

# **Making sense of mental illness: the importance of inclusive dialogue**

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## Abstract

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Making sense of mental illness: The importance of inclusive dialogue

People with diagnoses of mental illness have been described as the last minority group against whom it is socially acceptable to discriminate. Challenging the stigma of mental illness is a major social issue and public health concern. Despite a range of anti-stigma efforts being conducted in recent years, the problem persists. It has been argued that a good place to start when changing social attitudes is with young people, whose attitudes are in a state of flux, making them more open to alternative ways of thinking. However, school based educational approaches designed to address this issue are in their infancy. To date, the mental health stigma reduction agenda has largely been drawn up by those who hold most power in the field – predominantly psychiatrists. This has led to anti-stigma initiatives drawing primarily on a biomedical model. There is a growing body of evidence that this approach is not only ineffective, but can actually increase stigma. There is therefore a need to investigate and test alternative approaches. Furthermore, previous research investigating young people's knowledge of and attitudes about mental illness has been constrained by being conducted within the terms of the dominant discourse.

This research set out to investigate how young people construct their positions in relation to mental illness. A primary aim was to understand how they negotiate the ambiguities of the mental health discourse. In addition, it has looked at the impact of engaging in 'inclusive dialogue' about mental illness on young people's sense making. Mental illness is itself an essentially contested concept. Inclusive dialogue is an approach which takes seriously the variety of competing concerns which make up the ways in which mental illness is approached in day to day life, aiming to embrace the complexities and encourage people to grapple with them, bringing their own experiences and beliefs to bear.

The underlying purpose of the inquiry was to consider whether there is potential for educational initiatives to help young people adopt non-discriminatory stances in relation to mental illness. The research was conducted qualitatively, and engaged a group of seven year 10 pupils in a series of discussions, which took place over the course of a half term. In addition, individual interviews and follow up group sessions were carried out later in the academic year.

The results of this study indicate that engaging young people in inclusive dialogue is beneficial across a range of domains. The young people said that the discussions left them more comfortable in talking about mental illness and confident about their ability to respond to mental illness in people around them. The study revealed that context and the specific details of each situation are crucial in determining whether young people take up stigmatising or supportive positions towards people with a mental illness. Stepping outside the terms of the dominant discourse reveals that far from being the product of poor comprehension of biomedical psychiatry, 'stigma' may in fact be just one of a set of responses to people with mental illness. People who are mentally ill sometimes behave in ways that are disturbing and frightening, and it is vital that education accepts, rather than sidesteps, this reality. The findings of this investigation suggest that what is needed to improve social responses to mental illness is a reframing of the issues; a conceptual shift, wherein the notions of 'knowledge' and 'attitude' are not taken for granted and the aim of 'reducing stigma' is left behind in favour of the positively framed target of increasing solidarity.



## **Declaration of original contribution**

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## Dedication

In memory of Giles Brown and Alice Duncan for whom the stigma of mental illness played a part in lives ended too young.

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## Chapter 1: Introduction

*It is good to have an end to journey towards but it is the journey that matters in the end*

Ursula K. LeGuin (1969)

### 1.1 Why this topic?

People with diagnoses of mental illness have been described as the last minority group against whom it is socially acceptable to discriminate, stigmatise and exclude (Thornicroft, 2006).

Discrimination, stigma and social exclusion are very real aspects of living with a mental illness diagnosis and the consequences can be grave, leading to loss of opportunity in education, employment, housing and social functioning (Sartorius & Schulze, 2005). The impact of these consequences affects not only individuals, but also communities and society at large. There is a number of ways in which this problem is being addressed, including anti-stigma campaigns, protest and legislation (Corrigan, 2007). It has been argued that a good place to start when changing social attitudes is with young people, whose attitudes are in a state of flux (Bohner & Wanke, 2002; Tesser & Shaffer, 1990), making them more open to alternative ways of thinking. However, school-based educational approaches designed to address this issue are in their infancy (Pinfold, 2003).

Previous endeavours to counter the social problems of how mental illness is responded to have tended to exploit the concept of ‘stigma’ and focus on ‘changing negative attitudes’ (Pinfold, Toulmin, Thornicroft, *et al*, 2003; Schulze, Richter-Weling, Matschinger, *et al*, 2003). This tactic overlooks the fact that ‘stigmatisation’ is a relational process, a socially mediated phenomenon which is co-created by social difference and prejudice (Dovidio, Major & Crocker, 2000). It also disregards the possibility that ‘stigma’ may actually be a normal product of people’s limited cognitive resources in relation to social diversity (Neuberg, Smith & Asher, 2000). Consequently there is a need to probe the discourse around mental illness and investigate the possibilities presented by an educational approach to improving the way mental illness is understood, which embraces the reflexivity of the processes that lead to discrimination against those with mental illness diagnoses.

Unsurprisingly, scholarly interest in the issue of the stigma of mental illness and how to address it has come principally from the mental health disciplines. For reasons which will become apparent in this thesis, this has major implications for how anti-stigma work has been addressed, which has in turn led to damaging consequences for the success of such endeavours. Prior attempts to improve young people’s attitudes to mental illness through education have worked on the assumption that enhancing ‘knowledge’ will lead to reductions

in ‘stigma.’ This supposition has been taken for granted, without having explored in any depth how young people already construct their understandings. Therefore, there is an unmet need to broach the issue from a stance which places young people’s perspectives at the heart of the process, and attempts to engage them in dialogue which is inclusive at every level. It is this need which the present thesis seeks to address.

## 1.2 Why this topic interests me

I became interested in how mental illness is understood in society for personal reasons. My own experience of having had periods of mental illness has not only informed the work reported in this thesis, but also formed an integral part of the methodology, so it would be remiss not to tell some of my own story in introducing this work. I was diagnosed with manic depression (now known as bipolar disorder) at the age of 21. At the time of my diagnosis I was told that this was a severe, chronic illness for which there is no cure and that I would need to take medication for the rest of my life. I had recently graduated with a first class degree, and managed to get a competitive publishing job, working on a prestigious art magazine in central London.

The impact of manic depression on my life was profound. In a short space of time I went from being a young woman with the world at her feet, to being a mental patient with vastly reduced opportunities. I lost my job, and had to leave London to live with my parents in the small Yorkshire town I grew up in. Throughout my time at university I’d maintained friendships with my peer group from school, and quite a number of my old school friends were also living back at home after finishing university. That my old mates were nearby was at least something of a consolation in the face of everything I’d lost. The comfort didn’t last long, though. One of my closest school friends visited me in hospital. The experience of seeing me ‘not myself’ must have been too much for her, and when I left hospital she didn’t return my phone calls. Other friends in our group followed suit, and gradually it dawned on me that the group of friends I’d been part of throughout my teenage years no longer wanted to know me. This was my first taste of the stigma of mental illness.

One of the challenges I faced at the time was how to make sense of who I was in the face of manic depression. I’d always been a high flier. I had a lot of friends, people generally liked me, and I liked people. I was fun loving, knew how to have a good time, and tended to take life by the scruff of the neck and live it. I was socially confident, articulate and capable. People trusted me and friends confided in me. None of that seemed to square with being mentally ill. Having manic depression seriously threatened my image of myself, and there was strong

evidence to suggest it changed how other people viewed me too. Self-stigma set in. The struggle to reconcile both the label ‘bipolar disorder’ and the experiences it attempts to describe with the rest of my identity has continued to be a feature of my life ever since.

Fortunately, I have a supportive family, and friends from other parts of my life who, for various reasons, were less afraid by whatever this mental illness thing was all about, and remained close to me. I know now that while they found it painful and upsetting to watch me go through the experiences I was having, they didn’t lose sight of the bright, competent, affectionate Emma they’d always known. Their continuing belief in me was one of the cornerstones of my recovery and enabled me to regain a sense of my whole self, incorporating manic depression as well as everything else that makes me who I am. Nevertheless, the experience of having lost friends as a result of mental illness, combined with the impact on how I thought about myself made me seriously consider the importance of broader, societal understandings mental illness.

The topic was not one which was covered explicitly in my own schooling. It might be that if my peers had had more resources with which to make sense of mental illness, its onset need not have so profoundly changed the way they responded to me. I feel sure that the process of self-stigmatisation which caused me so much anguish could have been considerably lessened had I been better equipped to make sense of the experiences from a ‘normalising’ perspective. Better understanding of mental illness in general might improve the way people respond to others who experience it, but just as importantly, could help people experiencing mental illness to resist stigmatising themselves.

Although there are personal reasons why I was interested in researching this topic, it is important to acknowledge that just because this issue matters to me it doesn’t necessarily mean that it matters more broadly. Perhaps mental health education at school would have benefited me, but that is not sufficient reason to argue that mental health education would benefit all secondary school pupils. One of the tasks of this thesis is to consider the research questions dispassionately, and while the personal backdrop to this research is in some ways manifest throughout, it should not impinge on the trustworthiness of the thesis overall.

The reasons for my interest in this topic do not lie solely within my own experience of mental illness. Social inequality, prejudice and discrimination in all their guises have long interested me, perhaps partly as a product of growing up in a racially diverse, primarily working class town. The ways in which people make sense of and negotiate social difference are fascinating

to me, particularly in terms of what it is that enables some people to take non-discriminatory stances towards other people while others are unable to do so. My belief in the potential for educational processes to influence people's position taking in relation to others comes partly from having witnessed it in action, both during my time as a school pupil, and later in life as a facilitator of theatre-in-education. Having the opportunity to carry out this research has allowed me to explore these things in more detail.

### 1.3 Statement of the problem

Challenging the stigma of mental illness is a major social issue and public health concern. Despite a range of anti-stigma efforts being conducted in recent years, the problem persists (DoH, 2007; DoH, 2009; Rethink, 2008). To date, the mental health stigma reduction agenda has more or less exclusively been drawn up by those who hold most power in the field – predominantly psychiatrists (Pilgrim & Rogers, 2005). This has led to anti-stigma initiatives drawing primarily on a biomedical model, emphasising similarity between mental and physical illness, stressing that mental illness can happen to anyone, and can be treated with medicine (Read, Haslam, Sayce, *et al*, 2006). There is a growing body of evidence that this approach is not only ineffective, but can actually increase stigma (Read, 2007; Read, Haslam, Sayce, *et al*, 2006). Psychiatry has a contentious history, and criticism of its methods and practices continues unrelentingly, from both within and outside it (Bracken & Thomas, 2005; Coppock & Hopton, 2000; Crossley, 2006; Pilgrim & Rogers, 1999). Recent critics argue strongly that psychiatric practice is in fact the crux of the problem of the social exclusion of the mentally ill and therefore cannot be part of the solution (Bracken & Thomas, 2005; Sayce, 2000; Seedhouse, 2002). Bracken and Thomas (2005) contend that diagnostic labels are not only stigmatising but also that they are disempowering and dehumanising. Under the biomedical perspective, life experiences become 'symptoms of illness' and this can result in a lessening of the search for meaning of one's life. This in turn creates a situation whereby the mentally ill person regards him or herself as having a mind, or indeed a life, which is 'diseased' and of less value to others. So although on the surface it may appear that medical framing of madness is value-neutral, the reality is much more complicated. It has been suggested that it is quite wrong for psychiatry as a profession to implicitly assume it has the expertise to construct and deliver education to combat the social problems of mental illness (Pilgrim & Rogers, 2005).

These arguments apply to school-based interventions as much as they do to more widely administered anti-stigma campaigns but to date, school-based anti-stigma interventions which have tended to be based on medical model anti-stigma practice. There is thus a cogent need for *educational* research, which starts not with the assumption that the enlightened few already know the 'right' answers, but instead from a position which favours the dialectic over the



didactic. According to the principles of constructivist education, the development of meaningful educative processes requires the educator to begin with a thorough understanding of the learners' existing knowledge and ideas. Therefore, in order to devise fertile educative strategies to help young people make sense of mental illness, it is necessary first to understand how they construct and occupy discourse on the subject. While there has been some previous research investigating adolescents' knowledge of and attitudes to mental illness, this has largely been conducted from particular epistemological standpoints which carry limitations. Only one previous study I am aware of engaged groups of young people in discussions about how they understand mental illness (Secker, Hill & Armstrong, 1999) and this study is now somewhat out of date.

The present research sets out to investigate how young people construct their positions in relation to mental illness. A primary aim is to understand how young people negotiate the ambiguities of the mental health discourse. In addition, the research seeks to ascertain how the process of talking with peers about themes relating to mental illness may impact on young people's sense making on the subject. The purpose of both of these angles of enquiry is to consider whether there is potential for education to help young people adopt non-discriminatory stances in relation to others with mental illness experience.

## **1.4 Approach**

The research was conducted qualitatively, and engaged a group of seven year 10 pupils in a series of discussions which took place over the course of a half term. In addition, individual interviews and follow up group sessions were carried out later in the academic year. Although principally a data generation exercise, the discussions and interviews also functioned as a mental health education intervention. A broadly phenomenological approach was taken, which kept the idiographic accounts of the individuals central.

## **1.5 Research questions**

There are three overarching research questions which guided the enquiry, each of which was supplemented by sub-questions. These are shown below.

RQ1: How do young people construct and occupy discourse on mental illness?

- a. How did the young people make use of language?
- b. What sources of knowledge did the young people draw on in order to construct discourse?
- c. What communicative tools were employed in the occupation of discourse?

RQ2: In what ways does the process of discussion and engagement with themes relating to mental illness impact on young people's constructions?

- a. What discoveries and insights did the young people make during the process of discussion?
- b. What did the young people say about the impact of participation on them?

RQ3: What is the potential for education to help students construct non-discriminatory positions in relation to mental illness?

- a. What did the young people say about pedagogy?
- b. What features of this approach are particularly promising?
- c. How did positions I took as facilitator influence outcomes?

