome (4.8, 5.5, 5.6)	Frustration (10.2, 13.6)	Education (needed) (11.4, 11.5)
Limited approach to recovery (1.1, 1.4, 4.5, 4.6, 6.1, 6.3, 6.4, 6.5, 7.5, 12.4, 12.5.)	Self-critical (12.1, 13.6, 15.3)	Stigma prevalent (1.5, 2.5, 2.6, 5.8, 7.2, 10.3, 11.3, 14.1)
Over-dependence on medication (2.1, 2.3, 4.4, 5.4, 6.2, 6.6, 7.5. 7.7, 12.2)	Social comparison (2.9, 3.3, 3.4, 3.5, 14.1, 14.2)	Fear (drives stigma) (1.6, 8.7)
Stereotyping (2.2, 4.7, 5.9, 12.3)	Social withdrawal (6.7, 14.3, 14.4, 15.2, 15.5)	Limited acceptance (2.7, 3.2, 7.3, 12.1)
De-humanisation (5.7, 7.6, 15.4)	Secrecy (coping strategy) (1.5, 2.8, 3.6, 8.3, 9.4, 10.2, 11.1, 11.2)	Social exclusion (2.4, 3.7, 7.1, 7.4, 13.3, 14.3, 15.6)
	Anger (5.10, 15.6)	Distrust (3.1)

Table 4.33 shows three columns indicating the emergent superordinate themes of stigma from professionals, self stigma and stigma from the
general public. Each super-ordinate theme was made up of subordinate
themes which were listed under each heading. Because this is an IPA,
conceptions and interpretations were required to make sense of the subjective
experience. Through IPA, results were interpreted and given meaning.

The first column of table 4.33 shows the theme of stigma from professionals. Service users reported that they were not respected by healthcare professionals. They felt as if there was a generic treatment for all service users in that individuality was not recognised and most of their speech and behaviour were treated as symptoms of mental illness. Users reported not being involved in their own care and a failure to involve relatives and significant others. Concern was also expressed at the complacency of staff in supporting users to maintain contact with significant others and social roles.

There was an expressed feeling that staff did not engage in a therapeutic manner and failed to offer hope and encouragement. There was an over-dependence on medication to control symptoms which meant that users were discharged earlier but soon relapsed and needed re-admission. A cycle of admissions and discharges, known as a revolving-door syndrome, was used by service users to describe their experience.

The middle column of table 4.33 shows the super-ordinate theme of self stigma. Service users reported inadvertently stigmatising themselves by internalising the notions and perceptions of stigma from the general public, healthcare professionals, friends and significant others. As a result, they kept their illness a secret, withdrew from society, became socially isolated, experienced low self-esteem and felt as if they were not part of society. These

caused feelings of anger, frustration and resentment at the thought of being de-valued by society and powerless to do anything to change public sentiment.

The last column of table 4.33 shows the super-ordinate theme of stigma from professionals. Service users reported that the public had a very low mental health literacy, which means that the public did not know about mental illness, its effects or treatment. As a result of public ignorance about mental illness there is only a very limited acceptance of people with mental illness, which constitutes fear of the unknown. Fear was seen as a big driver for stigma and a factor which was evident in public reaction to people with a mental illness. Service users reported that the public needed education about mental illness as a step towards the removal of the stigma from mental illness.

Through the interviews with service users the effects of stigma became evident as they highlighted the impact it had on their lives. It appeared that stigma was perceived by service users in many social interactions with health care professionals and the general public. Service users described stigma as a barrier to care, social inclusion and therapeutic engagement with healthcare professionals.

4.16 Personal Constructs of Stigma

Repertory Grid interviewing techniques were conducted with five subjects from the public sample and five from the service users' sample. A Repertory Grid was used, as in Personal Construct psychology, to elicit personal constructs of stigma, which was essentially their own interpretation on the stigma of mental illness regarding events and regularities of their life, in an attempt to make them understandable.

Each grid took between 60 and 90 minutes to complete and yielded fourteen constructs, which were polar opposites, and 84 other bits of information. This totals 98 bits of information per Repertory Grid. However, each grid is unique to the individual who constructed it.

The Repertory Grids were examined, before being subjected to principal component analysis, in order to observe if there were patterns and similarity between constructs. A wide range of constructs were elicited regarding the similarities and differences between elements in the grid.

4.16.1 Public Constructs of Stigma.

The following constructs were reported by the public sample.

Non-judgemental, Irrational behaviour; no sense of belonging; Successful life; non-desirable state; Can be trusted; limited social contact; Difficult to communicate with; sociable; Unable to control self; self-confident; easy to form and sustain relationship with; focused and determined; Unpredictable actions; educated; disorganised lifestyle; difficult to communicate with; would like to understand; Unable to communicate; easy to communicate with; ability to cope; Unpredictable behaviour; Focused on goals; difficulty in engaging; unable to think clearly; more control over behaviour; can relate to; able to understand

Familiar with; able to understand behaviour; stable mind and behaviour; unable to form an opinion of; hope for the future; is aware of self; in a less than good situation; able to reach out to others; less desirable behaviours; able to manage stress of life; unable to understand behaviour; do not understand; balanced personality; no control over situation; easy to get

along with; behaviour out of control; whole integrated personality; unpredictable behaviour; lower appreciation; disturbed thoughts and behaviour; more positive attitude and ambition; difficult to communicate with; difficult to reach; do not understand; comfortable dealing with.

These constructs also showed similar negative attributes to people with mental illness. Listed constructs were from both left and right side columns of the RepGrid and indicated polar opposites of the constructions of stigma. Constructs were later subjected to factor analysis.

4.16.1 Continued.

Realist; normal behaviour; do not wish to emulate; Being judgemental; Act sensibly; failure in life; established community member; more balanced life; Cannot be trusted; good social contacts; over-involvement with others; less sociable; Able to exercise self-control; low self-esteem; difficult to engage; disorganised; Level headed and reliable; Ignorant; motivated and ambitious; easy to communicate with; Able to establish rapport; difficult to reach; unmotivated; already understood; Haphazard life; able to negotiate life; of sound mind; less challenging behaviour; less control over behaviour; no connection with; less able to understand; less familiar with; unstable mind and behaviour; have an opinion of; uncertainty; lacks self awareness; in a better situation; lacks the ability to reach out to others; undesirable behaviour; less able to manage stress; more able to understand behaviour; understand behaviours; unbalanced personality; more able to control situation; difficult to deal with; able to control behaviour; split personality; normal behaviour; more appreciation; pleasant thoughts and

behaviours; negative attitudes; easy to communicate with; easy to establish rapport; understand; uncomfortable to deal with;

4.17 Service Users' Constructs Of Stigma

The following constructs were reported by the service user sample. These constructs also showed similar negative attributes about mental illness from people with mental illness. The listed constructs are from both left and right side columns of the RepGrid and indicate polar opposites of the constructions of stigma. These were later subjected to factor analysis. The constructs are as follows.

Qualities which can be admired; successful in life; different reality to society; better able to be understood; difficult to communicate with; less dependant; normal behaviour; can be helped; difficult to communicate with; relate better to difficulty; positive characteristics; mentally healthy; motivating; less able to cope;

Limited help; no pressure to communicate; alienated from experiences; less desirable traits; mentally ill; less motivating; more able to cope; less good qualities; less successful in life; more normal part of society; less able to be understood; easier to communicate with; more dependent; unpredictable behaviour;

4.18 Interpretation

The emergent pattern and themes from constructs appeared to match 'self' and 'a person I admire' as being contrary to 'a person with schizophrenia' and 'a person you do not understand'. In other words, subjects did not construct people with mental illness in any positive light, and relied on

stereotypes and stigmatised views to show differences between self and people with mental illness.

4.19 Constructs of 'Self And Person Admired'

The following constructs showed how the public sample constructed 'self and a person admired'. These constructs were all positive and were as follows.

Realist, whole integrated personality, acts sensibly, behaves normally, positive role model, can be trusted, level-headed and reliable, of sound mind, pleasant in thought and behaviour, balanced life and focused on goals, self-confident and sociable, successful in life, understood by others, able to manage stress of life. Able to reach out to others, aware of self, have hope for the future, in a better situation, balanced personality.

4.19.1 Constructs of 'A Person With Schizophrenia And 'A Person I Do Not Understand' By The Public Sample

In contract, the public sample constructed 'a person I do not understand' and 'a person with schizophrenia' using similar negative constructs. These were as follows.

Unable to think clearly, unstable mind and behaviour, not in touch with reality, disturbed thoughts and behaviour, unpredictable behaviour, Difficult to communicate with, difficult to reach, not understood, Less appreciated in society, cannot be trusted, uncomfortable to deal with, Unbalanced personality, disorganised lifestyle, haphazard lifestyle, split personality, unbalanced personality, Lacks self-awareness, limited social contacts, failure in life, alienated in the community.

4.20. <u>Summary Of Personal Constructs</u>

The constructs from the sample group were examined and grouped.

Three main themes, communication, behaviour and attributes emerged and were the basis for the grouping. This is illustrated in figure 4.33.

Table 4.34 Public And Service Users' Constructs of Stigma Summarised Under Three Main Groupings

COMMUNICATION	BEHAVIOUR	ATTRIBUTES	
Difficult to communicate with	Unpredictable behaviour	Less able to cope with life	
Not in touch with reality	Irrational behaviour	Less successful in life	
Difficult to reach	Unable to control self	Negative role model	
Uncomfortable to deal with	Odd behaviours	Cannot be trusted	
Unable to think clearly	Challenging behaviours	Failure in life	
Different reality to society	Dangerous behaviour	Unbalanced and split personality	
Alienated from their experiences		No sense of belonging	
		Disorganised	

Table 4.34 shows the public and service users grouped constructs of stigma under three main headings. The constructs encompassed difficulty in engaging with service users, unpredictability, irrational behaviour of service users and the negative attributes ascribed to service users.

4.21 Principal Component / Factor Analysis Of Repgrid Data.

Constructs elicited from subjects were polar opposites in the RepGrid scale. For example, in the repertory grid technique, a subject was presented with three elements or a triad consisting of the elements of 'self' a 'person who has schizophrenia' and 'a person you admire'. The subject was then asked what made two elements similar and the third different? One response was that the difference between 'self and 'a person you admire' focused on goals and 'a person who has schizophrenia' has a haphazard life. 'Focused on goals' and 'haphazard life' then became polar opposites of the construct. The elements of the grid were then ranked, using a Likert-type scale of one to five, where one was the construct on the left and five the other part of the construct on the right. The result was a grid where each of the twelve elements were ranked according to each of the seven constructs.

The data from the ranked grid was subjected to principal component analysis to assess inter-correlations between constructs. The results indicated that subjects one and two responded in a similar manner, in that their constructs were broadly grouped under two matrices, which did not show much variance. The other eight subjects showed extremely high inter-correlations between all seven constructs. The results are summarised in the following table 4.35.

Table 4.35 Results from Principal Component Analysis of RepGrid data.