## 1.6 Some notes about language

*Words, like the chisel of the carver, can create what never existed before.*

Heidegger (1971)

There are some issues with terminology which it is necessary to address at the beginning of this thesis. This study has at its centre an interest in how young people make sense of mental illness. It is important to be clear that the phrase 'mental illness' is in many ways inadequate, both because it is imprecise and because the phenomena it refers to are not necessarily always construed as illness. It is also necessary to acknowledge that I made an active choice to primarily use the term 'mental illness,' despite its inadequacy, and with the awareness that there is a wide range of alternative terms which I could have chosen.

The phrase 'mental health problems' is more commonplace than 'mental illness' (Pickering 2006), very possibly because specialist services are currently described as 'mental health services.' There is a universal discourse about 'mental health' which actually denotes the management of mental *illness* (Vassilev & Pilgrim, 2007); people who say "I work in mental health" usually mean that they are involved in working with people who are experiencing mental illness. It has been suggested that this is a good thing, not least because adding 'problems' to invert the notion of 'mental health' is less damning than using the phrase 'mental illness' (Pilgrim 2005). However, in my view, the vagueness which comes with using the phrase 'mental health problems' can also act as a "diversionary euphemism" (Pilgrim 2005: p.5), heightening the muddled confusion of the discourse around mental illness. For example,

I observed young people saying things like “he’s got mental health” and “it’s a mental health illness,” both rather confusing (and possibly confused) turns of phrase.

These examples show how language adopted for its positive connotations can get in the way of saying precisely what we mean. I chose to use the term ‘mental illness’ because it makes it clear that we’re talking about something being ‘wrong’. My main reservation with ‘mental illness’ is its intrinsic alignment with the medical standpoint, given that there is great controversy as to whether it is logically correct, politically appropriate or philosophically accurate to describe ‘madness’ and ‘sadness’ as ‘illnesses’ at all. However, the need to be clear about what is being addressed in both fieldwork and the thesis meant that using the terms of the dominant discourse was advantageous. Furthermore, I did not feel that the available alternatives carried sufficient advantages to warrant favouring them. As well as ‘mental health problems,’ the main alternatives considered were ‘mental disorder,’ which is used in medical psychiatric texts and legal settings; ‘psychiatric disability,’ which is commonplace in academic literature and ‘mental distress,’ which is frequently preferred by people who have themselves experienced mental illness. Although ‘mental illness’ is my phrase of choice, I do not stick to it doggedly throughout the thesis. This is both for stylistic reasons, and also at times, because one of the other phrases has connotations which capture my meaning better than ‘mental illness’.

The language used to describe people who have, or might receive a diagnosis classed as mental illness is equally problematic. Many of the phrases used position people as patients, rather than people who happen to have some problems with their mental health; for example ‘mental patient,’ ‘person with psychiatric disability,’ or ‘psychiatric subject’. Other commonly used terms such as ‘service user,’ ‘consumer,’ and ‘survivor’ are problematic for a range of reasons, not least that they are very unclear. People can be a user or consumer of a raft of services other than mental health services, and can ‘survive’ all sorts of life experiences besides mental illness. The phrase ‘people with mental illness’ can have the connotation that mental illness is a constant characteristic, which is seldom the case. For this reason, I have tried to use phrases such as ‘people with a diagnosis’ or ‘people experiencing mental illness.’

The phrase ‘inclusive dialogue’ appears in the title of this thesis. I use it to refer to the particular educational approach which I recommend based on my findings. This approach facilitates dialogue between participants in small group discussions, in which everyone is encouraged to take an active role. It is inclusive in the sense they are encouraged to bring their own understandings and experiences to the discussion. It is also inclusive because it is structured to enable them to consider mental illness from a diverse range of perspectives.

## Chapter 2: Literature Review

The aim of this substantial chapter is to provide an introduction to the topic of mental illness, to explore how young people's conceptions of mental illness have been researched, and to examine earlier school-based educational interventions. The chapter is divided into two main sections. The first explores the question 'what is mental illness?' with an emphasis on the alternative ways in which it can be understood. Because mental illness is an essentially contested concept (Gallie, 1956), multiple ways of thinking and talking about mental illness coexist in society. These are the resources available to people, including young people, to draw upon in making sense of mental illness and it is therefore important to explore them in some detail. The second section narrows its focus onto young people, asking the question 'what role can education play in influencing young people's understandings of mental illness?' This will include a review of research investigating young people's knowledge of and attitudes to mental illness as well as a summary of studies reporting the effects of school-based interventions.

### 2.1 What is mental illness? - Introduction

*To define true madness is't but to be nothing else but mad.*

Hamlet (II. ii)

The first task of this literature review is to pose the question 'what is mental illness?' In a thesis in which the central interest focuses on young people's constructions of mental illness, it is important to begin by situating this within a wider picture which demonstrates and articulates the complex ways in which mental illness is understood more broadly. In exploring young people's understandings of the issues of mental illness, it is necessary to take account of the ways in which the topic has been made sense of already. Not to do so would make it much harder to interrogate and communicate what the young people are drawing on and making sense with as they explore mental illness. The first part of the chapter aims to do this by asking three sub questions – firstly, 'what is mental illness to *them*?' Here 'them' represents professional discourses, namely psychiatry, sociology and psychology. Secondly, 'what is mental illness to *us*?' This section will examine how public or lay understandings of mental illness have been represented in the literature. Finally, 'what is mental illness to *me*?' Here 'me' represents the first person account, and attention has deliberately been given to the perspective of those who have experienced periods of mental illness. These are three overlapping, but distinguishable ways of approaching the subject of mental illness and people with mental illness. This section will also consider how mental illness affects the individual generally, particularly in terms of discrimination.

One of the challenges that this section addresses is the assumption that the notion of ‘mental illness’ is self-explanatory. Making such an assumption overlooks the considerable complexity and controversy which surrounds the concept. Mental illness is not only complex and controversial; it is also rather problematic to sum up simply. This is demonstrated by the UK’s largest mental health charity, *Mind*, in its attempt to answer the question ‘what is mental illness?’ on its website. The answer it gives is as follows:

*“Mental illness is very common. About one in four people in Britain has this diagnosis, but there is a great deal of controversy about what it is, what causes it, and how people can be helped to recover. People with a mental illness can experience problems in the way they think, feel or behave. This can significantly affect their relationships, their work, and their quality of life.”* (Mind, 2010)

Mind’s attempt at defining mental illness demonstrates how problematic it is to answer the question in a straightforward and direct way. Before getting to anything descriptive, Mind first tells the reader that mental illness is both common and controversial. It is only by the third sentence that they reach a (slightly) more substantive answer to the question. Even here, there is a sense in which Mind is being tentative and cautious – they state that people with a mental illness “*can* experience problems in the way they think, feel or behave.” The use of the word “can” in this way carries the implication that it is also possible that the difficulties experienced by people with a mental illness cannot always be reliably framed in these terms. It is also the case that a person *without* a mental illness may experience problems in the way they think, feel and behave, so this description is potentially misleading. This demonstrates how difficult it is to pin down the meaning of mental illness. This difficulty is one which is echoed throughout the discourse concerned with mental illness.

### **2.1.1 What is mental illness to ‘them’? Professional discourses**

*Madness has in our age become some sort of lost truth*

David Cooper (1967)

The three professional discourses I shall be discussing in this section are psychiatry, sociology and psychology. Issues relating to the phenomenon variously described as madness, mental illness, psychological abnormality, mental disorder, mental health problems, psychiatric disability or mental distress are of interest to practitioners, writers and academics from all three disciplines. The subject of mental illness is clearly of profound concern to psychiatry - the medical specialism which ‘ought’ to know most about it. Behaviour and matters of the mind are also clearly of significant interest to psychologists, and there is a substantial literature on mental illness coming from this discipline, with differing explanatory frameworks for it put

forward. In addition to contributions from psychiatry and psychology, further theoretical and discursive contributions have come from the fields of sociology and philosophy. That there is such a myriad of literature discussing and addressing the complexities of defining what mental illness is, what causes it and how it should be responded to is itself of importance. The very concept of mental disorder is one which is essentially contested and has provoked and continues to provoke extreme variation in how it is approached. This section will map some of the most practically important ways of thinking about mental illness. Particular attention will be given to the biomedical model of psychiatry and criticisms of it. Psychological approaches to mental illness will be summarised, followed by a discussion of some of the critical perspectives on mental illness offered by sociologists.

### **What is mental illness? – The DSM's answer**

Although there are many voices in the debates about mental illness, the most dominant perspective is doubtless that of the psychiatric profession. Within psychiatry there are many conflicting views, which I will come to later, but very broadly speaking, psychiatrists tend to agree at least about the types of disorders with which they consider themselves to be concerned. The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the prescribing 'bible' which psychiatrists in most of the western world use to categorise and describe the illnesses they are trained to treat and in this sense is a central example of psychiatrists' professional discourse. The DSM is an American publication, produced by the American Psychiatric Association. It first appeared in 1952 and there have been five revisions since then, with gradually more disorders being included, and some being removed all together – a notable example being that of homosexuality. The current edition is the DSM-IV-TR (APA, 2000), a text revision of the 1994 version, issued in 2000. DSM-V is in preparation and is expected to be published in 2011. The manual itself is far from uncontroversial, with plenty of critics and considerable contention surrounding it (see for example, Cooper 2004) but, criticisms notwithstanding, it is put into practical use on a day to day basis, and is a major determinant of how western psychiatrists understand what mental disorders are. Whether or not one agrees with the taxonomy of psychiatry and the ontology underlying it represented in the DSM, it provides a catalogue of mental illnesses which is both descriptive and illustrative. So, a direct look at the *specific* disorders within the manual provides a relatively immediate, if somewhat reductive, answer to the question 'what is mental illness?'

The disorders are grouped into the following categories of disorder: adjustment; anxiety; dissociative; eating; impulse-control; mood; sexual; sleep; personality; psychotic; somatoform and substance. Within these category headings, the DSM-IV lists over 300 specific diagnoses, including posttraumatic stress disorder; anorexia nervosa; major depressive disorder; bipolar

disorder; schizophrenia; antisocial personality disorder and substance dependence. These examples of common diagnoses illustrate what it is that is being talked about when the phrases ‘mental illness,’ or ‘mental disorder’ are used. Some of these diagnostic terms have slipped into what one might call ‘common parlance.’ Most of us have heard of anorexia, and although we may not be able to provide a list of the symptoms required for a diagnosis of it, we probably have an intuitive sense of what substance dependence might be. Other diagnostic labels are more problematic – in the public imagination schizophrenia, for example, is very often equated with the notion of a ‘split personality,’ which is completely divergent from the condition described within the DSM. It immediately becomes apparent that the broad category of ‘mental disorder’ is incredibly wide ranging and diverse. There is a huge difference between each of the disorders, not to mention that the particular ‘symptoms’ experienced by one individual with any of these diagnoses are likely to be very different from those of another. Having said that, it is also clear that the disorders have things in common, and it is possible to group them by saying that this is a set of human experiences which affect the mood, emotions, behaviour and thoughts and in this sense they clearly belong in the domain of the ‘mental.’ Describing any of the mental illnesses in general terms, either by examining them in the most objective frame possible – i.e. by looking to the diagnostic criteria within the DSM - or by attempting a generalised description of the broader category of mental disorder is to depart markedly from the lived experience of any individual who is affected by that illness or disorder. Section 2.1.3 will attempt to acknowledge this difficulty by presenting and discussing some first hand accounts of the experience of mental illness.

The following section will describe the origins of biomedical psychiatry.

### **Biomedical psychiatry – the medical model**

*Canst thou not minister to a mind diseased,  
Pluck from the memory a rooted sorrow,  
Raze out the written troubles of the brain,  
And with some sweet oblivious antidote  
Cleanse the stuff'd bosom of that perilous stuff  
Which weighs upon the heart?*  
Macbeth (V.iii)

Although strange behaviour, madness and sadness are fundamental aspects of the human condition and have been part of human experience throughout history, medicalised responses to these phenomena are relatively recent. The development of psychiatry as a medical discipline began in the nineteenth century, and during this period it was in Germany that most significant development took place (Scull, MacKenzie & Hervey, 1996). The term ‘psychiatry’

was first used in 1808 by the German physician, Johann Christian Reil (Shorter, 1997). Etymologically, the word ‘psychiatry’ is derived from the Greek ‘psyche,’ which translates as ‘soul’ and ‘iatros,’ meaning ‘doctor.’ Although it was Reil who coined the use of the term ‘psychiatry,’ the most important figure in the advancement of the discipline was the German psychiatrist Emil Kraepelin (ibid.). Kraepelin’s impact on the orthodoxies of contemporary psychiatric practice cannot be underestimated and he has been described as the father of biomedical psychiatry, including diagnostic categorisation, as well as psychopharmacology and psychiatric genetics (Eysenck, Arnold & Meili, 1975). Kraepelin believed that the primary cause of mental illnesses was biological and genetic malfunction, a view which continues to underpin mainstream clinical psychiatry in the present day. Another important contribution of Kraepelin’s was to do with the classification and diagnosis of mental illness and the ways in which the categories within the contemporary DSM are arranged can be traced back to Kraepelin’s philosophy (Engstrom & Weber, 2007). Kraepelin theorised that there were a small number of discoverable types of mental illnesses, which could be identified by way of investigating symptoms, by direct observation of brain diseases or by finding out the causes of the illnesses (Bentall, 2003). Of these possibilities, the only method of classification that was practical was the studying of symptoms. Kraepelin held that people with the same illness, defined by the symptoms they experienced, could be assumed to be sufferers of the same brain disease and therefore identifying the illness in this way would eventually lead to an understanding of the aetiology of the illness (ibid.).