Subject	% Variance Explained	Component Matrix 1	Component Matrix 2
1	52.3	Var 1,2,3,4,5,6	Var 7
2	37.8	Var 1,2,4,5,7	Var 2,5,6
3	74.8	Var 1,2,3,4,5,6,7	
4	75.07	Var 1,2,3,4,5,6,7	
5	74.13	Var 1,2,3,4,5,6,7	
6	81.97	Var 1,2,3,4,5,6,7	
7	72.59	Var 1,2,3,4,5,6,7	
8	63.6	Var 1,2,3,4,5,6,7	
9	87.77	Var1,2,3,4,5,6,7	
10	95.44	Var 1,2,3,4,5,6,7	

Table 4.35 shows the results of PCA analysis showing subject, percentage of variance explained and the combinations of variables in the matrix. The very high percentages in variance explained, suggested that personal constructs regarding the elements of stigma were all responded to in like manner, which was uniformly negative regarding elements pertaining to mental illness and difference, and uniformly positive regard self and others deemed to have more desirable attributes.

4.22. Summary Of Qualitative Findings

The Interpretative Phenomenological Analysis of the interview data revealed that service users reported stigma from health care professionals as a source of stigma. Service users perceived stigma from professionals in

interactions with and interventions of approach to care. They also reported that stigma from the general public was rooted in ignorance about mental illness and fear. Both ignorance and fear served as drivers for distrust, limited acceptance and social exclusion of the mentally ill by the public. Service users also reported that they self-stigmatised. This appeared to be a result of frustration and anger of being stigmatised by healthcare professionals and the public. Service users withdrew from society as a result of social identity issues and employed secrecy as a coping mechanism for dealing with stigma.

Emergent patterns and themes from constructs of stigma appeared to converge around three elements, 'self' and 'a person I admire', 'a person with schizophrenia' and 'a person you do not understand'. The main grouping of constructs came under three main headings of communication described in negative terms, behaviour described as unpredictable and dangerous, and negative attributes such as having a split personality, cannot be trusted and a failure in life. These findings supported the notion of stigma as separating 'us' and 'them'. There were favourable attributes for 'self' and 'a person I admire' and negative attributes for 'a person with schizophrenia' and 'a person I do not understand'.

Principal component analysis of personal constructs revealed high, statistically significant correlations between all constructs of service user and the public sample alike. Regarding the stigma of mental illness, correlations amongst constructs suggested uniformity of a negative aspect.

4.23. Towards A Summary Model Of Findings.

Quantitative results suggested that there was a statistically significant difference between attitudes of the public sample and service users'

perception of stigma. The magnitude of this difference was significant at 28%. There was a statistically significant difference between the stigma scores of males and females.

The results from the interviews identified two main sources of stigma; professional stigma and stigma from the general public. Furthermore, there was a limited approach to treatment and negative interactions with service users by health care professional. Negative attitudes, poor public understanding of mental illness and people who were not mentally ill were the most significant factors for service users in perceiving stigma and in self stigmatisation. Stigma from the public and healthcare professionals resulted in self stigma and social exclusion for service users.

All of the findings from the quantitative and qualitative data demonstrated a convergence public, professional and self-stigma. As a result of the convergence of results, a model of stigmatisation of service users was developed to demonstrate the mechanism of stigma as perceived by service users and to serve as a basis for targeting programmes to reduce stigma and for mental health promotion initiatives.

The findings of the triangulated methodology were inter-related and supported a model of stigmatisation with possible consequences of self-stigmatisation and social exclusion for service users. The summary emergent model is illustrated in figure 4.21.

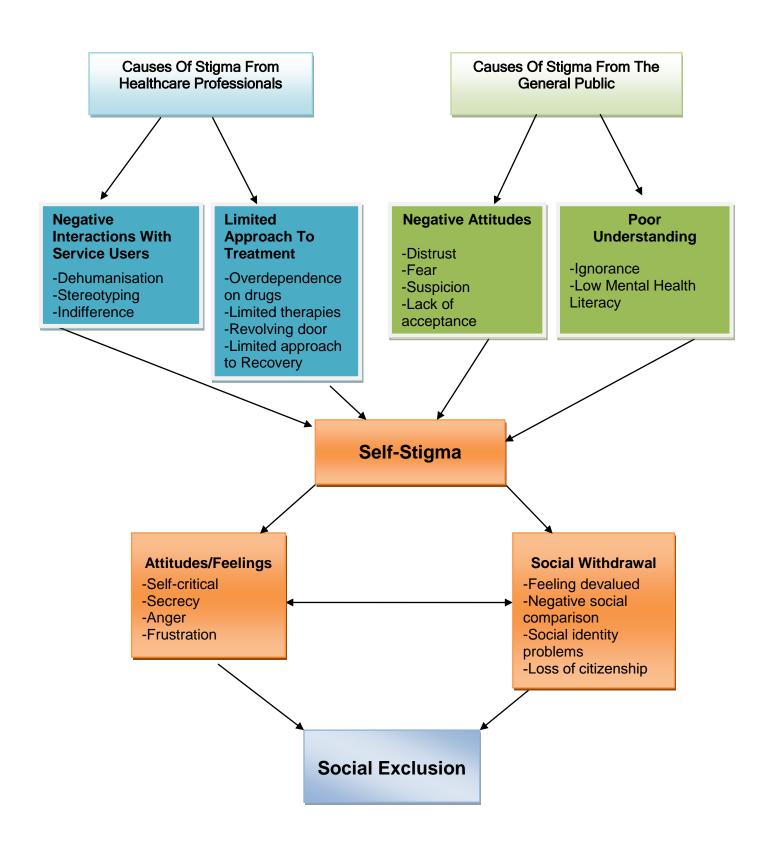


Figure 4.21 <u>Summary Model of Findings</u>.

4.24 Explanation Of The Summary Model Of Findings

The explanation for the model of emergent findings starts at the top of figure 4.21, and shows the two main sources of stigma, the public and healthcare professionals, as identified by service users (Table 4.33). Stigma from health care professionals was manifest in the interactions with service users and was seen in treatment described as dehumanising, stereotyping and indifferent. Another aspect of professional stigma was evident in their limited approach to therapy via overdependence on medication which caused a cycle of admissions and discharges over a short period of time, known as the revolving door syndrome, and limited use of the principles of recovery.

Stigma from the public was seen as being comprised of two elements, poor understanding and negative attitudes. Poor understanding and little knowledge of mental illness can lead to fear of the unknown, suspicion, distrust and lack of acceptance of people with a mental illness (Table 4.33).

Public and professional stigma impacted on service users caused them to feel angry, became frustrated and employed secrecy as a coping mechanism for dealing with the stigma. Service users also developed feelings of low self-worth and low self-esteem subsequent to feeling devalued by society.

In interviews and personal constructions, service users reported that the consequences of stigma from health care professionals and the public led to social isolation and exclusion. This emergent model of findings can also be useful in providing a focus for anti-stigma and health promotion initiatives.

CHAPTER FIVE DISCUSSION OF RESULTS

This chapter entails a critical discussion and interpretation of results. The results are viewed in relation to this study and common and uncommon trends and findings from previously published research evidence. The conceptual model of the stigmatisation of service users (figure 3.1) was developed to reflect service user variables, as tested in this study, and it is important to note that the discussion around factors in the model and findings of this study were not always comparable with previous research in this field, because much of this evidence base relied primarily on public attitudes and did not attempt to compare attitudes between service users and the public. The discussion also focuses on aspects of stigma as found amongst service users, healthcare professionals and the public.

5. 1 <u>Significant Difference Between Public Attitudes And Service Users'</u> Perception Of Stigma.

Results showed that there was a statistically significant difference to a magnitude of 28% between public attitude scores and service users' perception of stigma scores. These results supported the study's hypothesis and could have occurred because there was a genuine difference between the experience or perception of stigma as a result of mental illness, compared to no experience of mental illness. The evidence on stigma (Nunnally, 1961; Brockington et al., 1993; Huxley, 1993; Ingamells, et al., 1996; Wolff, et al., 1996; Angermeyer and Matschinger, 1997; ONS, 2007; ONS, 2008; Priory Group, 2007) suggested that it had a deleterious effect on people with mental

illness and it could be that service users scored lower on the attitude scale because they were better able to appreciate the negative impact of stigma, compared to the public sample.

Furthermore, the difference in scores between the sample groups provide support for evidence which suggested that attitudes from direct experience, as in this case with service users, had more information about the attitude object, stigma, and had greater predictive value than those based on indirect experience, as in the public sample (Fazio and Zanna, 1981).

It is also important to reiterate that the attitude scale was developed from autobiographical and biographical reports of people with mental illness about their experiences of schizophrenia and other mental illnesses. Moreover, the themes of prejudice, discrimination and negative attitudes, which were extracted from the reports, corroborated attitude scales from previous studies (Link, 1987; Link et al., 1989; Wahl, 1997). In this study, the attitude scale showed a high degree of reliability in the Cronbach Alpha score of 0.83 (Table 3.5 -3.6), which meant that the scale was not biased towards service users and identified real differences between the sample groups.

To minimise the element of chance differences between the public and service users' stigma scores, the 5% probability cut off was used. This meant that the probability of achieving these results by chance was less than 5%. Nevertheless, this result achieved statistical significance at the highest, 1% level, which suggested a higher degree of rigour and the probability of achieving such results was less than 1%. In addition, the high statistically significant difference between the scores of service users and the public was further supported by the eta squared statistic, which quantified the statistical

significance and showed that difference in stigma scores had a magnitude of 28% between the sample groups.

While there was a high level of rigour in analyses and methods which led to this finding, there is the possibility of a 'social desirability' bias. Members of the public would have worked out that the questionnaire was attempting to measure attitudes and could have chosen to respond positively to items they believed reflected socially desirable attitudes (Oppenhein, 1996). Similarly, service users could have over-rated their report of stigma on the attitude scale, resulting in lower scores. The presence of a social desirability bias in response to the attitude scale could have polarised scores toward the upper and lower limits of the scale. There is a possibility that the potential social desirability effect combined with an over-rated report of stigma, conspired to impact differences in scores, between the sample groups.

Validity for the difference in scores between the public and service users may be seen in the qualitative data and results. Service users perceived the public to be a source of stigma, which was manifested in public fear, distrust and ignorance regarding people with mental illness, while the public cited negative attributes of people with mental illness as the reason for their negative attributes. However, in the personal constructions of stigma, both service users and the public shared a similar set of social constructions. Despite having similar constructions of stigma, the public and service users' perceptions appeared to be antagonistic.

It can also be argued that positive attitudes from the public were not permeating to, or may not be perceived by, people with mental illness because of their expectations of being rejected by the public (Corrigan, 2005). Here, it can be seen that the combination of an expectation of rejection and

negative attitudes increased the perception of stigma and created artificial barriers to communication between the public and people with mental illness.

There was no evidence of similar, published research in this field, so it was not possible to compare the finding of a statistically significant difference between public attitudes and service users' perception of stigma.

The immediate relevance of this finding reinforces the need for the service user perspective and involvement in mental health promotion initiatives which involves establishing a measure of public attitudes and stigma reduction.

5.2 Education Level

In the public sample the average education level was diploma and degree, and at this level there were twice as many subjects (61) compared to the service users' group of 30. For service users, the average education level was primary to GCSE, with more than twice as many (100) at this level compared to the public sample, which had 46. There were no service users with skills based qualifications.

The difference in education levels between the public and service users was noteworthy and aberrant in light of the influence of education on attitudes toward mental illness. The difference in education levels may have arisen as a result of opportunities and challenges in dealing with a mental illness. Also, skills-based qualifications were usually acquired after secondary school, more towards the later teenage years. The onset of mental illness, especially schizophrenia, is also more likely to occur in the later teenage years (APA, 2000). Here, it can be seen how the time of onset of mental illness may be a

correlating factor which can account for the large numbers of service users in the lower levels of education and their absence of skills-based qualifications.

Furthermore, in the regression analysis, level of education was a significant factor (Table 4.29) which suggested that in isolation, education level was a very strong predictor of stigmatising attitudes. This finding corroborated previous studies (Brockington et al., 1993; Wolff et al., 1996) which also found that education exerted the strongest, independent effect on attitudes towards the mentally ill and a direct correlation between education and tolerance of the mentally ill.

Statistically significant correlations between attitude and level of education were borne out in the public sample in both the parametric and non-parametric testing (Tables 4.28 - 4.29). However, in the service users' sample no statistical significance was found, but here was an observed trend for more positive attitudes amongst subjects at degree level (Table 4.28). One reason why education did not attain statistical significance amongst service users can be related to the five subdivisions of the variable 'education', in combination with the power of regression analysis. It is also possible that the impact of stigma as a variable was so 'strong', that it wiped out any effect of education. In other words, education level made no difference to the level of stigma reported.

Level of education was a strong factor in determining stigmatising attitudes, as demonstrated by the regression and correlation analysis (Table 4.29). The correlation between higher levels of education and more positive attitudes towards mental illness was further supported by the regression analysis of the quantitative data, which reinforced the association between education and attitudes towards mental illness (Brockington et al., 1993).

5.3 Sex And Ethnicity

There was a statistically significant difference (p < 0.04) and a higher perception of stigma in male service users, than in female service users (Table 4.26). Stigmatising attitudes in males and females can be influenced by many factors, unaccounted for in this study, and in isolation and in combination with sex differences. If anything, the difference between males and females in their perception of stigma highlighted the need for further exploration of factors which mediated sex differences in the perception of stigma. In searching for corroborating evidence, there were no published reports on differences in the perception of stigma between male and female service users.

This study explored a range of variables in the model of stigmatisation of service users and it was these variables and their interaction with the variable of sex which needed further study. For example, one possible impact on sex may be its interaction with living arrangements, social contacts, employment, social support and other variables. In addition, there was a difference in the number of males and females in the sample, with males accounting for twice as many subjects as females. Evidently, males and females had similar care spans at level one (Table 4.14), which was up to five years contact with mental health services, but there were twice as many males having longer care spans, of ten or more years (Figure 4.14). Again, there were twice as many males treated in a mental health unit, compared to females (Table 4.16), but there was no appreciable difference between males and females in the numbers for treatment in a forensic unit.

In the quantitative results, male reports indicated a worse experience of stigma than females, which was evident in the T-Test comparison of score (Table 4.26). Possible explanations for a higher perception of stigma amongst

male service users, in comparison to females can be seen in the demographic data of the study (Tables 4.15 - 4.18). For instance, there were twice the number of males who lived in a group home or hostel, twice as many males were single, twice as many males were compulsorily detained under the Mental Health Act (1983), twice as many males interacted mainly with other service users and twice as many males were unemployed. This data suggested that males were more likely to be in high risk situations for stigmatisation and social isolation, than females. The finding of sexual differences in the perception of stigma corroborated evidence which highlighted that being male and single, living alone, such as in a group home and unemployment were significant in the perception of stigma (Bracken and Thomas, 2005; Corrigan, 2005).

There was no published research evidence to support sexual differences in service users' perception of stigma. However, cultural images of 'real men' being tough and emotionally inexpressive may be a significant factor, as men are still stereotyped as the macho breadwinner (Mind, 2009), which may be a factor in men being more self-critical and, hence, a higher perception of stigma. There was some limited evidence regarding stigma, associated with a combination of factors, such as sexual orientation, physical disability and gender, in relation to employment (Corrigan et al., 2005). However, as mentioned earlier, there was no published evidence on sex differences.

Regarding ethnicity, in the White and non-White groups of the total sample, there was a statistically significant difference in attitudes towards mental illness between the two groups (Table 4.25). The result of a difference in perception of stigma between Whites and non-Whites corroborated results

by Wolff et al., (1996) who also found that people of ethnic minorities had more negative attitudes. However, the Wolff et al., (1996) study had a small number of non-Europeans (N=48) and their comparison, which achieved statistical significance, did not indicate the magnitude of difference. For instance, this study's sample had a larger number and representation of non-Whites (143 or 54.2%) whose attitudes towards mental illness were significantly different compared to Whites, but the magnitude of this difference, according to the eta squared coefficient of 0.18 (1.8%), was indeed very small, and in context, appeared negligible.

One factor which could have impacted this study's result of a difference between ethnic groups was the small numbers of subjects in some of the groups, which were insufficient to yield meaningful analyses for the independent ethnic groups. For example, the Chinese, Bangladeshi and Pakistani ethnic groups had two subjects (Table 4.7). While it was expedient to combine all of the non-White groups for the purpose of analysis, the underrepresentation of subjects in each of the non-White categories, biased the result. One immediate implication for future research would be to have equal numbers in each ethnic group, so that inferences can be more robust.

From the results, it was evident that the White ethnic group had a higher number of subjects at all the levels of education. Despite Whites having higher numbers and higher levels of education, the magnitude of the difference compared to non-Whites, albeit statistically significant, was small, at 3.1% (Table 4.25). It has been noted that the experience of mental health services for non-Whites and minority group members was different, and this experience can be another factor in the perception of stigma. For example, young black men were more likely to be compulsorily detained under the Mental Health Act

(1983) and received unnecessarily higher doses of anti-psychotic medication (Healthcare Commission, 2005). If this disparity represented a social injustice for minority groups, then it can be seen how this can be translated to a higher perception of stigma amongst non-Whites, who were at an increased risk of being stigmatised by healthcare services and the public.

The higher perception of stigma in non-White ethnic groups can be examined in the light of another finding which suggested that among Whites, stigmatising attitudes dominated and were based on a lack of knowledge about mental illness (Crisp et al., 2000). However, 95% of the sample in Crisp et al. (2000) was white British and contrasted with findings by this study and Wolff et al. (1996) which indicated more negative attitudes amongst non-Whites.

Evidently, there was no emergent consensus on the perception of stigma amongst service users of ethnic minority groups. Also, there were no current published studies which attempted to identify and measure the socio-cultural mechanisms underlying ethnic differences in attitudes towards the mentally ill and mental illness. Of greater concern, this study's findings suggested that there was a difference in perception of stigma between ethnic groups, and even though this difference was small, it was indeed one which warrants further exploration. Apparently, culture can influence many aspects of mental illness, including how mental illness is expressed, the manifestation of symptoms, coping mechanisms and willingness to seek treatment (Corrigan, 2005). However, there was a dearth of evidence regarding the impact of culture on stigmatisation of mental illness (Littlewood, 2004), and this study's findings highlighted a focus for future research.

Furthermore, membership of an ethnic group is not a simple variable, but is linked to income, education, class and social status (Bradby and

Chandola, 2007) and it may be difficult to isolate the variable of 'ethnicity' from its socio-economic ramifications. This study's results suggested that ethnicity on its own, did not substantially account for a sizeable difference in attitudes toward mental illness. However, ethnicity in combination with level of education and education on its own were the strongest predictors of stigmatising attitudes, which were borne out in the statistical analyses of this study (Table 4.29).

5.4 Care Setting / In-Patient Stay

The correlation between in-patient stay, which involves a care setting where service users were treated for a mental illness, such as an acute mental health unit or a forensic ward, appeared to have a direct correlation with employment history (Table 4.27). Clients treated at a mental health unit were found to be more likely to have worked in the previous year, compared to users who were treated in a forensic unit.

This finding may be related to the fact that forensic care involved compulsory detention under the Mental Health Act (1983), so users who wanted to work were unable to leave the unit. In comparison, the period of treatment in a mental health unit was significantly shorter than treatment in a forensic unit. For example, in forensic treatment, which was sanctioned by crown court orders such as section 41 of the Mental Health Act (1983), discharge from hospital is restricted. In fact, the average amount of time in forensic treatment was seven years compared to five weeks, which was the average stay on an acute in-patient ward (WLMHT, 2006).

Service users who were detained under the Mental Health Act (1983) showed longer spans of care (Table 4.27) which meant that they had contact

with mental health services for a longer period of time. Consequently, longer spans of contact with mental health services also meant prolonged contact with other service users and healthcare professionals. The study's findings also showed that longer periods of detention correlated with a diminishing circle of social contacts (Table 4.27), which, in turn, predicted a higher perception of stigma.

This study's findings regarding prolonged contact with mental health services and a higher perception of stigma corroborated one study which also found an increased perception of stigma with prolonged admissions for treatment (Pattison et al., 1975; Holmes-Eber and Riger, 1990). Evidence suggested that frequent contact with other service users developed and perpetuated mentally deviant behaviour to the point that admissions and discharges increased (Perucci and Targ, 1982). As indicated by the correlations (Table 4.27), frequent contact with mental health services meant that service users with diminished social networks were more likely to have longer and more frequent hospital admissions. This finding suggested that an increased perception of stigma and longer spans of care can affect service users' ability to readjust to the community, find employment and build their social networks. In this finding, there is partial corroboration for Harvey et al. (2007) who found that social support during mental illness determined the outcome of future contacts, impacted not only reintegration into the community, but also the severity and rate of hospitalisation.

5.5 Employment History of Service Users

There were statistically significant parametric inter-correlations between employment history, care setting and compulsory detention (Table 4.27).

There were strong inter-correlations between these variables and it was reasonable to assume that these would be strong predictors of stigma. Subsequently, a regression model of these variables was tested to determine if any of these correlates would be significant predictors of stigma. However, despite the high inter-correlation between these variables, they were not statistically significant predictors of stigma (Table 4.28).

Results showed that as care setting changed from acute in-patient to a forensic setting, the span of care increased (Table 4.27). This appeared to be related to compulsory detention under the Mental Health Act (1983) for treatment, particularly in forensic settings. As seen through the correlations (Table 4.27), a prolonged admission impacted prospects for employment and social interaction. This would suggest that the impact of a prolonged admission should mean a higher perception or experience of stigma. However, from the regression analysis, this research was able to demonstrate that a higher perception of stigma as a consequence of a prolonged admission was not the case, as seen in table 4.28. It could also be seen that the variables in the regression model accounted for only 1.2% of the variance in stigma scores, and left 98.8% unresolved. This finding, which will be further addressed in section 6.4, suggested that there were other factors which mediated the perception of stigma, which in this study, were currently unaccounted for.

In the interview data, service users' reports indicated that healthcare professionals employed a limited approach to the principles of recovery (Table 4.33). The report of a limited approach to recovery was not explored, so it cannot be ascertained what service users were alluding to. However, one of the more salient aspects of the recovery approach is supporting people to

maintain contact with employers and seeking employment, and service users who were employed had a lower perception of stigma (NIMH, 2004). In early evidence, employment was shown to have a therapeutic effect on people with mental illness (Harding and Zahniser, 1994) and some service users were working full time, despite an ongoing experience of hallucinations and delusions (Harding et al., 1987).

The National Service Framework for mental health (DH, 1999) recommended health and social services to have action for employment, education and training as part of care plans, as a means of combating stigma and discrimination and promoting the social inclusion of service users. The findings discussed here suggest that service users who are actively supported to seek employment can have a positive benefit to their self-esteem and confidence, while the direct contact with the public may have an additional role in de-stigmatising mental illness (Table 4.33; Figure 4.21).