In the present day, the discipline of psychiatry is wholly embedded within the medical world and as such is broadly considered to be a legitimately functioning specialism within medicine. Medicine is concerned primarily with “identifying sick individuals (diagnosis), predicting the future course of their illness (prognosis), speculating about its cause (aetiology) and prescribing a response to the condition, to cure it or ameliorate its symptoms (treatment)” (Rogers and Pilgrim, 2005, p.2). The medical model of mental illness regards mental illnesses as being strictly analogous to physical illnesses. A physician might see a patient who is complaining of a persistent cough, wheezing and shortness of breath. A series of tests is undertaken, and a diagnosis is made of lung cancer. The physician can make reasonably reliable predictions about the future of the patient. The causes of lung cancer are multi-factorial and well-documented – and a treatment will be prescribed, which would, depending on the precise state of the disease, involve surgery, radiotherapy, and/or chemotherapy. The diagnosis, prognosis, aetiology, and treatment are perceived to be determined by objective, value-free science. The body (or a part of it) is not functioning as it should. Science can explain what is wrong, and how the problem can be alleviated.



By analogy, according to the medical model of mental illness, a patient presenting with a malfunctioning mind should be seen by a specialist doctor (a psychiatrist), trained in the science of medicine, who will take a history of the patient, carry out an examination, provide a diagnosis and prognosis, and prescribe a treatment (most frequently in the form of drugs, but sometimes other therapies such as electro-convulsive therapy, or even surgery). The foundation on which this approach to mental illness is laid is fundamentally biological, or organic (Clare, 1976). The medical treatment of mental illnesses through psychiatry is, according to this model, no less scientifically based and value-free than the treatment of lung-cancer.

Under the medical model, emphasis is placed on genetic, biochemical, physiological and neuroanatomical factors in the aetiology of mental illness. (Joyce, 1980; Schwartz, 1999). A fundamental assumption of this model of mental illness is that psychological problems are caused by biological disturbance; the psychological problem is an indicator that something has gone wrong with normal biological processes. It is assumed by psychiatry that biochemical imbalance or disturbance in the brain leads to abnormal behaviour. In this sense, mental illnesses are treated as though they are diseases. Even though some argue that evidence for physical causes of mental disorder is at best tentative (Bentall, 2003), drug treatments which target the physiology of the brain are currently by far the most dominant therapy offered to those who are experiencing mental distress ranging from depression and anxiety to psychosis and mania. Because drugs which target chemical processes in the brain are used in the treatment of mental illness, it is often suggested that mental illness is *caused* by chemical imbalance. However, the reality is not so straightforward. In the case of depression, for example, some research studies have found that people with severe depression have low levels of serotonin and norepinephrine (Davies & Bhugra, 2004). It is possible to suppose from these findings that this is evidence that the lowered levels of these chemicals are causes of depression. However, this is an assumption – what the research shows in fact is that there is a *correlative* relationship between depression and lowered levels of serotonin and norepinephrine, which does not actually amount to a compelling indication of causality in either direction. It is important to note that the effect of drugs was a massively significant factor in the development of the now prevalent view that mental illnesses are caused by neurotransmitter abnormalities (chemical imbalances). The theory that schizophrenia is caused by an excess of dopamine arose directly from discovery of the actions of anti-psychotic drugs which act on dopamine. Similarly, in the case of depression, the current prevailing idea that serotonin plays a role in depression is borne out of the development and introduction of selective serotonin

re-uptake inhibitors. (Moncrieff, 2004). The prescribing of specific psychiatric drugs for specific psychiatric disorders is now one of the main preoccupations of the practising psychiatrist, and this condition-specific prescription is seen as having had the effect of making psychiatry truly scientific (ibid.). Most importantly for this thesis is the effect that this has had on the way mental illness is understood within culture generally. It has allowed psychiatric conditions to be regarded as analogous with physical illnesses which can be diagnosed and treated with comparable scientific confidence. The following section will suggest that this is in fact a flawed assumption and deeply problematic.

### **Criticisms of biomedical psychiatry**

One of the criticisms of the biomedical model of mental illness is that it implies a somewhat passive view of people (Frude, 1998). Biologically based accounts regard people who are experiencing mental illness as “organisms who are at the mercy of their genetic make-up and their neurochemistry” (Frude 1998, p.14). While it might be the case that people with physical illness can be similarly regarded as being at the mercy of the biological processes which cause their disease without negative consequence in terms of a person’s view of themselves, the picture is slightly more complicated in the case of mental illness. The presence of mental illness is usually established by way of judgements made about the way a person behaves and when it is judged that a person’s behaviour is ‘diseased’ there is a significant likelihood that this will have huge consequences on how that person feels about themselves as a human being. The medical model disregards personal meanings and the bearing of life experiences which may be tremendously more significant and tangible to the patient than the rather impersonal idea of an imbalance in their brain chemistry. This view of the dehumanising potential of the biomedical model is expressed in Fisher (1999, p.131) as follows: “When I think that I am a group of chemical reactions, each with its own scheme and plan, I feel dehumanised and powerless. I feel that I am thinking, feeling, and acting at the whim of those chemicals, not through any effort or responsibility of my own.”

Another of the crucial ways in which biomedical psychiatry has been criticised is concerned with the questionable validity of its diagnostic processes (Johnstone, 2008). In general medicine, the process of diagnosis involves the identification of signs which indicate the presence of disease. In the case of diabetes, for example, it is possible to determine whether the patient is suffering from the condition by testing their blood and measuring the glucose level. The patient may have been experiencing symptoms such as feeling thirsty and tired and needing to go to the toilet frequently. These symptoms, although they do indicate the *possible* presence of the illness are not sufficient evidence to make a diagnosis of diabetes – the physician relies upon the results of a blood test (a sign) to make a confident diagnosis.

Psychiatric diagnosis does not work like this. Although it is assumed that there is a biological dimension to mental illness, there are no definitive physical indicators of mental illness which categorically and objectively confirm the presence or absence of the disorder. It isn't possible to test a person's serotonin level and thereby establish whether or not they are depressed and nor is it possible to carry out a blood test or x-ray to diagnose psychosis. Instead, psychiatric diagnoses are made by way of subjective observation or reporting of 'symptoms,' which are nearly always judgements about what people say and do. For example, one of the symptoms of depressive disorder presented in the DSM-IV is "markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others)" (APA 2000 p.327). This is clearly a very different sort of 'symptom' than the type of symptoms associated with physical illness – most notably because it is possible for the presence of the symptom to be established by the observation (and therefore judgement) of a third party. The problem of relying on subjective interpretation of symptoms to make diagnoses means that in practice there cannot really be any certainty that the symptoms identified are or are not evidence of the presence of particular mental illness (Johnstone, 2008). Johnstone also makes the point that there is a lack of certainty as to whether these collections of complaints are in fact meaningful at all, rather than simply being a chance association.

Furthermore, to identify the presence of symptoms such as "markedly diminished interest or pleasure" in activities it is inevitable that contextual, personal and particular judgements are called into play. An examination of the symptom lists for more or less any disorder within the DSM rapidly reveals that rather than being complaints about bodily functioning, they are examples of beliefs, experiences and behaviours (Johnstone 2008). Identifying diseased or disordered beliefs, experiences and behaviours simply cannot be a value-free process. There is no universal definition of the 'normal' amount of interest or pleasure that a person should take in their daily activities and this is something that is likely to vary from person to person according to a huge range of factors from the cultural to the contextual. So, it becomes clear that psychiatric diagnosis relies on criteria which are inextricably social and cultural, yet frames this process as being medical.

Further difficulties with the behavioural emphasis in processes of psychiatric diagnosis are explained by the social psychologist David Pilgrim (2005). Pilgrim highlights the *circularity* of the descriptive emphasis in identifying psychological abnormality – i.e. that symptoms are used in order to define a particular disorder, and the same symptoms are accounted for and

explained by way of noting the presence of that disorder. Pilgrim provides the following example to demonstrate this logic:

“Q: how do you know this patient has schizophrenia?

A: because she lacks insight into her strange beliefs and she experiences auditory hallucinations.

Q: why does she have strange beliefs and experience hallucinations?

A: because she suffers from schizophrenia.” (Pilgrim 2005, p. 8).

As Pilgrim comments, this type of circular logic is not a firm basis for making any diagnosis, and yet, irrespective of this, the psychiatric profession continues to diagnose and treat illnesses in this way.

Mental illness, then, is a category which includes a huge range of ‘conditions,’ identified by a broad variety of symptoms which usually relate to the way person behaves and how they appear to feel. Cultural and contextual judgments as to what are ‘normal’ behaviours and emotions are crucial to the identification of symptoms which indicate mental illness. While there is some evidence of a relationship between these symptoms and a person’s brain chemistry, it is often wrongly assumed that this relationship is causal rather than correlative.

### **Anti-psychiatry**

The points about diagnosis described above are important factors in the contentions of the American psychiatrist and psychoanalyst, Thomas Szasz, whose critique of psychiatry was a renowned cornerstone of the anti-psychiatry movement of the 1960s. Although 1960s anti-psychiatry has latterly been considered as a passed phase in the history of psychiatry (Tantam, 1991), there are ways in which its influence continues into the present day and it is worthwhile to consider the arguments here. In his important book, *The Myth of Mental Illness* (Szasz, 1960), Szasz argues that mental illness is a myth because it does not fulfil the criteria to describe proper illnesses. He says that mental illness is not a valid description of reality and that the term ‘mental illness’ can only properly be used metaphorically. Szasz builds on the conventional medical assumption that it is a requirement of establishing the presence of disease that *both* signs and symptoms are present in order for an assured diagnosis to be made. As we have seen above, the diagnostic processes in psychiatry do not and cannot unequivocally rely on identifying *any* signs of the illnesses. Szasz makes the distinction between neurological diseases which have psychological consequences and other mental illness. He says that some conditions – such as alcoholic psychosis - cause changes in people’s psychological function because of a direct and known somatic cause. However, these conditions are crucially

different from the majority of mental illnesses described by the DSM, for which the diagnostic process relies exclusively on examples of thoughts and actions which are perceived by others as deviant or abnormal. Szasz argues that people with these types of experiences are not really ill and states that a person's mind can only be sick in a metaphorical sense. Although Szasz boldly asserts that mental illness is a myth, he also makes it clear that he is not denying that people have the experiences of sadness or madness, but rather that these types of experiences are better described as “problems of living” than symptoms of illness.

Other figures associated with anti-psychiatry of this period include the Scottish psychiatrist R.D. Laing and the French philosopher Michel Foucault. Laing, like Szasz, was a psychiatrist whose views ran counter to those of the professional orthodoxy of his field (Gask, 2004). His most well known work was *The Divided Self* in which he attempted to make madness and the process of going mad, comprehensible (Laing, 1960). Laing, in common with Szasz, was critical of diagnostic process and felt that psychiatry was founded on a false epistemology. In addition, he argued that the expressed feelings of the individual patient should be regarded as valid responses and descriptions of lived experience rather than simply as symptoms of a separate underlying disorder. This emphasis on the importance of the individual's own experiences, both psychological and social was oppositional to the biological orthodoxy of conventional psychiatry which regarded, and continues to regard mental illnesses of occurring independently from and irrespective of an individual's life experiences.

Michel Foucault's writings of the 1960s also had a significant influence on anti-psychiatric thought. Foucault was generally concerned with the critical examination of social institutions, including psychiatry, but also the prison system, and medicine in general as well the human sciences (Gutting, 2005). Foucault's main work on psychiatry, *Madness and Civilization*, arose out of his doctoral dissertation, and although it was ostensibly a history of madness, it contained important arguments about the contemporary institution of psychiatry as a means of social control. Foucault contends that the position of the mentally ill is comparable to that of lepers in the middle ages, and that medical ‘treatment’ is really a means of social control for the convenience of (non mentally ill) society rather than for the benefit of the individual.

Although Szasz, Laing and Foucault have been described by others as being key figures in the anti—psychiatry movement (Cooper, 1967), it is important to note that the term ‘anti-psychiatry’ is not one which any of them chose to apply to their own philosophy. In fact, Szasz and Laing actively rejected the term.

## Critical psychiatry

The anti-psychiatry arguments of Szasz, Laing and Foucault made waves in the 1960s and 1970s. Although anti-psychiatry is now largely regarded as a closed chapter in the history of psychiatry (Tantam, 1991), criticism of biogenetic approaches to psychiatric practice have not simply faded away. Contemporary critics of the continuing biomedical psychiatric orthodoxy now tend to be seen as belonging to the *critical psychiatry* movement (Double, 2006). The Critical Psychiatry Network is a group of British psychiatrists which first convened in Bradford in 1999 to discuss their concerns about government proposals to change mental health legislation (CPN, 2000). Critical psychiatrists address issues such as how and why biomedical theories in psychiatry continue to prevail despite the lack of evidence to support them. They aim to draw attention to the ambiguity of the psychiatrist's role in relation to coercive and compulsory treatment of people diagnosed with mental illnesses. The social control element of medical treatment in this context is one which, according to the critical psychiatry movement, should not be taken for granted and requires re-examination. In terms of making sense of mental illness, this concerns the social positioning of people according to their illness. The dubious validity of diagnostic processes is another matter of concern, and the uncritical acceptance of biological assumptions in psychiatry is rejected. The critical psychiatry movement also argues that the perspectives of those who have mental illness experience should be taken more seriously, and that the power/ knowledge gulf between psychiatrists and their patients is potentially damaging. Critical psychiatrists suggest that service users' views on the appropriateness and helpfulness of the treatment they receive should be taken into account in not just a tokenistic way, but that their experience represents an important knowledge base in its own right (CPN, 2000; Double, 2006).

Another key focus of critical psychiatry is on the prevalent use of medication to treat mental illness and the power of the pharmaceutical industry in manipulating evidence for the efficacy of drug treatments. Medication for mental illnesses is notoriously unpopular amongst those who are advised (or indeed compelled) to take it (Perkins & Repper, 1999). The willingness, or not, to take medication is a phenomenon which is couched in terms of "compliance" by orthodox biomedical psychiatry and finding ways of improving patient compliance with drug treatment attracts considerable research attention (Cramer & Rosenheck, 1998; Kemp, Kirov, Everitt, *et al*, 1998). Critical psychiatrists make a link between the questionable validity of biological explanations of mental illness and the common rejection amongst service users of the idea that problems are caused by disordered brain chemistry to be rectified by medication. In addition, critical psychiatry draws attention to the fact that the problems of definition and validity in psychiatric diagnosis leave the field of psychiatry much more open to commercial

manipulation than other areas within medicine (Moncrieff, 2004). The pharmaceutical industry has significant vested interests in upholding the conviction that mental illnesses are caused by chemical disturbances which do respond positively to drug intervention (Moncrieff, Hopker & Thomas, 2005). Drug company marketing information both conveys messages about chemical imbalances to the public and also fervently reinforces these messages to the doctors who prescribe them, which has the effect of pushing psychiatry into a “biological straitjacket” (Moncrieff, Hopker et al. 2005, p. 84).

Contemporary critical psychiatry calls for a more expansive approach to mental illness, which is able to meaningfully and genuinely take account of the social, cultural and political realities of patients’ lives and the importance of these dimensions in determining their mental health status. They argue for changes to the education of psychiatrists, with a departure from assertions about biological explanations of mental illness and more critical engagement with issues such as the validity of the concept of schizophrenia.

### **Psychological models of mental illness**

While the biomedical model explains mental illness in terms of imbalanced brain chemistry, malfunctioning neurotransmitters, or genetic predisposition, the psychological models of explanation place emphasis on the significance of an individual’s life experiences and the ways in which they think about them. Theories of conditioning, perception, belief formation and internalized schemas of relationships are all regarded as being crucial to understanding the onset, course and particular presentation of mental illness (Kinderman, 2005).

Within the field of psychology there are various theoretical perspectives which take different approaches to mental illness. Each of these perspectives adopts its own view on general psychology (the nature of behaviour), psychopathology (how behaviour can become disordered) and intervention (how such behaviour can be prevented or remedied (Peterson, 1999). Established psychological models include the cognitive-behavioural (Tyrer & Steinberg, 2005) as well as the psychoanalytic approach, family systems approach and the existential-humanistic-phenomenological approach (Peterson 1999). These approaches represent different ways of making sense of mental distress and illness. The key assumptions of these models are summarised in Table 1.

**Table 1: Psychological Models**

	<b>Psychoanalytic</b>	<b>Cognitive-behavioural</b>	<b>Family Systems</b>	<b>Humanistic-existential-phenomenological</b>
<b>General psychology</b>	People are energy systems	People are information processing	People are products of their family	People choose and define their own existence

		systems		
<b>Psychopathology</b>	Problems result from the investment of energy in symptoms	Problems result from inappropriate thinking or learning	Problems result from family dynamics and the creation of an unhealthy homeostasis	Problems result from the failure of self-actualisation
<b>Intervention</b>	Treatment releases energy by encouraging insight	Treatment focuses on changing the environment and/ or thoughts	Treatment changes the family status quo	Treatment encourages authentic living

Adapted from Peterson (1999)

While these models take differing stances, there are core assumptions which they share. In coming to understand why a person has a mental illness, gaining an understanding of the events in a person's life and how they have reacted to those events is crucial under the all of psychological models. The personal meaning attributed by an individual to the circumstances of their own life is particularly important, rather than just the events alone. One way in which the psychological models are crucially different from the biomedical model is that psychological theorists tend to assume that mental abnormality and normality are continuous. This is because it is assumed that both normal and abnormal behaviour are produced by the same psychological mechanisms and therefore there is no discrete break between them (Peterson, 1999).

A further key distinction between the psychological approach to mental illness and the biomedical view is that individual differences are seen not in terms of biochemical factors underlying diagnostic categories, but in terms of individual psychological processes. Finally, approaches to treatment of mental illness are also crucially different under the psychological perspective, and clinical psychologists have developed interventions that aim to reduce distress by altering the psychological mechanisms which contribute to mental illness or to ameliorate the psychological consequences of experiencing mental illness. This is patently very different from the use of drugs which are the most common method of treatment under the biomedical framework.

### **Sociological approaches to mental illness**

Sociological perspectives on mental illness are crucially different from those of psychiatry or psychology. Each perspective has a differing view regarding the location of the primary cause of mental illness. (Tyrer & Steinberg, 2005). Although their particular viewpoints differ, both psychiatry and psychology regard the causes of mental illness to be fundamentally located



*within* the individual experiencing it and in this sense, internal. Sociological explanations look instead to environmental factors, and consider these external factors as being of greatest aetiological significance (Thoits, 1999). As we have seen in the earlier discussion about diagnosis, the presence of mental illness is, by and large, determined by the *social* behaviour of the sufferer. It is incontrovertible, therefore, that there are particular social aspects of mental illness which mark it out as fundamentally different to other types of (physical) illness.

Summarising the key sociological explanations of mental illness, the American sociologist Peggy Thoits presents three theories, namely Stress Theory, Structural Strain Theory and Labelling Theory (Thoits, 1999). Stress theory suggests that when events and strains accumulate in people's lives they can overwhelm people's abilities to cope. The theory argues that being overwhelmed by stress, pressure and difficulties sometimes simply becomes too much and symptoms of psychological disorder are generated as a result. Structural strain theory is similar but emphasises the distribution of stress. It holds that the ways in which societies are organized create general patterns of opportunity and risk for particular social groups. Under this theory, being a member of a less privileged and more economically disadvantaged group is regarded as a significant risk factor for mental illness. Labelling theory is based on the idea that people who are labelled as deviant, and treated as deviant become deviant. The sociological meaning of 'deviance' refers to the breaking of social norms. So, in the case of mental illness, the symptoms of psychological disorder are viewed as violations of social norms.

A number of comments can be made about these theories. Stress theory appeals to common sense. The idea of 'nervous breakdown' in the face of too much stress is one which has been said to be part of the common consciousness in relation to mental illness (Pickering, 2006). Although traditional biomedical psychiatry tends to assume primarily biochemical aetiology, the diathesis-stress model acknowledges the relevance of stress as a contributory factor (Bennett, 2006). The diathesis-stress model assumes that a person has a genetic or biological predisposition to mental illness and that stressful life events may act as a trigger which activates this vulnerability to bring about mental illness. Psychological approaches regard trauma and disturbance as being of critical importance in explaining the occurrence of mental illness. So, it appears that differing perspectives from both within and outside the professional discourse concur that 'stress' plays an important role in the evolution of mental illness.

Structural strain theory assumes that economic and social disadvantage increases the likelihood of experiencing mental illness. While there is some evidence that those from poorer

backgrounds are indeed at greater risk of developing a mental illness (DoH, 2006), it is demonstrably not the case that people from more privileged backgrounds are immune from mental illness all together. Pilgrim and Rogers (2005) show that certain types of mental illness are more associated with class disadvantage than others. It appears to be the case that psychotic disorders, such as schizophrenia, are more prevalent amongst poorer classes whereas affective disorders, such as depression and bipolar disorder tend to affect the middle classes more often (ibid.). However, it is important to note that greater prevalence of schizophrenia amongst the working classes does not necessarily mean that schizophrenia is in some way a product of being working class.

British writers use different language to describe similar perspectives, as well as identifying alternative sociological viewpoints on mental illness to those proposed by the American Peggy Thoits as discussed above. Anne Rogers and David Pilgrim authored *A Sociology of Mental Health and Illness* (Rogers & Pilgrim, 2005), an important text in this field in the UK. Rogers and Pilgrim identify four major sociological perspectives. These are social causation, critical theory, social constructivism and social realism. They mention labelling theory in addition, but consider this category in a separate chapter, suggesting that they regard it as being a category apart.

The social causation perspective essentially accepts the legitimacy of constructs such as 'schizophrenia' or 'depression' and considers them to be authentic descriptions of diagnoses of real illnesses. The focus of social causation is on questions derived from role of socially derived stress in the aetiology of mental illnesses. In this sense, this perspective has much in common with 'structural strain theory' described by Thoits. One of the emphases of social causation as explained by Rogers and Pilgrim is on tracing the relationship between social disadvantage as indicated by low social class or poverty. Studies investigating this relationship tend to be epidemiological in nature, looking at the distribution of mental illness in populations and examining relationships between mental illness prevalence and variables including not just social class indicators, but also race, gender and age. Rogers and Pilgrim identify a number of disadvantages of this approach, including that epidemiological studies primarily investigate correlations and correlations do not necessarily indicate causal relationships. It may be that there is a greater prevalence of mental illness amongst those who are economically disadvantaged, but that it is not to say that the economic disadvantage is necessarily the cause of mental illness.

Social constructivism is another sociological perspective summarised by Rogers and Pilgrim. The key tenet of social constructivism (sometimes called social constructionism) is the view that reality is not fixed, stable, self-evident and waiting to be revealed, but rather that it is a product of human activity and in this sense, constructed by humans. The anti-psychiatry arguments put forward by Thomas Szasz, described earlier in this section can be said to have their foundations in social constructivism. Under this framework then, mental illnesses are not 'natural kinds' - that is, an entity which is not random and is internally consistent (Zachar, 2000) but rather a socially created category.

The final sociological perspective put forward by Rogers and Pilgrim is that of social realism. Although the authors call it social realism, what they go on to describe is really a version of Roy Bhaskar's critical realist philosophy, which accepts that reality really does exist (unlike a strict constructionist view), but that it is divergent from social causationism. This perspective argues that "human action is neither mechanically determined by social reality nor does intentionality (voluntary human action) simply construct social reality. Instead, society exists prior to the lives of agents but they become agents who reproduce or transform that society." (Rogers and Pilgrim 2005, P.17). Critical realism contends that social science and natural science necessitate different methodologies and that social phenomena cannot be equated to natural phenomena even though social phenomena cannot exist without natural phenomena. Rogers and Pilgrim describe the implications of critical (social) realism for the field of mental illness. They say that because of the critical realist contention that social structures do not exist independently of the activity they govern, objective or impartial actions within the field of mental health work are untenable. Mental health work is embedded in wider social structures and because of this it is simply impossible for mental health practitioners to operate in a disinterested way. Rogers and Pilgrim explain that under this framework, social structures do not exist independently of people's conceptions of what they are doing in their activity. Because of this, the structure and organisation of mental health work is formed and influenced by the particular formulation of professional 'knowledge' by the people doing that work. A further important point is that mental health work is historically and geographically situated and must be understood specifically in terms of the context in which it is happening.

Sociological contributions to the field of mental illness are diverse. A major message to take from this discourse is that adverse social positioning of individuals who experience mental illness can be as disabling and debilitating as the illness itself.

## **The biopsychosocial model**

The above discussion has shown that biological, psychological and sociological explanations of mental illness each regard the phenomenon differently and place particular emphasis on one aspect of human life. In the late 1970s, the American psychiatrist George Engel published a paper in the journal *Science* (Engel, 1977) which posited the need for a new model for all types of illness which would incorporate all three dimensions, taking into account the particular relevance of each. He called this the 'biopsychosocial' model, and theorized that bodily, psychological and social factors were all significant in understanding health and ill health. This marked an attempt at a move away from the reductionist supremacy of the biomedical model and was based on the view that factors from all three domains influence the experience and course of a person's illness, and it is important to take them and the interactions between them into account when providing treatment and care. This sounds like a very sensible synthesis, acknowledging that all three perspectives can offer useful insights into the onset and course of illness. It seems to have particular relevance for mental illness, given, for example, the specific problems with viewing mental illnesses as diseases and the insights of critical realism. During the 1980s, the biopsychosocial model was embraced by the Institute of Psychiatry in the UK, to the extent that it has been described as becoming part of the psychiatric orthodoxy (Pilgrim, 2002).

However, the extent of the applied uptake of the biopsychosocial model cannot be taken for granted. Some writers and practitioners have actively rejected the adequacy of the model. For example, Tavakoli (2009) argues that the biopsychosocial model creates an artificial and ultimately confusing distinction between the biological and the psychological which he says is unhelpful in efforts to destigmatise mental illness. He goes on to say that arbitrary distinctions between organic and nonorganic should not be made, and that people are ultimately biological beings. This represents a view which overtly champions biological psychiatry and is resistant to accepting the importance of the interplay between factors which influence people's lives and their experience of mental illness.

Since the 1980s there has been a marked shift towards the applying the biopsychosocial model in one specific branch of mental health care. This area is dementia care, where new approaches have emerged, such as the person-centred approach (Kitwood, 1997), underpinned by biopsychosocial thinking. Adherents of these approaches view behaviour changes previously regarded as symptoms of underlying neurological impairment as comprehensible responses to the experience of living with dementia. From this perspective, so-called symptoms such as 'wandering' and 'challenging behaviour' can be addressed by

interpreting the meaning of behaviour rather than controlled with sedative medication. Crucially, biopsychosocial thinking has stressed how much behaviour is influenced by the way people are treated by others. Close observation of care settings reveals that numerous interactions take place in which people with dementia are disempowered and demeaned (Kitwood, 1990). So-called challenging behaviour frequently occurs in response to this treatment, and the overall experience of unfavourable social positioning (Downs & Bowers, 2008).