5.6 Education and Stigma (Public And Service Users)

Results suggested that higher levels of education exerted the strongest independent effect and correlated significantly with more positive attitudes towards the mentally ill (Table 4.29). Level of education was of high statistical significance in predicting attitudes towards mental illness.

The finding that higher levels of education correlated with more positive attitudes can be accounted for by looking at education in general, and its role. It could be that with a higher level of education, one is able to reason more objectively and have better information on mental illness than someone at a lower level of education. In this study, level of education was easily measured, but knowledge is a complex construct and one which is difficult to

operationalise. One study, which employed a ten-item 'knowledge of mental illness' questionnaire, showed that higher knowledge of mental illness, correlated significantly with a more positive attitude towards the mentally ill and mental illness (London and Garman, 2007).

The published evidence on the impact of education on service users' attitudes and stigma was indeed sparse, but public attitudes were shown to correlate positively with education (Taylor and Dear, 1981; Brockington et al., 1993). Evidence suggested that the public had knowledge about mental illness, which may be based on stigmatised views and stereotypes (Jorm, 2000), so there is a need to educate the public about mental illness (Corrigan and Penn, 1999; Byrne, 2000), which, in evidence, can have an unwarranted effect, such as polarisation of fear of people with mental illness (Wolff et al., 1996). As illustrated in this study (section 4.14.4.1, page 246), education was a factor in public stigmatisation and corroborated evidence which suggested a link between a lower level of education and fear and anxiety about people with mental illness (Corrigan, 2005).

5.7 Stigma From Professionals

In the semi-structured interviews, service users described an experience of stigmatising attitudes from interactions with healthcare professionals and reported that stigmatising attitudes were manifested through staff indifference, a limited use of the Recovery approach, an overdependence on medication therapy and a lack of individualised care (Table 4.34).

Stigma from professionals was seen by service users as a barrier to care because it inhibited their recovery (table 4.33). This finding was also evident in the summary model of findings (Figure 4.21). These results corroborated

similar findings which reported that professional stigma and discrimination, in treatment, was the biggest barrier to recovery in mental health, effective care and treatment (Sartorius, 2002). The results of this study further demonstrated a mechanism by which professional stigmatisation occurred, namely nurses not spending time with service users, being treated with indifference, over-reliance on medication and a limited approach to recovery (Table 4.33). Indeed, it is an axiom of mental health care for a relationship with service users (Barker, 2000), and it would appear that professional stigmatisation caused service users to experience alienation and acted as a barrier to meaningful engagement and care (Table 4.33 & Figure 4.21). Hence the significant finding that professional response to service users is an important factor in stigmatisation and appears to alienate service users.

The finding of professional stigmatisation in this study suggests that there is a vital role for mental healthcare professional staff in supporting service users to develop social links, helping with education and employment opportunities and, generally, challenging stigma and discrimination. This finding also corroborated evidence which recommend that these aspects be prioritised and addressed by healthcare professionals (DH, 1999; NIMHE, 2004; DH, 2006). It can be seen that healthcare professionals were an identified source of stigmatisation (Table 4.33 and Figure 4.21), which suggested the need for good therapeutic relationships and reaching out to service users through the use of humanity, common sense, empathy, respect, trust and compassion (Connor and Wilson, 2006), so that the perception of stigma may be minimised.

Through IPA (Table 4.31b) one service user reported that nurses did not spend time with service users and was aware of the impact this was having on

their care, treatment and recovery. Here it can be seen how one factor in stigmatisation, as identified by service users, may be impacted by resources. Staff shortages could mean being less able to provide for, and meet the needs of, service users (Table 4.33). In evidence, mental health staff have complained about low ratios of staff to service users (Nolan and Smojkis, 2003), which were as little as two registered nurses to twenty service users. It appears that insufficient staffing levels may mean only being able to provide the minimum of care, such as a safe environment and minimisation of untoward incidents.

In this study, it was also possible that because service users were stigmatised by professionals (Table 4.33) and the nature of stigma, that service users may not bring it up as an issue with mental health professionals because of fear of further stigmatisation. Also, it may be the case that healthcare professionals did not enquire from service users if they experienced stigmatisation, the nature of discrimination they might have experienced or how stigma might have affected their self image and perceptions. More importantly, as the findings of this study suggest (Table 4.33 & Figure 4.21), there is an implication that professionals should acknowledge the existence of discrimination of service users and take action to raise it as an issue with service users and to address it.

5.8 Stigma From The General Public

In the semi-structured interviews, service users reported that their perception of stigma from the general public was evident in public fear and lack of knowledge about mental illness (Table 4.34). Service users reported

that there was only limited acceptance of the mentally ill by society and that people with mental illness were generally excluded from social domains and deemed to be dangerous (Table 4.33). This finding of the study corroborated a sizeable body of evidence which suggested that there were negative public attitudes towards the mentally ill (Crisp et al., 2000; Byrne, 2001) a decrease in positive attitude (ONS, 2007), the mentally ill were still regarded by the public as unpredictable, scary and dangerous, and people with mental illness were unable to lead fulfilled lives (ONS, 2008; Priory Group, 2007).

It was proposed that the public feared mental illness and the mentally ill because of unfamiliarity, and fear was a key factor in the stigmatisation of people with mental illness (RCP, 2000). In this study, the notion of fear of mental illness and the mentally ill was evident in both the public and service users' constructions of stigma (Table 4.33 and Table .4.34).

This study's personal constructions of stigma (Table 4.33) corroborated findings which showed that service users were stigmatised because of public fear and attributes of unpredictability and dangerousness (Hayward and Bright, 1997). It was evident that the public and service users' sample held similar ideas and both described people with a mental illness as 'dangerous, unable to control their behaviour and unpredictable, difficult to communicate with and having difficulty in thinking clearly' (figure 4.34).

5.9 Self-Stigma

The attitude scale, semi-structured interviews and Personal construct of stigma showed how the combined effect of professional and public stigma

on service users followed a path towards self-stigmatisation and social exclusion (Figure 4.21).

Service users reported feeling devalued, compared themselves to people without mental illness, were self-critical and expressed anger and frustration at being unable to change their situation (Table 4.33). For service users, evidence of self-stigmatisation came about as a result of perceptions of stigma from the public and healthcare professionals. It was also seen that service users, through comparison of self with people without mental illness, recognised deviance and employed secrecy and social withdrawal, both as an acknowledgement and reinforcement of stigma and self-stigmatisation, and as a coping mechanism (Table 4.33 and Figure 4.21).

Through interactions with staff, service users described feeling dehumanised and treated in a stereotypical manner, with indifference. Service users also reported that the care approach of staff showed an over-reliance on the use of medication, a limited approach to recovery and limited access to talk therapies (Table 4.33). For example, the following two extracts from service user interviews indicate perceptions of stigma from professionals.

'I was over-medicated to get me out of hospital. Had they taken their time with me, I would probably have worked for the past 20 years, so it was false economy.'

'I find the new way of nursing, with virtually no patient contact by nursing staff is unproductive and does not help speedy improvement on the part of the patients. They give you medication, but not much else. They do not listen to what I have to say about my mental illness.'

From the service users' perspective, it can be seen that the 'false economy' in early discharge meant that service users were quickly

discharged, without best interventions, and then re-admitted shortly thereafter. It is apparent that a 'false-economy approach' to care can cause a spiral into a cycle of admissions and discharges (Rosenblatt and Mayer, 1974). Early discharge and subsequent early re-admission was also one source of anger and resentment for service users who felt that best interventions would speed up their recovery (Table 4.33).

Service users reported feeling unaccepted and the public treated them with fear and distrust. From the study data, it became apparent that service users' notion of self-stigma resulted from being stigmatised by health care professionals, who were meant to be supportive in helping them through their difficulties, and from the public (Table 4.33).

The evidence (Table 4.33 and Figure 4.21) suggested that service users became self-critical and angry because they felt powerless to change their situation, which had ramifications for their social identity and led to anger, frustration, social withdrawal and social exclusion.

Self-stigma was perceived and affected service users, namely by lowering their self esteem, through internalisation of stereotypes of stigma, social avoidance, leading ultimately to social exclusion (Figure 4.21). This study's finding of self-stigmatisation corroborated evidence which proposed intra-psychic processes, such as the internalisation of stigma and lowered self-esteem (Gallo, 1994; Guimon et al., 1999; Corrigan and Lundin, 2001; Link and Phelan, 2001; Corrigan and Matthews, 2003), and self-stigmatisation leading to alienation and loss of citizenship (Bracken and Thomas, 2005). In addition, through the emergent model of findings (Figure 4.21), and as explained in section 4.24, the study data demonstrated a

mechanism wherein service users moved from the experience of stigma and self-stigma to social exclusion.

It appeared that self stigma had origins in stereotypes of mental illness, but could have arisen and be reinforced by negative attitudes from health care professionals in the course of treatment. This study's findings on self-stigma and the role of healthcare professionals supported another aspect of professional stigmatisation, which showed that the process of care can disempower service users in a manner similar to institutionalised methods and care practices (Barker and Stevenson, 2000).

Furthermore, self stigma led to demoralisation and lowered self-esteem (Figure 4.21 and Table 4.34) which suggested that service users were unlikely to seek employment or live independently. In turn, this lack of motivation can escalate and further impact on self-esteem and overall ability to pursue life goals. Self stigma appeared to have the potential to feed into and exacerbate a cycle of stigma and social exclusion (Figure 4.21).

5.10 Overall Impact Of Stigma

One of the issues that emerged from the findings with service users and stigma was that their varied perceptions of stigma, which referred to feelings of shame, discrimination and self-stigma, differed widely. For instance, a service user may have experienced overt stigmatisation, internalised notions of stigma and self-stigmatised. This study demonstrated a link between stigma, self-stigma and social exclusion (Figure 4.21). It appeared that perceptions of stigma had the potential to lead to a vicious circle from stigma to social isolation.

Societal notions of stigma impacted service users, with ramifications for their perception and internalisation of prejudice. There were reports of overt discrimination from healthcare professionals and situations where stigma was perceived (Table 4.33), but there were no reports of overt discrimination from the public. Of more importance, it appeared that whether stigma was overt or perceived, for service users the effect and ramifications were the same (Table 4.33, 4.34 and Figure 4.21). Evidence indicated that in the course of socialisation everyone learnt how society reacted and behaved towards people with a mental illness (Link, 1987), and this social learning may be a significant factor in shaping service users' expectations of stigmatisation and rejection.

It would appear that service users' perceptions of stigma can be influenced, not only by an actual experience of rejection, but also by an expectation of rejection (Table 4.34), and service users may use these as a guide to avoid situations where there might be a high risk of stigmatisation. For example, a service user might not apply for a job or seek to make new friends because of the expectation of rejection. However, if service users avoided situations in which there was a high risk of stigmatisation, it should follow that they should have fewer encounters of rejection, and hence, a lower perception of stigma.

In this study, stigma impacted service users in various ways and their experience of stigma was relatively high and appeared to be pervasive (Table 4.33 and 4.34). Also, it was shown how service users internalised their notion of stigma and became critical, angry, and secretive about their illness and frustrated (Figure 4.21). This finding corroborated evidence which showed that service users perceived stigma as leading to self-stigmatisation, and

ultimately, social exclusion (SEU, 2004; Bracken and Thomas, 2005). Similarly, it corroborated evidence which indicated that as a result of stigma, people with mental illness often had negative feelings of incompetence or weakness about their character and developed negative emotional reactions, such as low self-esteem and low self-efficacy (Guimon et al., 1999; Corrigan and Lundin, 2001). Similarly, the findings corroborated evidence which noted that mental health professionals promoted social exclusion, through negative attitudes, defensive practice and paternalistic attitudes (Campbell, 1999; Bertram and Stickley, 2005). For example, the semi-structured interviews suggested that there was an over dependence on drugs in mental illness, a limited range of therapies, a cycle of admissions and discharges or revolving-door type admissions and a limited approach in embracing the principles of recovery (Table 4.33).

Evidence suggested that frequent admissions and discharges, or revolving-door type admissions (Rosenblatt, 1984) could be impacted by professional and public stigma. In this study, service users perceived stigma from health care professionals in the course of treatment, and felt they were discharged prematurely (Table 4.33). Furthermore, in the community, service users perceived stigma from the public, which impacted relapse and readmission (Johannsen, 2003). If re-admitted, the impact of stigma meant a prolonged stay, which had the potential to increase the perception of stigma (Table 4.27). Here it was seen how admissions and discharges forced socialisation with service users and healthcare professionals and exacerbated the impact of stigma, which, in turn, increased admissions and created a vicious cycle of stigma (Perucci and Targ, 1975).

In addition, revolving-door type admissions may be related to stigma, the emphasis on community care and the resultant competitive pressure for fewer in-patient beds (DH, 1999). Consequently, service users can be discharged before recovery and need admission shortly thereafter (Table 4.33).

Admissions remove service users from the environment in which their illness developed and may even have the effect of lengthening their period of recovery (Corrigan, 2005). Indeed, in-patient treatment and care was implicated as a factor in stigmatisation (Harvey et al., (2007). This suggests that hospital-based care can be potentially stigmatising (Table 4.33), and supports the idea that community care can remove aspects of iatrogenic stigmatisation, enhances social contacts and minimises stigmatisation.

This study showed that male service users were more likely to be unemployed and admitted to hospital (Table 4.15 - 4.20 and 4.37). Consequently, it was likely that males experienced more frequent admissions and higher levels of professional and public stigma, and these may be the reasons why they had a higher perception of stigma than females. In support, evidence suggested that previous admissions were the most significant factor in determining readmissions for unemployed males to a mental health unit (Rosenblatt, 1984).

5.11 Public And Service Users' Personal Constructs Of Stigma

The public as well as the service users' sample viewed someone with a mental illness as being less able to cope, having difficulty in communicating and were a less valued member of society (Table 4.34). Regarding service

users, this finding suggested that there could be a strong element of self-stigmatisation, but it was not possible to differentiate between their constructs being influenced by self-stigma or actual experiences in the course of mental illness. It was also evident that the public and service users' constructs of stigma were based on common stereotypes of mental illness (Table 4.34) and this corroborated a similar finding by Harding and Zahniser (1994).

Public constructs (Table 4.34) regarding communication included 'difficult to communicate with', 'not in touch with reality', 'difficult to reach' and 'unable to think clearly'. The behaviour of service users was constructed and described as 'unpredictable and dangerous', 'irrational', 'odd', 'challenging' and 'unable to exercise control'. Attributes included 'less successful in life', 'cannot be trusted', 'disorganised' and 'unbalanced, split personality', which again, are familiar stereotypes of people with mental illness.

In the personal constructs of stigma, all of those from the public sample were predominantly negative. Indeed, the results from the public sample appeared and could be grouped as a pattern which is commonly recognised as the stigmatisation of mental illness. The public constructs suggested that people with mental illness exhibited disturbed, dangerous behaviour which was 'disruptive and challenging' 'had an unbalanced, split personality' and they were deemed 'failures in life' (Table 4.34). Public constructs of stigma were also reflected in findings from the semi-structured interviews with service users (Table 4.33), who reported that the prevalence of the public stigma was related to low mental health literacy and fear, which was a driving factor for limited acceptance and social exclusion of people with mental illness (Figure 4.21).

In the principal component analysis of the personal constructs of stigma, for service users and the public, all of the constructs of stigma by all of the subjects were uniform, as evident in the high correlation coefficient between all of their seven constructs (Table 4.35). In other words, this result was equivalent to being asked the same question in seven different ways and getting the same response each time.

Results from the personal constructs also corroborated an aspect from the seminal work on stigma (Goffman, 1963), which showed how attributes were ascribed to people with mental illness, leading to a stereotypical picture of unpredictability and dangerousness (Table 4.34). Also, notions of 'spoiled identity' seemed to be relevant from the public constructs, and coping mechanisms, such as 'covering' and 'secrecy' were employed (Figure 4.21) by service users (Goffman, 1963).

In the personal constructs, it was demonstrated how people with mental illness were distinguished from more 'desirable' elements, such as 'a person I admire' and negative attributes or labels were used to describe and separate people with mental illness from those without, seen as a 'them and us' separation. The personal constructs also corroborated and showed how people with mental illness could be socially excluded as a result of stigma (Link and Phelan, 2001).

Service users reported that the impact of stigma was negative, impacted their quality of life, caused them to compare their past and current social situation and meant a struggle for recognition and acceptance in society (Table 4.33). The results from semi-structured interviews and personal constructs of stigma corroborated similar evidence of judgement, personal understanding of mental illness and comparison (Knight et al., 2003).

5.12. Model Of Emergent Findings (Section 4.23. & Figure 4.21)

Through interpretation, results of the attitude questionnaire, the interviews with service users and personal constructs of stigma appeared to triangulate the results of this study towards an emergent model of stigmatisation. Service users reported that healthcare professionals and the public were the main sources of stigma. Service users described their interactions with healthcare professionals as 'dehumanising, stereotyping, overdependence on medication, a limited approach to recovery and access to only a limited range of therapies' (Table 4.33). The combined effect of limited therapies, over reliance on medication and a limited approach regarding the principles of recovery, led to discharge at a time when users felt they did not have sufficient support to cope with living in the community. Furthermore, a premature discharge from hospital meant that service users were re-admitted, not long after discharge (Table 4.31). This finding corroborated evidence which suggested that repeated admission and discharge led to a vicious cycle of the same, often referred to as the revolving-door syndrome (Rosenblatt, 1984).

Evidently, short cycles of discharge and re-admission were seen as a significant factor in the perpetuation of stigmatisation of service users (Perrucci and Targ, 1982). For example, one service user described this as false economy because money was constantly spent in patching up lives instead of keeping users in hospital for a longer period (Table 4.31), with discharge at a time of a well-defined level of recovery. As mentioned earlier, this finding suggests that the revolving-door syndrome may also be a factor in causation, effect and perpetuation of professional stigma, which was manifested as indifference towards service users (Table 4.33).

Diminished social networks through repeated admissions for treatment may impact the revolving-door syndrome (Perucci and Targ, 1982). Admission to hospital may be affected by stigma from family and friends and that experience of stigma can serve to limit social networks, which in itself can have a further impact on hospital admissions and symptoms of mental illness.

A vicious circle of stigma may develop and be maintained because service users delayed help-seeking and contact with services, because of the fear of being stigmatised. Consequently, this means that their illness is detected and treated at an acute phase and results in a longer period of treatment and recovery. The existence of negative staff and public attitudes and a delay in help-seeking, suggests that the stigma of mental illness was perpetuated.

The results from the semi-structured interviews, personal constructs and RepGrids suggested that professional and public stigma resulted in self-stigmatisation and social exclusion (Table 4.33 & Figure 4.21). Service users reported that their experiences of self-stigma were manifested in anger and frustration at being treated as second class citizens, and they became self-critical and secreted their mental illness from everyone, except very close family and friends. The experience of lost social identity, lowered economic status and negative social comparison resulted in social withdrawal (Figure 4.21). The implications of social withdrawal meant that service users became socially excluded.

CHAPTER SIX REFLECTION, CONCLUSION AND RECOMMENDATIONS

In this chapter, I reflect on and evaluate aspects of this study, consider ways in which future research could be more rigorous and make recommendations for practice. Part of the process of learning while undertaking this research was to analyse what had been done, in an unbiased way, to justify reasons for using one approach over another and to formulate new understanding and methods to improve on future research and practice.

6.1 Reflection on the research

This study aimed to compare public attitudes toward mental illness with the perception of stigma amongst service users and to incorporate service users' perceptions into the evidence base on stigma. The main comparison was achieved by the use of an attitude scale, so that both the attitudes of the public and service users were quantified and analysed to establish statistical significance and correlations. In the interest of rigour, personal constructs of stigma in a sample of service users and the public, which yielded quantitative and qualitative data were analysed in order to establish if both sample groups had similar constructs, which facilitated valid comparisons between the two groups. In addition, service users were interviewed, and the data was analysed with the use of Interpretative Phenomenological Analysis, in order to identify themes and the meaning of stigma as a lived experience of mental health service users.

Through its quantitative and qualitative methodology, the study demonstrated that there was a sizeable difference between public reported attitudes toward mental illness and service users' perceptions of stigma. Examination of personal constructs

by the public and service users revealed that both groups constructed stigma through the use of stereotypes, such as unpredictability, dangerousness, split personality and descriptions which reinforced 'them and us' categories. The study also provided an important insight into responses and coping mechanisms employed by service users in dealing with stigma, and identified processes which lead to self stigmatisation and social exclusion. Service users' perspectives on stigma highlighted a mechanism of stigmatisation which was shown to be from self-stigmatisation, as well as public and professional attitudes. The involvement of service users in this research study provided a focus which could be valuable in mental health advocacy, to develop initiatives aimed at de-stigmatisation, user-led initiatives and empowerment.

It became apparent that there was a chasm between the public's reported levels of attitudes toward the mentally ill and the perception of public and professional stigma amongst service users. It can be seen that the positive attitudes reported by the public, were not perceived and may not be permeating to service users. It has been an argument of this thesis that service users' perception of stigma may be a better gauge of public attitudes towards mental illness and the mentally ill.

The perception of stigma amongst service users, as a function ethnicity, sex and age, was relatively high and pervasive. Also, the level of education in the public sample was a significant predictor of attitudes toward mental illness and the mentally ill. More importantly, males had a worst experience of stigma than females. It appeared that the combined effect of stigma from professionals and the public resulted in self-stigma and social exclusion for service users.

The length of contact with mental health services impacted on the perception of stigma. For example, longer periods of contact with services, increased the likelihood for compulsory detention and treatment under the Mental Health Act (1983), with consequential poor employment history, limited social contact, limited life chances and

a higher perception of stigma, again, this was especially relevant for male service users.

Of equal importance, stigma acted as a barrier to care, hindered therapeutic engagement between service users and professionals, was an identified factor in self-stigmatisation, which ultimately, led to social exclusion (Figure 4.21). Because there were reports of stigmatisation from healthcare professionals in in-patient settings, the study concluded that care in the community could be advantageous to service users, who would not be removed from the environs in which their illness developed, and this would reduce contact with healthcare professionals, maximise contact with family and significant others, and in effect may reduce introgenic stigmatisation.

The Personal Construct psychology results suggested that both the public and service users' personal constructions of stigma were based on similar prejudices, attitudes and stereotypes of mental illness. Personal constructs described people with mental illness as difficult to communicate with, unpredictable and dangerous, split personality and that they were failures in life. People with mental illness and the public both held stigmatised views of the mentally ill and mental illness.