Biopsychosocial thinking appears to be less prevalent in the front-line care of people with functional mental illness than in organic mental illness such as dementia (Gabbard & Kay, 2001) and the equivalent growth of enthusiasm for psychosocial approaches to care has been slower. It has been argued that although the biopsychosocial model represented an important reaction against biomedical reductionism in its time, it has ended up being weakened by its eclecticism (Ghaemi, 2009). Ghaemi suggests that the widely employed rhetoric of the biopsychosocial model gives eclectic freedom which results in a paradox whereby psychiatrists and others enact their own dogmas, which usually results in them opting for more of the 'bio' and less of the 'psycho' and 'social.' Theoretical models which acknowledge the importance of social and psychological factors are useful, but as Read (2005) argues, employing rhetoric is one thing, whereas making changes in care systems is another. Read suggests that although biopsychosocial approaches to psychiatry are widely talked about, in practice this amounts to little more than lip-service, and biological hegemony continues to prevail. Read suggests that the psychosocial elements of the model are so marginalised in practising general psychiatry that it may as well be called the "bio-bio-bio model." Nonetheless, the biopsychosocial model is an important reminder that many factors influence behaviour, not just impaired biological processes which may be associated with mental illness.

### **Making sense**

This outline of some of the perspectives on mental illness from what I have called the 'professional discourses' shows that the question 'what is mental illness?' cannot be answered simply. The critiques of psychiatry offered by the anti-psychiatry and critical psychiatry movements show that mental illness is not only complicated, it is an issue fraught with political tensions. In addition, there is a danger that any discussion about 'mental illness' involves such a lack of specificity that it can be misleading or even meaningless; anorexia, substance abuse, schizophrenia and post natal depression are such vastly different human experiences that it may not make sense to treat them as one category. We have seen that the notion of mental illness provokes considerable interest from a range of academic and applied disciplines including psychology and sociology as well as psychiatry. In the real world, mental

illness has no existence outside the lived experience of those who have it. It seems probable that some mental illnesses have a biological dimension of some kind and it makes good sense to investigate this and look for suitable treatments. However, miracle cures seem unlikely in the treatment of mental illness and for many people with a diagnosis it is a recurring or chronic part of their lives. Living with mental illness inevitably has psychological and social consequences and for this reason it is clear that the three domains of psychiatry, psychology and sociology all have something to offer to understanding the lived experience. Furthermore, discrimination is irrefutably a social process rooted in group psychology, and it seems clear that appreciating that there are social, psychological and biological aspects to mental illness is essential when promoting non-discriminatory stances in relation to it.

### **2.1.2 What is mental illness to ‘us’? Public understandings**

*What we say about mental illness reveals what we value and what we fear*

Juli McGruder (2002)

The previous section has shown how mental illness and disorder are formulated, conceptualised and contested within what might be called the ‘professional’ discourse. This section asks ‘what is mental illness to ‘us’?’ where ‘us’ represents ordinary people. What I would like to have been able to do in this section is to explore how mental illness is understood and talked about by people that have neither a professional nor academic interest in mental illness. However, when I examined the literature addressing ‘lay’ understandings of mental illness, I discovered that although there was research which purports to describe ordinary people’s views, these perspectives were constrained by the terms of their own discourse. It may be that there is a body of literature examining people’s beliefs about mental illness more anthropologically, but if so, I was unsuccessful in identifying it. Therefore, this section will describe how lay understandings have been presented differently according to the particular ‘lens’ applied by those writing about them. Approaches to making sense of public understandings of mental illness include the ‘folk psychiatry’ model, and the mental health literacy approach, both of which will be explored in this section. Attitudes to mental illness and discrimination on mental health grounds will also be discussed. Before examining this literature, I will briefly consider how mental illness seems to play out in popular discourse.

#### **Mental illness in popular discourse**

That mental illness is heavily stigmatised and in some senses, taboo, is well established (Corrigan, 2006; Thornicroft, 2006). Stigma and taboo notwithstanding, it is also the case that the notion of mental illness generally as well as specific types of mental illness are firmly

entrenched in the fabric of day to day life in terms of ordinary experience (Pickering, 2006). In the introduction to his book *The Metaphor of Mental Illness* (2006), Neil Pickering proposes that the concepts or ideas of mental illness, and precise labels beneath that umbrella, like schizophrenia or ADHD are deeply ingrained in the language, institutions and constitutions of the UK as well as throughout the western world. Taking the example of the UK, Pickering points to common vernacular terms such as ‘nervous breakdown,’ relating directly to mental illness, along with other, more derogatory expressions such as ‘schizo’ and ‘psycho.’ Pickering describes popular factual accounts of the experiences of people who are mentally ill, including well known films, novels and autobiographies. He goes on to recall the “often vast buildings sometimes of nineteenth century origin in which the mentally ill were housed and treated” (Pickering 2006, p. 2), making the point they too are an element of the general consciousness about mental illness in society. Pickering draws attention to the way in which stories in the media have brought terms like ‘paranoid, schizophrenia’ and ‘posttraumatic stress disorder’ into the public eye and made these familiar expressions.

It has been suggested that the power and strength of the psychiatric discourse described in section 2.1.1 has taken hold amongst the general public (Tsao, 2009). The psychiatric notion that mental illnesses are ubiquitously rooted in genetic, physiological and neuroanatomical abnormalities has captured the public imagination. It is common for people to regard even quite mild forms of social deviance as being biologically based and pharmaceutically treatable. For example, it has become the norm to accept that an energetic child who finds it difficult to sit still for long periods of time and would rather run around than concentrate on their numeracy exercises has ADHD, and should be prescribed Ritalin. Other mental illnesses, like anorexia and bulimia are familiarised through widely publicised accounts of the experiences of prominent actresses or princesses – Pickering (2006) states Calista Flockhart and Princess Diana as examples.

So it becomes clear that however troublesome and slippery it may be for individuals, communities and societies, mental illness is a real phenomenon; a part of life which most people have awareness of as well as thoughts and feelings about.

### **Folk Psychiatry**

Folk psychiatry is the phrase used by the Australian psychologist, Nick Haslam to refer to his model for describing ordinary people’s understandings of mental illness (Haslam, 2003; Haslam, 2005; Haslam, Ban & Kaufmann, 2007). In setting out his four dimension model, Haslam identifies a need for an approach which considers ordinary people’s views in their own terms. He argues that the starting point for making sense of mental illness is the recognition that something is wrong. Haslam (2003) refers to this process as ‘pathologising’

and suggests that the thinking underpinning it is complex. In his view, it involves ideas such as viewing changes in a person's behaviour as uncommon, incomprehensible, internally caused (i.e. caused by something amiss within the person rather than by a social process or context) and seeing the person as a member of a broader social group of the mentally disordered. Acknowledging the complexities entailed in identifying that there is a problem is valuable, but in labelling this process as 'pathologising', and in associating it with internal causation, Haslam betrays a biomedical bias and undermines his claim that folk psychiatry allows lay people to express their understanding in their own terms.

Haslam's work on this topic resonates with an earlier study carried out in the US by Charlotte Schwartz. Schwartz (1957) interviewed 20 women whose husbands had been hospitalised for psychosis to investigate how they explained what was wrong with them. Her analysis showed that interviewees used three general frameworks of explanation which she labelled 'characterological', 'somatic' and 'psychological'. Haslam (2003) proposes three very similar explanatory dimensions, namely 'moralising', 'medicalising' and 'psychologising', and as he does not cite Schwartz, it appears that he arrived at them independently.

Schwartz's description of the characterological framework is that the wives regard their husbands' behaviour as being weak or lazy, and that they are responsible for it. This has similarities to the 'moralising' dimension of Haslam's folk psychiatry model. He explains that it involves responding to the behaviour as though it is a moral violation, which is the actor's own responsibility. In simple terms, the mentally ill person is judged to be 'bad.' In his discussion of the moralising dimension, Haslam references Conrad and Schneider's (1980) illustration of the many examples in the history of psychiatry of conditions which have first been considered as forms of immorality before becoming accepted as mental disorders. Substance abuse, addiction, psychopathy and homosexuality are cited as examples, with homosexuality being unique in that it has passed from immorality to disorder and then being reclassified again through a process of depathologising. Haslam suggests that for homosexuality and some other examples there remains a degree of ambivalence between moral and psychiatric stances in relation to deviant behaviour. Despite the main project of folk psychiatry being to provide a model of cognitions in relation to mental disorder, Haslam concedes that in the case of the moralising dimension, it cannot be reduced to its cognitive aspects, because it is rooted in societal and cultural contexts.

The second of Schwartz's frameworks – the somatic - involved the women interpreting their husbands' difficulties as being as a result of physical impairment or something being wrong



with the body. To 'medicalise' mentally ill behaviour, according to Haslam, is to consider that it is the product of some kind of bodily abnormality which is beyond the person's control and therefore analogous to any other type of disease. As we have seen earlier, contemporary psychiatry is dominated by the biomedical view, which undoubtedly influences how the general public think about mental illness. In keeping with his aim to build a cognitive model of public understandings of mental illness, Haslam argues that the medicalisation dimension is underpinned by a mode of thought which he says is best described as essentialist thinking. He explains that this type of thinking represents an ontological assumption that mental illness behaviour is the product of discrete natural kinds – i.e. fixed bodily aberrations.

Finally, Schwartz found that the women in her study also opted for explanation in psychological terms. Similarly, Haslam offers the 'psychologising' dimension of the folk psychiatry model. This is presented as being closely related to the moralising dimension in that both dimensions make reference to mental states and processes. Haslam argues that psychologising is fundamentally different from moralising because of its emphasis on explanation in terms of causes, whereas moralising centres on explanation in terms of reasons. He also makes the point that psychologising resembles medicalising in that it is concerned with causes, but the fundamental distinction here is that psychologised explanations represent these causes as being mental rather than somatic.

Haslam's work is situated in cognitive psychology, and he seems to assume that a particular tradition of thinking about thinking – Western epistemology – can adequately capture how all humans think. His model of folk psychiatry appears to be firmly rooted in Western medical approaches to mental disorder and may work well for the purpose of contributing to theory in cognitive psychology, but it could be argued that non-Western thinking is on another plane and cannot be adequately captured by his model. Certainly his attempts to assimilate conceptions of mental illness such as spirit possession to his model seem to obscure, rather than elucidate, the significance of alternative and possibly healthier ways of thinking about mental illness such as those described in Watters (2010).

Nevertheless, the folk psychiatry model has strengths. It is open to the idea that lay people actively construct their understanding of mental disorder, drawing upon cultural and other resources. Haslam's work recognises that the ways in which members of the public process the phenomenon of mental illness are multifaceted, meriting proper consideration and analysis. Furthermore it recognises that lay conceptions influence public attitudes to mental illness and also where, and how, people seek help. Haslam points out that discrepancies

between professional and lay conceptions get in the way of an alliance between “sufferers and those charged with treating them” (ibid., p. 621). Haslam is also explicit about the fact that his theoretical proposals are speculative and that further study may call his suggested dimensions into question.

### **Mental Health Literacy**

Another way of approaching what the public think about mental disorder has been framed as ‘mental health literacy.’ The term “mental health literacy” was introduced by the Australian psychologist Anthony Jorm and colleagues in 1997 (Jorm, Korten, Jacomb, *et al*, 1997). The idea of mental health literacy has since been taken up by other writers and expanded upon by Jorm himself, becoming a dominant framework for researching and writing about understandings of mental illness amongst the public (Burns & Rapee, 2006; Farrer, Leach, Griffiths, *et al*, 2008; Goldney, 2001; Jorm, 2000; Jorm, 2006a; Jorm, 2006b; Jorm, 2007; Lauber, 2003). A search for “mental health literacy” on the PubMed database revealed 125 published papers which contain the term, of which 49 included “mental health literacy” in the title.

In laying the foundation for their definition of mental health literacy, Jorm et al. provide Nutbeam et al.’s (1993) description of *health* literacy as follows: “the ability to gain access to, understand and use information in ways which promote and maintain good health”. They remark that while the importance of health literacy for physical wellbeing has been given significant attention, in the domain of mental health it has been comparatively neglected. Mental health literacy, then, is defined as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention.” (Jorm et al. 1997: p. 166). It is interesting first to note that this is an example of the euphemistic use of the phrase ‘mental health.’ Although mental ‘health’ literacy is defined as knowledge about *disorder*, it is not referred to as ‘mental disorder literacy.’ On the face of it, this definition may seem relatively value-neutral, but an examination of how the concept is further explained and utilised in research reveals that this is far from so.

In an article published in the British Journal of Psychiatry, Jorm (2000) states that mental health literacy consists of a number of components. These are

- “(a) the ability to recognise specific disorders or different types of psychological distress;
- (b) knowledge and beliefs about risk factors and causes;
- (c) knowledge and beliefs about self-help interventions;

- (d) knowledge and beliefs about professional help available;
- (e) attitudes which facilitate recognition and appropriate help-seeking; and
- (f) knowledge of how to seek mental health information.” (Jorm 2000: p.396).

The first of these components is essentially concerned with the extent to which members of the public are able to operationalise the diagnostic strategies of the psychiatric profession that we have just explored. Much of the research derived from Jorm’s definition of mental health literacy focuses on this first component and it is this notion of ‘recognition’ which has really come to dominate the use of the literacy concept.

In Jorm et al.’s original (1997) study, recognition of depression and schizophrenia from vignette descriptions of the two conditions were assessed. The same instrument for assessing recognition of schizophrenia and depression was used in a study by Goldney et al. (2001). Similarly, Lauber (2003) carried out a study in Switzerland which aimed to determine whether the public were able to recognise a person depicted in a vignette as either mentally ill or experiencing a crisis. The vignettes used in this study are unfortunately not presented in Lauber’s paper although it is explained that two vignettes were used – one depicting depression and the other portraying schizophrenia. A survey of 844 participants was conducted, in which the vignettes were read and half of the sample were asked whether the person depicted therein was *either* suffering from a ‘mental illness’ or ‘experiencing a crisis.’ One problem with this mode of questioning is that the closed questioning style insists that respondents choose one of the two conditions. It also overlooks the possibility that an individual may consider that suffering from a mental illness is an experience which could *itself* be described as a crisis – the two conditions provided as possibilities are not necessarily mutually exclusive. However, the main point I would like to make about this study is that it, like all mental health literacy research, aims to measure the degree to which members of the public are familiar with and endorse professional knowledge about specific mental disorders.

Studies which investigate the extent to which laypeople are able to ‘recognise’ disorders are using the notion of recognition in terms defined by their own dominant understandings. The emphasis on ‘correct’ recognition of specific disorders amounts to an assessment of the extent to which the beliefs and understandings of members of the public correspond to those held by professionals. The view overlooks the possibility that it could be entirely appropriate for laypeople to conceptualise mental disorder differently to those in the profession and doing so doesn’t necessarily amount to ‘illiteracy’ on their part. Given the controversies and complexities surrounding the definitions and understandings of mental illness within the

professional discourse, there are good reasons to suggest it would be wholly reasonable and very likely that non-professional people may construct their own intersecting ‘literacy.’

Published criticism of the mental health literacy approach to understanding lay beliefs about mental illness is sparse but not entirely absent. Gattuso, Fullagar and Young (2005) are sceptical about the ‘literacy’ approach, particularly in relation to women’s beliefs about depression, arguing that it takes insufficient account of women’s belief structures. They describe mental health literacy as “unsophisticated one way models of communication in which individuals are supposed to ‘absorb’ correct health messages. People who refuse to take up the expert view of depression as illness can only be seen as non-compliant, ignorant, or, in the dominant discourse, “illiterate.” (ibid, p. 1642). Read et al. (2006) are also critical, saying that ‘mental health literacy’ is a term “coined to describe the degree of belief in biogenetic explanations and the ability or willingness to apply diagnoses.” (p.305).

Aside from recognition of disorders, the remaining components of mental health literacy as defined by Jorm are also derived from a perspective which puts the views of the professional into pole position. The second component – knowledge and beliefs about risk factors and causes – implies in using the idea of ‘knowledge’ that there is a truth to be reached and that literacy in this context is determined by the extent to which the public concur with what is regarded as ‘correct’ in this respect. Similarly, the public’s knowledge of the help available to them – whether self-help or professional help -implies that the ‘experts’ who propose this model ‘know’ definitively what this help is: again, that there is a ‘right’ answer with which the public are either literate or not. The fifth component of the literacy component is to do with “attitudes which facilitate recognition and appropriate help-seeking.” That the help-seeking mentioned in this component is delineated explicitly as “appropriate” is a clear indicator of the value-laden nature of it. Who determines what appropriate help-seeking is? The implication is that what is deemed appropriate is for the individual to request the services of mental health professionals or to engage in self-help strategies deemed to be appropriate by those professionals. The overriding problem with all of the components of the mental health literacy approach is that it presents the public’s understandings of mental disorder from the standpoint of professional knowledge rather than making it possible for understandings to be considered in their own terms. The mental health literacy concept assumes a collective body of unanimously held knowledge against which all other bodies of knowledge are measured. This is ironic given the lack of unanimity and prevalence of controversy in psychiatry itself, as demonstrated in section 2.1.1. However it is perhaps not surprising that it is the conventions

of the biomedical approach that are represented and upheld by the mental health literacy model.

### **Attitude to mental illness**

Mental health literacy and folk psychiatry offer two explicit models for approaching the public's understandings and beliefs about issues relating to mental illness. In addition to these approaches, there is a body of research which uses epidemiological surveys investigating the public's attitudes to mental illness. Attitudes represent a person's tendency to respond to an object positively or negatively according to their personal predisposition (Ajzen & Fishbein, 2000; Petty, Wegener & Fabrigar, 1997). If mental illness is the object in question, the principle purpose of attitude research is to establish the degree of positivity or negativity held by individuals towards others with mental illness.

In a review of population surveys investigating public attitudes to mental illness, Angermeyer and Dietrich examined a total of sixty one published studies taking place between 1990 and 2004 (Angermeyer & Dietrich, 2006). These studies employ a range of different survey based measures for assessing public attitudes, a common method being the presentation of a vignette describing a particular mental illness based on DSM-IV diagnostic criteria, followed by a series of attitudinal statements which the respondent has the opportunity to agree or disagree with to varying degree (i.e. Dietrich et al. 2004; Hall et al. 1993; Link et al. 1999). Other surveys ask respondents to respond to attitude statements or social distance statements based not on a vignette description but on a diagnostic label alone (Paykel, Hart & Priest, 1998; Stuart & Arboleda-Florez, 2001).

In their review, Angermeyer and Dietrich (2006) summarise the key findings of fifteen years of attitude research based on a meta-analysis of the sixty one studies they examined. They conclude that the majority of the public consider others with mental health problems as being in need of help and this is interpreted as evidence of pro-social, positive attitudes. However, alongside this finding, it is reported that a substantial proportion of laypeople perceive those with mental illness as being unpredictable and dangerous. Fear is a common reaction and there is "an observable tendency to distance oneself from people with mental disorders." (Angermeyer and Dietrich, 2006, p. 174). The strong link in the public imagination between mental illness and dangerousness is one of the elements which contributes significantly to members of the public having negative or discriminatory attitudes towards others with mental illness (Corrigan, River, Lundin, *et al*, 2000).

Where specified disorders are researched, Angermeyer and Dietrich report that “people with schizophrenia or alcoholism are more frequently considered as unpredictable and violent than people with depression and anxiety disorders.” However, many of the studies investigate public responses to ‘mental illness’ or ‘mental disorder’ in general, which may well be misleading, given the substantial differences between one mental illness and another, not to mention the fluctuating quality of most mental illnesses. These studies often ask respondents to make judgements based on the phrase ‘mental illness’ and it is not known how this term is understood by individual respondents. Rogers & Pilgrim (2005) suggest that lay people tend to spontaneously view ‘mental illness’ as referring principally to psychotic or unintelligible behaviour, although there is little in the way of empirical evidence to support this suggestion. Terms such as ‘stress’ and ‘depression’ refer to states which are seen by many members of the public as part of normal existence and not necessarily belonging to the category ‘mental illness’ (Pilgrim & Bentall, 1999). If it is true that most people understand ‘mental illness’ to mean more extreme (mad) behaviours which come under its umbrella, it may also follow that fear and social distancing responses do not apply to other less extreme experiences which belong in the (medical) category of mental illness, such as depression. However, little research has been done to investigate these types of differences, and the potential for enormous discrepancies in understandings of terms used in attitude studies investigating public responses to mental illness calls the validity of such studies into question.

One of the broad impressions given by these quantitatively based surveys of public attitudes to mental illness is that lay epidemiologies tend to locate the causes of mental disorder in psychosocial rather than biomedical explanations (Angermeyer & Matschinger, 1994; Brockington, Hall & Levings, 1993; DoH, 2006; Furnham, 1992; Furnham, 2004). It is often the case that this difference between lay and professional views on aetiology is interpreted by those conducting the studies as evidence of a lack of knowledge rather than being given credence as a valid perspective, in line with the principles of the mental health literacy approach (Hugo, Boshoff, Traut, *et al*, 2003; Lauber, Nordt, Falcato, *et al*, 2004; Watson, Otey, Westbrook, *et al*, 2004). However, that the public express a tendency to reject biomedical explanations of mental illness should be taken seriously, particularly in relation to efforts to counter stigma and discrimination (Read, 2007; Read, Haslam, Sayce, *et al*, 2006).

So, what is mental illness to ‘us,’ the public? The mental health literacy approach regards the public’s views on mental illness in terms of the extent to which a particular professional perspective (the biogenetic model) is endorsed. Folk psychiatry suggests cognitive dimensions along which lay people make meanings to explain mental illness. Attitude research shows that

while fear and social distancing are common responses to the abstract idea of ‘mental illness,’ this is sometimes accompanied by empathy and understanding. In considering how ordinary people make sense of mental illness, it is important to remember that the ‘public’ or ‘laypeople’ are not a homogenous mass – they are individuals each with their own set of experiences and values. The ways in which individuals respond to surveys designed to measure their mental health literacy, or those enquiring as to their ‘attitude’ to mental illness are most likely to be rather different from the ways in which they respond to real people whom they encounter in their everyday lives.

### **2.1.3 What is mental illness to ‘me’? Personal representations**

*All you have to lose is one connection and the mind uncouples.*

Kay Ryan (2000)

What emerges from the professional discourse on mental illness, and representations of the public’s understandings of mental illness is that this is a complex phenomenon, understood in a range of sometimes conflicting ways, depending on the perspective adopted. In short, mental illness is difficult to pin down. While an examination of some of the key issues in describing and defining mental illness from these sources begins to shed some light on the abstract question ‘what is mental illness?’, a more ingenuous answer might be reached by looking to accounts of the experience of mental illness as described by those who have experienced it. The perspectives of those who have first-hand experience of mental illness are easily overlooked and in an attempt to answer the question ‘what is mental illness?’ it would be remiss to completely ignore the possibility of answering this question from a subjective, personal angle. Therefore this section is included, and will present and examine some examples of how writers who have attempted to describe their own mental illness do so. However, it is important to point out that these authors accounts are rooted in their own experience of one particular mental illness and are not always discussing mental illness in general.

There is no dearth of first hand accounts of mental illness in literature, and critical examination of these types of accounts is a field attracting increasing attention. The American professor of psychology, Gail Hornstein, has a particular interest in mental illness narratives and has compiled a bibliography of over 600 first person accounts of madness written in English . Hornstein has also recently published a book which uses these accounts to explore meanings of madness (Hornstein, 2009) as well as a study examining how subjective experiences of madness are presented in first person accounts in terms of narrative structure (Adame & Hornstein, 2006). Other writers have collected and anthologised first hand

accounts of the experience of mental illness which appear in a number of edited volumes (for example Barker, Campbell & Davidson, 1999; Gray, 2006; Read & Reynolds, 1996). The subject of mental illness narratives, therefore, is a research field in its own right and it is beyond the scope of this thesis to go into a great deal of detail on the topic. The sheer volume of published accounts of mental illness is demonstrated by Hornstein's bibliography, so necessary selectivity was inevitable in compiling this section, not only in selecting accounts to present, but also in which aspects of those accounts to consider.

Three primary sources will be drawn upon – two written memoirs, plus artwork depicting the experience of mental illness. It is coincidental that all three accounts I include come from women. The writers which have been selected for this purpose are Elyn Saks and Kay Redfield Jamison. Elyn Saks is an American professor of law and psychiatry at the University of Southern California Gould School of Law. She has a diagnosis of schizophrenia, and in 2007 published a memoir which describes her experiences of psychotic illness, *The Centre Cannot Hold* (Saks, 2007). Kay Redfield Jamison is professor of psychiatry at the John Hopkins University School of Medicine and has a diagnosis of bipolar disorder. She also published a memoir of her illness, *An Unquiet Mind* (Redfield Jamison, 1996). Both Saks and Jamison are in some ways exceptional in that they are successful academics who are outstanding professionally, able to make full and meaningful contributions despite their lives being punctuated with episodes of mental illness. Saks herself comments that “crazy people don't make the evening news for successfully managing their lives” (Saks, 2007, p. 267) and it is partly for this reason that I have chosen to present these particular portrayals of their experiences of living with mental illness. In addition, both authors bring both personal and professional understandings to their work. Excerpts from the memoirs will be considered with two questions in mind. Firstly, what is the experience of mental illness actually like? In all the preceding discussion about professional and public discourses on mental illness, this experiential description is completely missing. Secondly, what effects does mental illness have on a person's life? The artworks which are included come from the British artist Bobby Baker. Baker studied fine art at St Martin's in London, graduating in 1972 and going on to have a very successful career as a performance artist. She began experiencing mental health problems which impinged on her daily life in 1994, admitting herself to a day centre and later being diagnosed with borderline personality disorder.



### What is mental illness like?

At the age of 15 or 16, Elyn Saks experienced what she went on to describe as the first real, clear sign of the types of experience which later led to her diagnosis of schizophrenia. She describes this first experience as follows:

“One morning in class, I suddenly decided that I needed to get up, leave school, and walk home. Home was three miles away. As I walked along I began to notice that the colors and shapes of everything around me were becoming very intense. And at some point, I began to realise that the houses I was passing were sending messages to me: *Look closely. You are special. You are especially bad. Look closely and ye shall find. There are many things you must see. See.*

I didn't hear these words as literal sounds, as though the houses were talking and I were hearing them; instead, the words just came into my head – they were ideas I was having. Yet I instinctively knew they were not *my* ideas. They belonged to the houses, and the houses had put them in my head.” (p. 27).

Hearing voices, or in medical language ‘auditory hallucinations,’ is an experience associated with schizophrenia, but Saks’s experience of the illness was not quite like this, and the above excerpt shows how she had a qualitatively different sensation of *thoughts* (rather than voices) coming into her head from outside. The description she gives is clear, and for the reader who has not had a comparable experience, this particular rendition of it is illustrative and illuminating. At other points in Saks’s memoir, though, it seems that describing psychotic experience in such specific and precise terms is not always possible, as the following excerpt demonstrates:

“I began to be regularly invaded by the strangest fantasies, very intense and hard to escape – they weren't exactly hallucinations or waking dreams, but they were extremely vivid and, for me, not entirely distinguishable from reality. They'd come out of the blue, with no warning, and no reason that I could understand... ... Whole hours would go by at night when I was stuck in this alternative universe, struggling to decipher what was going on inside my head. Scenarios came and went of their own accord- it was like being unable to get out of the theatre while demented movies ran all night.” (p. 48)

Here there is a sense in which Saks is struggling to find satisfactory language to describe her experience. She uses the word “fantasies” to explain what was happening to her, but she gives the impression that this isn’t quite adequate by also saying the fantasies were *not* hallucinations and *not* waking dreams. In this passage the strangeness of what was happening to Saks is expressed, but the particularity of what that experience might actually feel like comes across rather more flimsily than in the previous excerpt. Elsewhere in her memoir, Saks gives a vivid impression of herself during episodes of psychosis by presenting pieces of dialogue in which she speaks in ‘word salad,’ jumbling her speech with word associations. For example:

“ “What’s going on?” Berryman asked.