Reported public attitudes were significantly higher and more positive than the perception of stigma amongst service users. This may be the result of the difference between the lived experiences of mental health service users as opposed to hypothetical reckoning by the public.

It is the conclusion of this study, that stigma has a potential to take mental health service users into a vicious cycle, which can increase and perpetuate the perception of stigma. People who suffer from mental illness may not be willing to engage in treatment because of fears, perceptions, experiences and the ramifications of stigmatisation by the public and health care professionals. If people with mental illness do not engage with services at an early stage of their illness and receive

stigma-free care, then it is more likely that they would have compulsory detention and treatment as their illness becomes acute.

In addition, the results of this study suggested that longer spans of contact with mental health services and service users increased the perception of stigma and corroborated evidence which noted that stigma can impact the likelihood of repeated admissions and discharges, as well as reducing life chances for employment and socialisation (Pattison et al., 1975). If people with mental illness were having prolonged and repeated contact with services, this may give the impression that mental health treatment is not effective, which may inadvertently increase the associated stigma.

In public health policy (DH, 1999; DH, 2000; WHO, 2005), there was an emphasis on de-stigmatisation and mental health promotion. However, despite the increase in policies on de-stigmatisation and mental health promotion, and as evident in this study, public health policy had no apparent impact on public attitudes or the perception of stigma amongst service users.

6.2. The Contribution Of This Research Study

Stigma is a well-researched concept, but despite the large body of evidence, there is relatively little attention given to the process of the eradication of stigma towards people with mental illness. It is in this present area of research that this study offers a modest contribution. While there is much less research on how stigma can be eradicated, it is generally accepted that a key aspect of stigma is the perception of difference (Goffman, 1968), it was shown that people with mental illness perceived differences in the public and professionals, and the public perceived differences in the mentally ill (Table 4.33)

Historically there has been a top-down approach to anti-stigma initiatives such as the 'Changing Minds' (RCP, 2000) campaign. Similarly, studies on stigma adopted a top-down approach, with researchers tending to focus on the public and public attitudes, through the use of case vignettes, surveys and interviews. Even with the recognition and recommendations for user involvement in research, very few published studies attempted to incorporate the lived experience of service users into the discourse. However, when service users were involved in research, the methodologies usually took the form of focus groups or interviews, for example Knight et al. (2003).

This research study challenged the status quo of research on the stigma associated with mental illness and contributed in the following ways;

- a) It stood out in its endeavour to compare public attitudes and service users' perceptions of stigma
- b) This research adopted a bottom-up approach, by involving service users as subjects and objects and by incorporating their lived experience from conception to the development of research tools.
- c) This study's triangulated, mixed, methodology sets it apart from published research in the field, which usually employed a public sample and a single methodology. Also, there were no published studies which combined a quantitative survey, semi-structured interviews and personal Construct Psychology Repgrids.
- d) In addition to gauging the gap between service users and the public,
 this study highlighted a focus for health promotion initiatives.
- e) The study's data was quantitative, from the survey, qualitative from the interviews and both quantitative and qualitative from the RepGrids. This

rich amount of data meant that more rigorous analyses were carried out and convergence of findings was more rigorous in supporting inferences.

- f) A conceptual model of stigmatisation (Figure 3.1), based on research evidence and clinical experience was developed and tested.
- g) A questionnaire, with psychometric properties of validity and reliability was developed, and piloted, to capture data from both sample groups.
- h) The summary model of emergent findings (Figure 4.21) of the three methods revealed what service users perceived as sources of stigma, how they responded and mechanism of stigmatisation.
- i) In the use of RepGrids to compare how the two sample groups constructed the phenomenon of stigma.
- j) This research also contributed to evidence which suggested that service users' perception of stigma could be a better gauge of public attitudes, because it targeted people who were most likely to be affected by stigma and incorporated their lived experiences.
- k) This research stood out, because, to date, there was no evidence of similar published research on comparison of public attitudes and service users' perceptions of stigma.

6.3 Limitations Of This Research

Despite the attention to rigour, as with all research, there are limitations to this study. For example, the conceptual model of stigmatisation (Figure 3.1) did not encompass all factors in stigmatisation, and accounted for only 10% of the variance in stigma (Section 14.4). Also, there were limitations regarding the quantitative methodology. For instance, the attitude scale

puts attitude on a linear continuum, but as was seen in the regression analyses, attitudes are more complex.

In addition, there was the potential for researcher bias. For example, in the IPA (Table 4.33), interpretation of the data and results were from the researcher only. If there were additional resources of time and money, there could be another researcher or researchers involved, so that there is researcher triangulation. The quantitative data would not need similar treatment as it was analysed with the use of inferential statistics, which are based on mathematical models.

Regarding sample size, the Personal Construct psychology [PCP] (Table 4.34) the RepGrid data was derived from ten subjects. PCP is rooted in phenomenology and yields both qualitative and quantitative data. While small numbers of subjects is acceptable, there are advantages to using larger size samples, such as having more data for factor analyses, and larger convergence on similar constructs.

On reflection, comparing public attitudes and service users' lived experience of stigma is a relatively new area of research, and while this study employed a conceptual model (Figure 3.1), it can be seen that this field of study warrants more variables and definitive parameters.

6.4 Future Research

While this research has enhanced understanding of practical and theoretical research processes and methods, it has also highlighted limitations and areas for future research. For example, in future research, the public and service user sample could be chosen from a wider sampling frame, and be facilitated by an on-line survey. This can mean access to a wider range of

service users, from primary care, the community and in-patient-services, with a varying range of functioning, demographics and abilities. The evidence from this study suggested that it may be more beneficial to measure stigma amongst service users, a population where stigma was most likely to be a lived experience, and there is a potential for the development of criterion validity. It would also be beneficial for future research to be longitudinal, as this may facilitate a better measure, over a time period. Such a study could also facilitate comparisons between cultural groups, different populations of service users, such as in-patient and community, and with the public.

This research also highlighted the need for a study which is better able to account for the unexplained variance in stigma scores and can examine behavioural correlates of stigma. It can also be seen that future research needs to take into account more of the multivariate aspects of professionals, service users as well as environmental factors. For instance, regarding the 'contact hypothesis', definite parameters for what is meant by 'contact' between the public, service users and health professionals, need to be clearly defined.

From this study, it was seen how an empirical, quantitative approach benefited from being complemented by phenomenological approaches, such as, semi-structured interviews and personal constructs, and how these helped to unravel mechanisms in stigmatisation, functions of stigma and how such functions impacted and perpetuated stigma. In the sample, service users were not passive recipients of stigma, so it was necessary to make research findings relevant to empowerment and advocacy work and include service users' agenda in the study design.

The findings of this study are mainly applicable to its sample population, but replication could mean that findings can then be extrapolated to general populations. In addition, specific, unexpected findings, such as a higher perception of stigma in men, need to be explored in future research, so as to unravel its mechanism and address relevant issues.

In addition to the implications for future research, this study has possible implications for clinical practice in therapeutic engagement and the adoption of a user-led recovery-oriented service, which is empowering to service users and puts them at the top of the care agenda.

6.5 Reflective Account Of Learning Through This Study

It was essential for me to reflect, not only on learning, but also on my influence in the research process. My initial reflection focused on the beginning stages, where I submitted the proposal, applied for ethical approval and designed and collected all the data from subjects. Self awareness is crucial in the research process, especially where the researcher acts as the main research tool (Frankel and Devers, 2000), which was precisely the case in this study, in the semi-structured interviews and PCP Repgrid interviews.

I started with having significant experience of demanding clinical and managerial roles within mental health in-patient and community services, limited research experience on stigma, but with insight of working with clients who were impacted by the effect of stigma. This standpoint facilitated the identification of gaps in the knowledge base on stigma and the realisation that despite the presence of policies and guidelines, service user involvement appeared tokenistic. I felt able to make a difference regarding stigma, by combining my role in clinical leadership with research evidence.

I was aware of subjectivity associated with having previous knowledge and preconceived ideas about what the findings would be. To some extent, research can be used to confirm what we already believe, so I was particularly aware of the need for rigour. To this end, I was methodological in the development of the attitude scale and other research tools, which were submitted for peer review to highlight any biases that could compromise the objectivity of the research. In addition, I was cautious to avoid overvaluing my previous experience and insight into the service users' perspectives. My commitment to incorporate the experience of the service user increased my awareness for objectivity, and discussions with my supervisor tested biases.

The Literature review was the first undertaking in this study and it provided the evidence and rationale for adopting a model of stigmatisation and a mixed methodology. In addition, because stigma is such a broad construct, it was very easy to become distracted from the main focus, while attempting to understand the mechanisms of stigmatisation and how this was linked to research evidence on stigma and service users. There seemed to be so much information, even though not all was particularly relevant to this study's aims and objectives. The research questions proved helpful in keeping a focus on aims of the review and the development of a model of stigmatisation.

Of particular mention, the application for ethical approval was initially deemed a very tedious and frustrating process. This required the completion of a 75 page document, which did not allow progression if there were unanswered questions. Also, all documentation and research tools were to be submitted with the application. I learned that the ethical application was designed to protect subjects and help the researcher to think through the process of research in a thorough manner. It was only at the end of this

process that I realised how much clearer my thoughts were regarding research tools and minimising harm to potential subjects. For example, the process caused me to think about psychological support for potential subjects who may become upset at recalling experiences of stigmatisation.

At the collection of data phase, I felt that it would not be long before completion of the study, but it became quickly apparent that this was only the beginning. For the service user sample, I visited clinical areas throughout the trust and soon learnt that it would take months to reach the target sample of 132, and even more time to collect the interview and RepGrid data. As it turned out, it took eight months to complete the data collection, and I realised that this had to be at the pace of service users. I also became aware of the need to be consistent in following the research protocols, so that I was professional in manner and subjects felt comfortable to participate. What also became obvious was the repetitive aspect of giving information about the research and seeking signed consent from potential subjects, but my patience and discipline developed from the early stages.

Some of the reports of stigma from service users particularly challenged my own professional assumptions. While I had more of a theoretical understanding of stigma, reports of lived experiences were striking. I became aware that professionals stigmatise service users through the approach to care. The interviews with service users were particularly enlightening, and those who agreed to be interviewed, were willing to report their experiences or perception of stigma, and despite initial concerns about participating, they reported being able to identify with the aims of the research. I was surprised that none of the service users wanted their interviews to be tape-recorded, and wondered if this approach was an aspect of stigmatisation,

or evidence of the 'power' of the service user. I opted for contemporaneous notes during the interview (Tables 4.31a - 4.31h).

At the conceptual stage of this research, during and after the collection of data and throughout the study, results and findings had been systematically disseminated amongst a wide body of service users, peers and health care professionals (see appendix v), in order to fulfil a moral duty, give and receive feedback and generate discussion with service users and the public, who invested their time and energy in this study. In addition, the feedback from service users and professionals was helpful, as they challenged some of my preconceptions and assumptions.

The research proposal was presented at students' and service users' fora and at supervision sessions. The research findings were progressively disseminated to service users at service users' fora, to multi-disciplinary professional meetings within the mental healthcare trust, at the WLMHT annual research conference, at the postgraduate students' research day at Brunel University and at national and international conferences.