“There’s cheese and there’s whizzes,” I told him. “I’m a cheese whiz. It has to do with effort and subliminal choice. Vertigo and killing.”

Berryman’s voice was calm, “You sound as if you’re not feeling too well,” he said.

“Your friends are worried about you.”

“Oh they’re nice. Do you like spice? I ate it thrice. They’re all hurting me! They’re hurting me and I’m scared!” ” (p.177).

Kay Redfield Jamison’s first experience of bipolar disorder, like Saks’ first psychotic experience, took place during her adolescence. She describes her first manic episode as follows:

“ I raced about like a crazed weasel, bubbling with plans and enthusiasms, immersed in sports and staying up all night, night after night, out with friends, reading everything that wasn’t nailed down, filling manuscript books with poems and fragments of plays, and making expansive, completely unrealistic plans for my future. The world was filled with pleasure and promise; I felt great. Not just great, I felt *really* great. I felt I could do anything, that no task was too difficult. My mind seemed clear, fabulously focused, and able to make intuitive mathematical leaps that had up to that point entirely eluded me. Not only did everything make perfect sense, but it all began to fit into a marvellous kind of cosmic relatedness. My sense of enchantment with the laws of the natural world caused me to fizz over, and I found myself buttonholing my friends to tell them how beautiful it all was.” (p. 37).

The mania portrayed here seems to be a sparkling, exciting and pleasurable experience. The joyful side of her manic episodes is further expressed later in Jamison’s memoir:

“The ideas and feelings are fast and frequent like shooting stars, and you follow them until you find better and brighter ones. Shyness goes, the right words and gestures are suddenly there, the power to captivate others a felt certainty. There are interests found in uninteresting people. Sensuality is pervasive and the desire to seduce and be seduced irresistible. Feelings of ease, intensity, power, well-being, financial omnipotence, and euphoria pervade one’s marrow.” (p. 67).

As Jamison continues with her account of how she experiences mania there is a sense of a tipping point, at which the pleasantness dissipates, and the experience becomes all together more frightening:

“The fast ideas are too fast, and there are far too many; overwhelming confusion replaces clarity. Memory goes. Humor and absorption on friends’ faces are replaced by fear and concern. Everything previously moving with the grain is now against – you are irritable, angry, frightened, uncontrollable, and enmeshed totally in the blackest caves of the mind. You never knew the caves were there. It will never end, for madness carves its own reality. It goes on and on, and finally there are only others’ recollections of your behaviour – for mania has at least some grace in partially obliterating memories.” (p. 68).

As well as periods of mild and severe mania, Jamison’s illness involves periods of acute depression. She describes her first experience of the depressive phase of her illness as follows:

“The bottom began to fall out of my life and mind. My thinking, far from being clearer than a crystal, was tortuous. I would read the same passage over and over again, only to realise that I had no memory at all for what I had just read...” (p. 37).

“Each day I awoke deeply tired, a feeling as foreign to my natural self as being bored, or indifferent to life. Those were next. Then a gray, bleak preoccupation with death, dying, decaying, that everything was born to die, best to die now and save the pain while waiting. I dragged exhausted mind and body around a local cemetery, ruminating about how long each of its inhabitants had lived before the final moment. I sat on the graves writing long, dreary, morbid poems, convinced that my brain and body were rotting.” (p. 38).

Later in her memoir, Jamison further describes her experiences of depression with stark precision:

“Depression is awful beyond words or sounds or images. It bleeds relationships through suspicion, lack of confidence and self-respect, the inability to enjoy life, to walk or talk or think normally, the exhaustion, the night terrors, the day terrors. There is nothing good to be said for it except that it gives you the experience of how it must be to be old, to be old and sick, to be dying; to be of slow mind; to be lacking in grace, polish and coordination; to be ugly; to have no belief in the possibilities of life, the pleasures of sex, the exquisiteness of music, or the ability to make yourself and others laugh.” (p.217)

She goes on to make the distinction between the experience of deep clinical depression and ‘ordinary’ low mood associated with life’s undulations:

“Others imply that they know what it is like to be depressed because of they have gone through a divorce, lost a job, or broken up with someone. But these experiences carry with them feelings. Depression, instead, is flat, hollow and unendurable. It is also tiresome. People cannot abide being around you when you are depressed. They might think that they ought to, and they might even try, but you know and they know that you are tedious beyond belief; you’re irritable and paranoid and humourless and lifeless and critical and demanding and no reassurance is ever enough.” (p. 218).

These excerpts from written memoirs about what mental illness feels like give the reader some tools for imagining what those experiences may be like. The artist, Bobby Baker expresses her experience of mental illness not in writing but through a series of diary drawings, which ‘speak’ to the observer in a different manner. After being referred to a therapeutic day centre in the face of severe depression and self-harming (later diagnosed as borderline personality disorder), Baker resolved to draw a diary entry picture on a daily basis. A selection of her drawings taken from diaries 1997-2008 appeared in an exhibition at the Wellcome Trust in 2009. Three examples of her pictures are shown here, by way of contrast with the verbal accounts of mental illness already presented.

The first image is a self portrait, which seems to illustrate the feeling of an inner, tortured world concealed behind the relatively ordinary visage seen by the rest of the world:



This next image is titled “running away from depression” and has a cartoon-like craziness about it, the artist showing herself with six legs. The sadness in the position of her eyebrow, and grim-set of her mouth show clearly that this feeling is no joke, however, and the image vividly conveys the precariousness of her experience of being mentally ill.



In the third image Baker shows herself contorted under the weight of the torrents of tears streaming from her eyes. She paints herself literally bending over backwards, and upside down, and the image expresses a sense of acute disruption.



Baker's diary drawings offer a different type of answer to the question "what is mental illness?" Like Saks' and Jamison's memoirs, her paintings are particularised and entirely personal, acting as a window into her unique experience of mental illness, showing the observer how it felt to her. The diary drawings offer a discrete type of insight, distinct from the written memoirs. The pictures elucidate the mental illness experience aesthetically, arguably illustrating the feeling of that experience more directly than it would be possible to articulate in words.

### **What effects does mental illness have on a person's life?**

Living with a mental illness is obviously very different for one person than for another, depending on the circumstances of their life, the particular illness they have and the particular way in which that illness is manifested.

Saks describes how living with mental illness interrupts the flow of 'normal' life:

"Dropping in and out of your own life (for psychotic breaks, or treatment in a hospital) isn't like getting off a train at one stop and later getting back on at another. Even if you can get back on (and the odds are not in your favor), you're lonely there. The people you boarded with originally are far, far ahead of you, and now you're stuck playing catch up." (p. 266).

For Saks, the impact of living with schizophrenia is felt particularly keenly in relation to developing relationships with others. She explains:

“A key part of forming a friendship is sharing personal histories, which can be a precarious rite when you’re schizophrenic. The gaps in your life – how do you explain them? You can always make up stories, but beginning a friendship with a lie about your life doesn’t feel very good. Or you can say nothing about how you’ve spent the last few years, which strikes people as odd. Or you can choose to tell them about your illness, and find out the hard way that most people aren’t ready to hear about it. Mental illness comes with stigma attached to it, and that stigma can set off a negative reaction, even from the nicest people, with good intentions and kind hearts. Even for many of these people, those with mental illness are *other*; they’re not like “us.”” (p.266).

The difficulties presented by talking openly to others about having a mental illness are shared by Jamison:

“There is no easy way to tell other people that you have manic-depressive illness; if there is, I haven’t found it. So despite the fact that most people that I have told have been very understanding – some remarkably so – I remain haunted by those occasions when the response was unkind, condescending, or lacking in even a semblance of empathy.” (p. 199).

Writing about one particular relationship with a colleague, Jamison explains how telling people about her illness is somehow necessary for relationships to move beyond anything but a superficial level:

“After some time, I began to feel the usual discomfort I tend to experience whenever a certain level of friendship or intimacy has been reached in a relationship and I have not mentioned my illness. It is, after all, not just an illness, but something that affects every aspect of my life: my moods, my temperament, my work, and my reactions to almost everything that comes my way. Not talking about manic-depressive illness, if only to discuss it once, generally consigns a friendship to a certain inevitable level of superficiality.” (p. 200).

Both writers illustrate that there are practical and personal implications of having a mental illness. Saks also describes how having schizophrenia impacts on her sense of herself as a person:

“Who was I, at my core? Was I primarily a schizophrenic? Did that illness define me? Or was it an “accident” of being – and only peripheral to me rather than the “essence” of me? It’s been my observation that mentally ill people struggle with these questions perhaps even more than those with serious physical illnesses, because mental illness involves your mind and your core self as well. A woman with cancer isn’t Cancer Woman; a man with heart disease isn’t Diseased Heart Guy; a teenager with a broken leg isn’t The Broken Leg Kid. But if, as our society seemed to suggest, good health was partly mind over matter, what hope did someone with a broken mind have?” (p236).

This passage illustrates some of the existential challenges thrown up by living with a severe mental illness like Saks’s. Jamison confronts similar issues, asking herself at the end of her book whether she would be cured from manic depression if she had the choice. Having described within her memoir how vitally important drug treatment with lithium has been for her (saying she feels sure she would be either dead or insane without it), Jamison only feels able to answer the question on the assumption that lithium is available to her. Assuming that it is, she says that “strangely enough” she would choose to have the illness. She explains why:

“Because I honestly believe that as a result of it I have felt more things, more deeply; had more experiences, more intensely; loved more, and been more loved; laughed more often for having cried more often; appreciated more the springs, for all the winters; worn death “as close as dungarees,” appreciated it – and life – more; seen the finest and the most terrible in people, and slowly learned the values of caring, loyalty and seeing things through.” (p.218)

As she writes, it becomes clear that she is writing about her whole life, and that a life without bipolar disorder is perhaps unimaginable to her; her sense of self is inseparable from the life that she has lived and her ‘illness’ is in a way integral to who she is. She goes on,

“I have run faster, thought faster and loved faster than most I know. And I think much of this is related to my illness – the intensity it gives to things and the perspective it forces on me.” (p. 218).



The excerpts from Saks's and Jamison's memoirs along with Baker's drawings presented here are really only snapshots of the narratives of mental illness they each tell, but including them here gives at least an impression or indication of the subjective reality of mental illness, something which sections 2.1.1 and 2.1.2 were not able to do. Professional discourse leaves little space for inclusive understandings of individuals' complex experiences of suffering, coping, recovering and making sense of mental illness in the context of their everyday lives. While the idiographic accounts included here cannot give an absolute answer to the question 'what is mental illness?' they certainly offer an additional, compelling perspective.

#### **2.1.4 Living with mental illness - discrimination in practice**

Both Saks and Jamison make reference to being treated differently on account of their mental illnesses in terms of interpersonal relationships. However, as successful academics, neither Saks nor Jamison has experienced the extremes of social exclusion which many less advantaged people with mental illness face. There is a substantial body of literature which provides evidence of differential treatment amounting to discrimination faced by people with mental illness, across many aspects of their lives. This discrimination can lead to loss of opportunity in housing, education, employment and personal relationships (Corrigan, 2006; Crisp, 2004; Thornicroft, 2006) as well as unfair treatment in relation to immigration, health care, insurance and parental rights (Sayce, 1998). Some of these forms of discrimination are put into effect by way of legal or policy structures, examples of which are given below.

In the UK, an MP will automatically lose their seat in parliament if they are sectioned under the mental health act, although if they are unable to perform their duties due to a serious physical illness (i.e. a stroke) no such expulsion would occur (Mental Health Act, 1983). Furthermore, law which derives from the reign of Elizabeth the First still stands which prevents from "lunatics" from either standing as an MP or voting in elections. Foreign nationals arriving in the United States are asked on a visa waiver form whether they have a mental disorder. The mental disorder category appears alongside a raft of other undesirable characteristics including terrorist activities and espionage. Although a process of investigation may conclude that a person admitting to mental disorder may be granted permission to enter the country, the policy of stopping the 'insane' from entering remains in place (Immigration and Nationality Act, 1952) – clear evidence of prejudice towards those with mental illness.

Discrimination on mental health grounds also operates on more personal levels, within the community. Verbal and physical abuse because of mental health problems is relatively common. Read and Baker (1996) found that 47% of the 778 people they surveyed had been

either verbally or physically harassed in public because of their mental illness. Fourteen percent had been physically attacked, for example having eggs thrown at them while being called a “nutter,” having dog faeces put through their letterbox or being spat at in the street. Personal relationships are also affected by mental illness. People with depression report that their ‘mate value’ was lowered by their illness, meaning that they felt there were fewer people they could realistically have as friends (Kirsner, Figueredo & Jacobs, 2003). Those with schizophrenia seem to have smaller social networks than others and tend to have friendships which are more dependent than interdependent (Buchanan, 1995). For people who have spent long periods of time in hospital for mental illness, it is common that social contacts are largely with other service users and with staff providing services (Dunn, O’Driscoll, Dayson, *et al*, 1990). Intimate relationships and marriage prospects also seem to be affected by mental illness, and research investigating the experience of people with schizophrenia found that in Europe, the diagnosis reduces a person’s chance of getting married (Thornicroft, Tansella, Becker, *et al*, 2004).