The objective of dissemination of research findings was to present clear, objective information to audiences in order to demonstrate how the conclusions were supported by the data and how the study design and sample supported the findings. It was also helpful to receive constructive, objective feedback and questions from audiences, which helped in the development and addition of a rigorous methodological approach. Also, a significant amount of learning was realised in the preparation and designing of poster presentations and material for oral presentations. As a matter of fact, it was at the dissemination of findings that the research became 'alive' and had a more pertinent meaning.

The discussions from dissemination were helpful in bringing a realisation to the idea that education alone may not be sufficient to bring about a change in clinical practice. However, dissemination has proved to be a useful method for presenting and facilitating access to the research, to service users, healthcare professionals and the public.

In attempting to reconcile the research evidence on stigma with current social affairs in the UK, I appreciated that there was an ongoing need for academic responses to contemporary media articles, which had negative portrayals of people with mental illness. For instance, one newspaper reported on the iconic use of Sir Winston Churchill for an anti-stigma campaign by Rethink, a mental health advocacy service. The responses to media articles were thought to be necessary because of the negative portrayal of people with mental illness, misinformation and the need for giving voice to the service users' aspect, so that a balanced view was presented. I also realised and appreciated how emotive mental illness and the stigma of mental illness were for the public and service users alike.

I began this study with some knowledge and prior experience of quantitative research methodology, and felt comfortable with the thought of analysing the survey data. However, as I developed the study, I realised that I would have to learn about qualitative enquiry and analysis of such data. A significant amount of learning was realised as I looked at phenomenology and related concepts and the use of Interpretative Phenomenological Analysis in qualitative data.

Moreso, the experience of combining methods and triangulating data and results has been valuable to my understanding of research and my

personal and professional development. Of even greater concern, was the realisation that phenomenology is as powerful a paradigm as positivism, and this study, with its mixed methodology was able to produce more valid and reliable data, with similar results. Indeed, both my theoretical and practical skills in research have been greatly enhanced. On a more personal note, the process of this study has helped me to appreciate that in research, thinking is equal to, or perhaps more important than doing.

6.6 Conclusions

- There was a chasm between public reported levels of positive attitudes and the perception of stigma amongst service users.
- This gap between the public and service users may be evidence of lived experiences versus hypothetical reckoning, and consequently, service users' perception was a better gauge of stigma.
- Amongst service users, ethnicity and sex significantly predicted the perception of stigma.
- For service users, the combined effect of stigma from professionals and the public led to self-stigma and social exclusion.
- Education lowered the perception of stigma.
- ➤ The higher perception of stigma amongst male service users meant poorer social outcomes and longer periods of in -patient treatment.

- Stigma acted as a barrier to care, hindered therapeutic engagement, and was a factor in self-stigmatisation and social exclusion.
- The public and service users held stigmatised views of the mentally ill and mental illness.
- Stigma had the potential to develop a vicious cycle, which increased and perpetuated the perception of stigma, increased the likelihood for compulsory detention and prolonged recovery.
- Stigma had the potential to impact help-seeking behaviour of people with mental illness.
- Amongst service users, contact with mental health services increased the perception of stigma.

6.7 Recommendations

The following are recommended

- Further strategies need to be developed for addressing the social inclusion of people with mental illness. There are many strategies in place, and need to be evaluated for impact on knowledge of mental illness and attitude change.
- Service users' perspective and involvement in mental health promotion initiatives, especially those which involve establishing a measure of public attitudes and stigma reduction.
- Research into why there is a higher perception of stigma amongst male service users, non-white ethnic groups and the cultural impact of stigma

- ➤ Health care professionals should focus on early detection and interventions to minimise the impact of mental illness. This can be addressed through assertive outreach services and primary care.
- Mental healthcare professionals should examine their own attitudes and be aware of stigmatising practices and how these impact service users. They need to challenge stigma, encourage user involvement, empowerment and value equity and social justice.
- ➤ Healthcare professionals need to promote social inclusion, by helping people to access the roles, relationships and activities that are important to them, so that they maintain social contact.
- Healthcare professionals should include action for employment, education and training in care plans, as a means of minimising stigma and discrimination and promoting the social inclusion of service users.
- ➤ Involve people with mental illness in, planning, evaluation and monitoring of mental health services, so that they are actively involved and not just passive recipients of care.
- Further development of care in the community initiatives can be advantageous to service users, who would not be remote from the environs in which their illness developed. This will also mean reduced contact with healthcare professionals in an institutional setting, which can maximise the potential for contact with family and significant others, and thereby reduce iatrogenic stigmatisation.

Service users can learn from and be strengthened by the experience of mental illness and move to a life that meets current and future needs. With small changes in practice, health care professionals can empower service users to manage in a manner whereby they can lead a fulfilling, meaningful life, have a positive sense of belonging to a community and be able to make positive contributions (NIHME/ CSIP, 2006).

This study also suggests that health care professionals need to be aware of the need for a team approach to therapeutic engagement with service users and the need to tactfully challenging stigmatising attitudes, which can have subtle overtones that convey negative notions to or about a service user. This research recommends that mental health professionals reflect on, and in clinical practice, in order to confront their own perceptions and attitudes about mental illness and their approach to service users, so that they are not unwittingly exacerbating the experience or effect of stigma. And finally, it is only when equity and social justice for service users achieves prominence and value, that social inclusion can be enhanced and the impact of stigma minimised (London and Scriven, 2008).

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Appendices

Appendix i



NHS Trust

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Research Project An exploration of reported public attitudes to mental illness and

perceived stigma as experienced by mental health service

users

Investigator Mr Carlyle London

West London Mental Health Trust

Uxbridge Road

Southall

UB1 3EU Tel: 02083548464

Sponsor: none

The purpose of this study is to assess stigma and discrimination among individuals diagnosed with and receiving treatment for mental illness. This research will identify areas where service users experience stigma and develop a strategy for mental health promotion.

I am looking for eligible individuals who may be interested in volunteering to participate in this study. Participation involves the completion of a questionnaire, taking approximately 30 minutes; it has no impact on the treatment and/or care that you receive.

If you are interested in participating in the study, your signature on this form provides permission for me to come and speak with you about the study. You will also have the opportunity to ask questions about it. You may then choose to participate, or you may choose not to participate.

If you are not interested in participating in the study please do not sign this form.

I am interested in being approached about this study

Name and signature	
Date:	
Clinician's name and signature	
Date	



Stage 2 consent form

Research Project An exploration of public attitudes to mental illness and

perceived stigma as experienced by mental health

service users

Investigator: Mr Carlyle London

West London Mental health trust

Uxbridge Road

Southall UB1 3EU

Declaration of interest: none

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more details about something mentioned here, or information not included, you are free to ask. Please take the time to read this carefully and to understand any accompanying information.

- The purpose of this study is to assess stigma and discrimination among individuals diagnosed with and receiving treatment for a mental illness. The reason for this research is to identify and develop anti-stigma interventions from the viewpoint of persons with a mental illness.
- Your participation in this study would involve completing a questionnaire, which will be given and explained to you by myself. The questionnaire will take about 30 minutes to complete. You do not have to answer any questions that you are not comfortable with. You can postpone or discontinue your participation at any time.
- While you may not gain immediately from your participation, it is hoped that in the future, this study will help to inform policies and programmes that will benefit individuals with a mental illness.
- Your participation in the study is entirely voluntary. Your participation or non-participation in this study will in no way affect the treatment and/or the quality of health care you receive. No one will be informed as to whether you decided to participate, or not, nor would the extent of your participation be made known.
- All the information you provide will be kept confidential. Your responses will not be shown to anyone involved in your care. Your name will not appear on the questionnaire. Your name will appear on the consent form. The consent forms will be kept separate from your questionnaire in a secure file. Your completed questionnaire and consent forms will be

destroyed five years after the study is completed. Prior to that, these will be stored in a locked cabinet.

- There is no cost for participating in the study.
- In the unlikely event that you suffer injury as a result of participating in this research, no compensation will be provided to you by Brunel University, West London mental Health Trust or the Researcher. You still have all your legal rights. Nothing said here about treatment or compensation in any way alters your right to recover damages.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have, further questions concerning matters related to this research, please contact:

Mr Carlyle London 02083548464

Participant's name	Signature
Clinician's name Date	Signature
Investigator's Signa Date	ature

A copy of this consent form has been given to you and the original will be kept in your notes.

Appendix ii

Mental health service users' experience of stigma' questionnaire

I am interested in learning how people with an identified mental illness are treated by others in the community. In addition to asking members of the public what they think about people with mental health illness, as some researchers have done, I would also_like to hear directly from mental health service users about their personal experiences. I am asking that you fill out the following questionnaire concerning your experience of stigma.

You do not have to put your name on the questionnaire.

It is possible that thinking about some of your experiences may be distressing, but there are no other foreseeable risks to you in this study.

If you begin to experience any sign of distress do not continue to fill out the questionnaire.

Your participation is voluntary. The information provided will be treated as confidential and there is no possibility of linking you to your responses.

This study is being conducted by Carlyle London, a Ph.D student of Brunel University, Borough Road, Isleworth TW7 5DU and is supervised by Dr Sebastian Garman of Brunel University.

If you need more information about this study please contact Carlyle London on 0208 354 8464 or in writing to Carlyle London, K Block, West London Mental Health NHS Trust, Uxbridge Road Southall, UB1 3EU

Many thanks for your participation

All responses to this questionnaire will be treated as wholly confidential and will be unattributable to individual respondents

Thank you for your support

Sex

Male	
Female	

Age

15-19 years	45-49 years
20-24 years	50-54 years
25-29 years	55-59 years
30-34 years	60-64 years
35-39 years	65-69 years
40-44 years	70 + years

To which ethnic group do you feel you most belong, please tick one box only

White English/ Scottish/ Welsh	Indian	
White Irish	Pakistani	
White Other(Please describe)	Bangladeshi	
Black African	Chinese	
Black Caribbean	Any other Ethnic group (please describe)	

How long have you received care for your mental illness?

Less than one year	
One to five years	
Six to ten years	
More than ten years	

I had an in-patient stay in (tick as many that apply)

Mental health unit	
Mental health ward in a general	
hospital	
General hospital	
Medium-secure mental health unit	
Forensic unit	
Private sector mental health unit	
Other (please specify)	

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No	
Yes	

I am

Single (never married)	
With a partner (but not married)	
Married	
Separated	
Divorced	
Widowed	

I live

Alone	
With spouse or partner	
With parents or siblings	
In a group home	
Other (please specify)	

Level of formal education achieved

Primary school	
GCSE / O level	
A level	
Diploma	
Degree	
Higher degree	
Skill-based qualification/ s (please state)	

I am employed or worked regularly over the past year

Yes	
No	

I interact mainly with

The following statements express various opinions about mental illness. Tick one column that most fits your opinion. It is your first reaction which is important. Please respond to all statements.

	Strongly disagree	disagree	agree	Strongly agree
I believe most people would feel afraid to talk to someone who has a mental illness				
I think most people would feel uncomfortable working with someone				
Who has a mental illness I believe most people would stay				
friends with someone who has a mental illness, once they found out about the mental illness				
I think most people would feel uncomfortable living with someone				
who has a mental illness I think most people would not date someone who has a mental illness				
I believe most people would not marry someone who has a mental illness				
I think most people believe that receiving care in a mental health unit is a sign of personal failure				
I think most people believe that people with mental illness could be intelligent				
I believe most people would ignore the opinions of someone with a mental illness				
I believe most employers would pass over the application of someone who has a mental illness in favour of someone else				
I believe most people think that a person who has a mental illness is likely to harm others				
I believe that most people would not hire someone who has a mental illness to take care of a family member (e.g. child, elderly person)				
I think most people would feel ashamed if others knew someone in their family had a mental illness				
I believe most people would be against having a group home for the mentally ill in their street				
I believe that much more money should be spent on mental health services				
I believe people with mental illness can perform in jobs of the highest level				

	Strongly disagree	disagree	agree	Strongly agree
I have seen or read things in the mass				
media (TV, press) about people with				
mental illness, which I find hurtful or				
offensive				
I have heard people say unkind things				
about the mentally ill				
I have been told by a health care				
professional to hide my mental illness to				
avoid rejection				
My parents, who know I have a mental				
illness, have been supportive				
Friends, who know I have a mental illness,				
have been supportive				
I have been rejected by an education				
provider because I have a mental illness				
Once others knew I had a mental illness, I				
was treated as less able to do a job				
Others have avoided or did not speak to				
me because of my mental illness				
I have avoided indicating on written				
applications that I have a mental illness				
for fear that the information will be used				
against me				
I have been turned down for a job for				
which I was qualified, when I disclosed my mental illness				
I have been treated fairly when seeking				
mental health care via A&E services				
My mental illness was used against me in				
court disputes (e.g. divorce)				
I have had support from my religious				
community when I told them I have a				
mental illness				
I keep my diagnosis a secret to avoid				
rejection				
When I am with others I try to hide any				
visible signs of mental illness				
I try to explain my mental illness to others				
to help them understand				
I have claimed to have a different				
diagnosis to avoid rejection				
I have worried that others would view me				
unfavourably because of my mental				
illness				
Because of my illness, I have been				
advised to lower my expectation for				
accomplishments in life				

You may use this space for any comments or to elaborate on any experience you have had.

Appendix iii



Date as postmarked

Dear Resident

You are invited to participate in this research, which looks into ideas about mental illness. Your name was selected from the telephone directory.

This research is subject to the highest standard of academic and ethical rigor and has the endorsement of West London Mental Health (NHS) Trust, Brunel University, London West Research and Development Consortium and has been vetted by Ealing Local Research Ethics Committee.

The supervisor for this research is Dr Sebastian Garman of Brunel University, Osterley Campus, Borough Road Isleworth, TW7 5DU.

I would be most grateful if you would complete the enclosed questionnaire and return it in the stamped addressed envelope, which is provided.

If you have any query or comment about this research please contact

Carlyle London at West London Mental Health (NHS) Trust Uxbridge Road, Southall, UB1 3EU
Tel 0208 354846 or carlyle.london@wlmht.nhs.uk

Your participation in this study is entirely voluntary and you do not have to complete the questionnaire, unless you so desire. You do not have to answer any question that may make you feel uncomfortable. You can discontinue your participation at any time.

By returning this questionnaire, your consent to participating in this study is inferred.

All the information you provide will be treated as absolutely confidential and it will not be possible to link your name to your returned questionnaire. You do not have to put your name on the questionnaire.

With thanks for your participation.

Please respond to each statement All responses to this questionnaire will be treated as wholly confidential and will be unattributable to individual respondents Thank you for supporting this project

Age

Male	
Female	

15-19 years	45-49 years
20-24 years	50-54 years
25-29 years	55-59 years
30-34 years	60-64 years
35-39 years	65-69 years
40-44 years	70 + years

To which ethnic group do you feel you most belong, please tick one box only

White English/ Scottish/	Indian	
Welsh		
White Irish	Pakistani	
White Other(Please	Bangladeshi	
describe)		
Black African	Chinese	
	Any other Ethnic group	
Black Caribbean	(please describe)	

Level of formal education achieved

Primary school	
GCSE / O level	
A level	
Diploma	
Degree	
Higher degree	

The following statements express various opinions about mental illness and the mentally ill.

Read each statement and the put an X in the box that most accurately describes your reaction to each statement. It is your first reaction that is important. Do not be concerned if some statements seem to be similar to previous items.

	Strongly disagree	disagree	agree	Strongly
I believe most people would feel afraid to	_			
talk to someone who has a mental illness				
I think most people would be feel				
uncomfortable working with someone who				
has a mental illness				
I believe most people would stay friends				
with someone who has a mental illness,				
once they found out about the mental				
illness				
I think most people would feel				
uncomfortable living with someone who				
has a mental illness I think most people would not date				
someone who has a mental illness				
I believe most people would not marry				
someone who has a mental illness				
I think most people believe that receiving				
care in a mental health unit is a sign of				
personal failure				
I think most people believe that people				
with mental illness could be intelligent				
I believe most people would ignore the				
opinions of someone with a mental illness				
I believe most employers would pass over				
the application of someone who has a				
mental illness in favour of someone else				
I believe most people think that a person				
who has a mental illness is likely to harm				
others				
I believe that most people would not hire				
someone who has a mental illness to take				
care of a family member (e.g. child,				
elderly person)				
I think most people would feel ashamed if				
others knew someone in their family had a				
mental illness				
I believe most people would be against				
having a group home for the mentally ill in				
their street				
I believe that much more money should				
be spent on mental health services				
I halfana a anda mish mansad illusa a ana				
I believe people with mental illness can				
perform in jobs of the highest levels				
The same and a same and the sam				
I have seen or read things in the mass				
media (TV, press) about people with				
mental illness, which I find hurtful or				
offensive				
I have heard people say unkind things				
about the mentally ill				<u> </u>
To avoid rejection the mentally ill			_	
should hide obvious symptoms of their				
illness				
I would support my child if he/she				
developed a mental illness				
actoloped a montal lilliess	I	J		

	Strongly disagree	disagree	agree	Strongly agree
If a friend developed schizophrenia, our friendship will not be affected				
Mental illness should not be a barrier to accessing higher education				
People with mental illness are no less capable of doing a job than those without a mental illness				
I am not afraid to socialise with the mentally ill				
When applying for jobs the mentally ill should not declare their illness				
I would prefer not to employ someone with a mental illness even though they may appear to be well				
Staff working in A&E departments need to be especially careful when dealing with the mentally ill				
Mental illness should not be a factor in a court's decision in awarding custody of children				
The mentally ill should seek support from their religious community				
If I had a mental illness I would keep it a secret				
If I had a mental illness I would hide any visible symptoms				
I would be more sympathetic if I understood what mental illness is				
I would feel better with a diagnosis of depression rather than schizophrenia				
Public attitudes to mental illness does not affect people with mental illness				
People with mental illness should lower their expectation of achievements in life				

You may use this space for any comments or to elaborate on any experience you have had

Appendix iv

QUALITY OF STUDY INSTRUMENT

Adapted from Smith and Stullenbarger (1991)

Elements and requirements

Score*

INTRODUCTION

1 2 3 0 N/A

Justification for study
Conceptual framework
Statement of problem / purpose
Critical review of research
Methodological issues
Hypotheses / Study questions stated
Operational definitions
Sum= n=

METHODOLOGY

Design described
Control of validity threats
Sufficient sample size
Representative sample
Data collection procedures described
Instrument validity described
Instrument reliability described
Sum= n=

DATA ANALYSES AND RESULTS

Statistical treatment
Data presentation
Results related to problem / hypotheses
Findings substantiated by method used
Sum = n =

CONCLUSIONS / RECOMMENDATIONS

Discussion related to background / significance
Conclusion logically derived from findings / results
Recommendations consistent with findings
Alternate explanations advanced
Sum= n=

n = sum = mean =

(*1 = low, 2 = medium, 3 = high, 0 = absent)

Appendix iv-b

Questions to ask of various sections of a research report (Cormack, 2000)

Title

Is the title concise?
Is the title informative?
Does the title clearly indicate the content?
Does the title clearly indicate the research approach used?

Authors

Does the author(s) have appropriate academic qualifications? Does the author(s) have appropriate professional qualifications and experience?

Abstract

Is there an abstract included?

Does the abstract identify the research problem?

Does the abstract state the hypothesis (if appropriate)

Does the abstract outline the methodology?

Does the abstract give details of the sample subjects?

Does the abstract report major findings?

Introduction

Is the problem clearly identified? Is a rationale for the study stated? Are limitations of the study clearly stated?

Literature review

Is the literature review up to date?

Does the literature review identify the underlying theoretical framework? Does the literature review present a balanced evaluation of material both supporting and challenging the position being proposed? Does the literature clearly identify the need for the research proposed? Are important references omitted?

The hypothesis

Does the study use an experimental approach? Is the hypothesis capable of testing? Is the hypothesis unambiguous?

Operational definitions

Are all terms used in the research question / problem clearly defined?

Methodology

Does the methodology section clearly state the research approach to be use? Is the method appropriate to the research problem?

Are the strengths and weaknesses of the chosen method stated?

Results / discussion

Are the practical and theoretical implications of the research discussed? Can the findings be extrapolated to other populations and time periods? Who sponsored the research and was there a conflict of interest?

Appendix v

PEER-REVIEWED CONFERENCE PRESENTATIONS:

UK Public Health Association 15th Annual Public Health Forum. 'Generation to Generation: Sustainable directions for public health. Edinburgh, 28th - 30th March 2007 **Poster presentation** 'Mental health service users' perception of stigma: A study of community and in-patient service users.'

The 19th International Union of Health Promotion Educators [IUHPE] World Conference. Health Promotion Comes to Age: Research, Policy & Practice for the 21st Century. Vancouver, June 10th - 15th, 2007Perceptions of stigma: Poster presentation 'Insights from a study of community and in-patient mental health service users'

Royal College of Nursing 12th European Conference. Expanding Horizons: Future challenges in mental health nursing: <u>Paper presentation</u> 'Service users' perspectives on barriers to social inclusion: A study of community and inpatient mental health service users'. Chester March 6-7th 2008

London West Research and Development Consortium 12th annual Research and Development Conference. 14th June 2007, Charing Cross Hospital Postgraduate Medical Centre. <u>Paper presentation</u>. 'Stigma: a pathway from mental illness to social inclusion.

Faculty of Public Health of the Royal College of Physicians of the United Kingdom. Challenging problems, sharing solutions: Working together for public health. 3-5th June 2008, Cardiff City Hall. <u>Paper presentation</u> '<u>Telling it like it is: the experience of stigma amongst mental health service users'.</u>

West London Mental Health NHS Trust 2nd Annual Nursing Conference. 'Mental Health Nursing: Where is the evidence?' 5th February 2009. Novotel London West, Hammersmith. **Paper presentation** 'The voice of the service user: the evidence for de-stigmatisation'.

Expanding our Horizons: Moving Mental Health and Wellness Promotion into the Mainstream. Toronto 4th-6th March 2009. The Clifford Beers Foundation and the Mental Health Commission of Canada. Paper presentation 'Stigma and mental health service users: the impact on therapeutic engagement'. Expanding our Horizons: Moving Mental Health and Wellness Promotion into the Mainstream. Toronto 4th - 6th March 2009. The Clifford Beers Foundation and the Mental Health Commission of Canada. Paper presentation 'Risk Factors in Frequent Psychiatric Hospitalisation: A Service Users' Perspective'.

Expanding our Horizons: Moving Mental Health and Wellness Promotion into the Mainstream. Toronto 4th-6th March 2009. The Clifford Beers Foundation and the Mental Health Commission of Canada. **Poster presentation** 'Public beliefs about depression in Iceland'.