There is also widespread evidence that having a mental illness diagnosis results in reduced opportunities in the workplace, both in terms of getting and keeping a job (Boardman, Grove, Perkins, *et al*, 2003; Corrigan & Lundin, 2001; Glozier, 2004; Repper & Perkins, 2003). Reasons for this include that employers discriminate against applicants who disclose a diagnosis of mental illness. In a study of employers in the UK, fewer than 40% of those responding said that they would consider employing a person with a history of mental health problems (Social Exclusion Unit, 2004). One study found that employers perceive depression as being likely to be linked with poor performance at work, and are more off put by this factor than the possibility of absenteeism (Glozier, 1998). It is not clear whether the concern about low productivity is founded purely on prejudice, or contains some truth. An American study found that people with major depression displayed impaired ability to focus on tasks at work which was equivalent to 2.3 days lost to work each month (Wang, Beck, Berglund, *et al*, 2004). However, there is strong evidence that being employed promotes good mental health, helps people with mental illness to recover and restore meaning to their lives (Mental Health Foundation, 2002; Rogers, 1995; Warr, 1987). Furthermore, with the implementation of reasonable adjustments, including the flexibility to work at home, there is contrasting evidence from the UK that having a mental health problem need not interfere with overall productivity (Irvine, 2008). Despite most people with mental illness wanting to be in employment, only 20% are in paid work (Social Exclusion Unit, 2004). The most common way of describing the combined effect of these negative impacts of having a mental illness is in terms of *stigma*. The

following section will describe how stigma has been conceptualised, and identify some difficulties in the use of the stigma concept.

### **Conceptualising stigma**

The concept of stigma in general is explored thoroughly by Erving Goffman in his 1963 volume, *Stigma: Notes on the Management of Spoiled Identity*. Goffman describes stigma as resulting from an attribute which is deeply discrediting. The recognition of this attribute by others leads the person to be regarded as no longer whole or usual, but reduced to being a tainted or discounted person. Goffman presents stigma as being the product of a relationship between a particular attribute and the stereotypes held about that attribute.

Jones and colleagues (Jones, Farina, Hastorf, *et al*, 1984), built on Goffman's work to develop a conception of stigma with six dimensions. Under their framework, stigma occurs when the 'mark' links the person to undesirable characteristics which are discrediting. The dimensions of stigma they propose are concealability; course; disruptiveness; aesthetics; origin and peril. Concealability refers to the extent to which the characteristic responsible for the stigma can be hidden from others. Course describes whether it is possible for the stigmatising condition to get better or go away over time. Disruptiveness is the degree to which the stigmatising condition places strain on relationships and interactions with others. Aesthetics is concerned with whether the difference results in a reaction of disgust or is perceived as unattractive. Origin refers to the cause of the condition and whether the individual is perceived as being responsible for it. Peril is about the extent to which the difference provokes feelings of threat or danger in others. This framework may be a helpful aid to understanding the mechanics of stigma.

Link and Phelan (2001) have expanded this, specifically in relation to mental illness stigma, offering the following definition of stigma: "the co-occurrence of its components: labelling, stereotyping, separation, status loss and discrimination." (Link and Phelan, 2001, p. 363). Link and Phelan's model regards stigmatisation as a process in which a person is labelled with a difference that has social relevance. This labelled difference is then linked to inauspicious characteristics. The social label makes it possible to separate "us" from "them" and the labelled person or group of people can then be regarded as being fundamentally different from everyone else. Once an individual has been labelled, stereotyped and separated in this manner, a foundation has been established which allows them to be devalued and excluded.

Corrigan (2006) proposes an approach in which stigma is categorised as either public stigma or self stigma. Public stigma describes the public's attitudes towards others with mental illness,

whereas self stigma refers to people's own stigmatisation of themselves on the basis of their mental illness. Within both categories, Corrigan describes stigma as being composed of three components, namely stereotype, prejudice and discrimination. He explains that stereotypes are knowledge structures (beliefs) which are learned by members of a social group and are efficient means of categorising information about groups of people. Stereotypes about people with mental illness include that they are dangerous, incompetent and weak minded (Corrigan, River, Lundin, *et al*, 2000). Although people may know about a set of stereotypes about a particular group of people, not everybody necessarily agrees with them. However, some people will agree with stereotypical ideas and this endorsement of stereotypes is prejudice. Discrimination is the behavioural response which may be the result of prejudice.

### **Problems with 'stigma'**

The notion of stigma, then, very much dominates the discourse about the unfair treatment experienced by people with mental health problems. However, there have been a number of important criticisms levelled at the use of stigma as a conceptual framework for discussing the negative effects of having a mental illness. Liz Sayce explains how stigma is problematic because it locates the problem within the person with the mental illness (Sayce, 1998). This has the effect of individualising what is really a social problem (Harper & Vakili, 2008). The notion of stigma carries with it the implication that there is something inherently discreditable about the person in receipt of it and this means that blame is lodged outside the hands of the stigmatiser. Sayce argues that the 'mark of shame' which stigma represents ought not to be attached to the mental health service user but instead with the people who behave unjustly towards them. Sayce goes on to assert that the questions raised here are not merely semantic and that different conceptual models actually carry great power in terms of understandings about where responsibility ought to lie.

Sayce illustrates this with the example of racism. Using the term 'racism' means that attention is concentrated on the collective and individual perpetrators of discrimination, which allows for solutions which are based on challenging racist ideas and actions. If the same phenomenon was instead conceptualised in terms of the *stigma* of being black, attention would be shifted to the self-image of the black person. In this case, solutions might focus on helping black people to have improved self confidence and to liberate themselves from feeling inferior or insecure. It has been suggested that the lack of language to describe discriminatory treatment of people with mental illness is one reason why the use of 'stigma' prevails (Byrne, 2001). Racism, sexism, ageism and homophobia are all recognized descriptions for prejudiced beliefs, the prevalence of which has contributed to the success of efforts to reduce discrimination on the grounds of race, gender, age or sexuality (Thompson & Thompson, 1997). There is no

comparable term used in relation to people with mental illness. The term 'mentalism,' has been suggested (Sayce, 1998) along with 'psychophobia' (Byrne 2001) but neither of these has been taken up.

Graham Thornicroft (2007) argues that models of stigma always end up with discrimination being the product. While he accepts that problems of knowledge and problems of attitude are part of the overarching stigma process (Thornicroft, Rose, Kassam, *et al*, 2007), he shares Sayce's view that stigma is a potentially damaging concept, and that the problems it seeks to describe are better conceptualized in terms of discrimination.

Despite these convincing concerns, 'stigma' continues to dominate the discourse, and efforts to improve the ways in which people with mental illness are regarded by others is universally described as 'reducing stigma.' (Corrigan, 2007; Corrigan, 2004; Hocking, 2003; Phelan, 2002; Pinfold, Thornicroft, Huxley, *et al*, 2006; Pinfold, Toulmin, Thornicroft, *et al*, 2003; Rosen, Walter, Casey, *et al*, 2000; Sartorius, 2002; Watson, Otey, Westbrook, *et al*, 2004). Stigma reduction strategies include public health broadcasting, campaigns to change representations of the mentally ill the media, changes in legislation and educational interventions (Corrigan, 2006; Crisp, 2004; Sartorius & Schulze, 2005).

Experiencing a period of mental illness is clearly a challenging life event in and of itself. That the wider social world responds to the mentally ill with suspicion and discrimination creates an additional layer of difficulty. Indeed it has been reported that for some people, stigma and discrimination can be more personally damaging than the symptoms of mental illness itself (Corrigan, 2006; Hinshaw, 2007; Sayce, 2000; Thornicroft, 2006). Section 2.1.2 demonstrated how members of the public approach the topic of mental illness with confusion, often exhibiting negative reactions underpinned by fear. The impact of this in terms of the individual experience can vary in magnitude from the kind of social awkwardness and discomfort described by Elyn Saks and Kay Redfield Jamison to more extreme examples of harassment and persecution reported in Read & Baker's (1996) study. Observing this leads to important questions. What can be done to reduce discrimination against people with experience of mental illness? How can social exclusion of the mentally ill be prevented?

## 2.2 What role can education play in influencing young people's understandings of mental illness?

*You must always be puzzled by mental illness. The thing I would dread most, if I became mentally ill, would be your adopting a common sense attitude; that you could take it for granted that I was deluded.*  
Ludwig Wittgenstein (1981)

Section 2.1 has demonstrated that mental illness is a real part of the world in which we live. It is understood and interpreted in a range of ways, some of which have been explored. This illustrates that young people are living in a world of discourse which is structured by many different influences. As well as those already discussed there are others which have inevitably been left out of the account so far. The following section asks the question, 'what role can education play in influencing young people's understandings of mental illness?' The first stage in answering this question is to review literature relating to young people's understandings of mental illness through examining studies which have investigated both knowledge and attitudes. One of the crucial findings of these studies is that discriminatory thinking and negative attitudes (stigma) towards others with mental illness are prevalent amongst young people. A survey of studies which report school-based interventions targeted at the reduction of stigma in relation to mental illness is then presented.

### 2.2.1 Young people's knowledge of mental illness

There is a relatively small body of research which investigates young people's conceptions of mental illness. Generally, the methods chosen to explore young people's understandings have been quantitative (Leighton, 2010), with very few studies using qualitative methods (Wahl, 2002). The vast majority of studies which have taken place have been within the 'literacy' type paradigm described in 2.1.2 – research is usually carried out by practitioners in the mental health field who are principally interested in the extent to which young people are able to recognise mental illness and respond to it 'appropriately.' There is a number of recent studies which explicitly frame their investigation in terms of 'mental health literacy' (Burns & Rapee, 2006; Cotton, Wright, Harris, *et al*, 2006; Jorm, Kelly, Wright, *et al*, 2006; Kelly, Jorm & Rodgers, 2006; Leighton, 2010; Wright, Jorm, Harris, *et al*, 2007). Those studies which pre-date the descriptor largely examine similar domains, focusing on young people's ability to recognise and identify mental illness, the ways children and young people define the causes of mental illness and relate to possible treatments or interventions (Bailey, 1999; Coie & Pennington, 1976; Maas, Marecek & Travers, 1978; Marsden & Kalter, 1976; Novak, 1974; Poster, 1992; Roberts, Beidleman & Wurtele, 1981).

Marsden & Kalter (1976) presented participants with vignettes describing the behaviour of boys with varying degrees of mental illness, representing a normal child, a child with school phobia, a child with passive-aggressive character disorder and another child with psychosis or borderline psychosis. They reported that children aged 9-12 were able to differentiate between the behaviour of the normal child from that of the children with mental illness and that the respondents were also able to distinguish between the severities of the different types of behaviour represented. Coie & Pennington (1976) also reported that children aged 9 to 10 and upwards were able to distinguish between normal and disordered behaviour, but that younger children (aged 6 to 7) in their study had more difficulty in doing so. Novak (1976) conducted a study involving 326 children aged 9 to 12 in which vignettes representing depressed, phobic, immature, aggressive and schizoid personalities were presented to the participants, along with a description of a normal child. Respondents were asked to rate the vignette characters according to attractiveness, social distance and how similar they perceived the characters to be to themselves. Novak reported that participants in the study rated the normal child more positively than those with behaviours indicating mental illness on all three measures, suggesting an ability to differentiate between the types of behaviour represented, along with reticence to socialise with characters with mental illness. The relationship between gender and ability to differentiate between 'normal' and 'mentally ill' behaviour as represented in the vignettes in these studies is not definitive. Some of the research indicated that there was no effect of gender in their data (Coie & Pennington, 1976; Novak, 1974), whereas others did find differences (Marsden & Kalter, 1976; Norman & Malla, 1983).

Roberts et al. (1981) presented 34 young people aged 9 to 13 with vignettes which depicted children with medical and psychological disorders. Four vignettes were used in the study, two of which represented medical problems, the other two presenting what the researchers described as mild psychological disturbance, demonstrated by screaming and kicking other children, and severe psychological disturbance, described as believing in monsters from outer space. As indicators of mental illness, these descriptors are clearly problematic – screaming and kicking other children could be a sign of underlying psychological disorder, but the antisocial nature of the behaviour is likely to eclipse any more subtle interpretations. Similarly, believing in monsters from outer space seems to be a rather unsubtle depiction of psychological disorder. Children taking part in the study were asked to read the vignettes and then write answers to questions such as "What do you think is wrong with this person?" and "What do you think made this person this way?" The study reported that the children regarded psychological disorders as being as a result of innate aggressive tendencies (i.e. "he can't control his temper") or because of a propensity to the distortion of reality ("he has too

big an imagination”), which are unsurprising explanations given the content of the vignettes presented. The authors state that a significant finding of their study was that children regarded the child in the mild-psychological vignette (described as “acting out”) as having more severe problems than the child in the severe-psychological vignette (described as “hallucinating”). It seems likely that this finding is mainly to do with the content of the vignettes -screaming and kicking other children are behaviours which are surely more socially troubling than the idea of a child who believes in monsters from outer space.

In a later American study, Poster (1992) also used vignettes to investigate young people’s knowledge about mental illness. 168 children aged 9 to 12 were presented with six vignettes, half of which depicted adults with symptoms of schizophrenia, anxiety and depression and half of which showed children with the same disorders. The participants in the study were asked to read the vignettes and then write answers to questions, including those designed to assess their recognition of mental illness (‘what is the name for the way he/she is acting?’). Poster reported that less than a third (27%) of the children surveyed assigned mental illness labels to the vignettes, which is interpreted as indicating a lack of knowledge. The responses from participants varied according to the type of mental illness depicted in the vignette. Poster reported that children were more likely to give psychiatric labels to the character with schizophrenia than to those with the other mental illness diagnoses.

More recently, Burns and Rapee (2006) investigated young people’s knowledge of depression. They presented 202 Australians aged 15-17 with five vignettes depicting young people going through a range of life difficulties and their responses to the difficulties. Two out of the five vignettes (Emily and Tony) were composed with “strong evidence that the focus character had significant signs of depression, with each having at least five symptoms of a Major Depressive Episode, as described in the DSM-IV” (p.228). The other three characters were shown going through normal life crises, such as the death of an elderly relative, splitting up with a boyfriend and being caught by parents after getting drunk. Respondents were asked to read the vignettes and then complete a questionnaire which asked them what they thought was the matter with the person, how worried they were about each of the characters, and how long they thought it would take for each young person to feel better. Analysis of the responses focused on the extent to which participants differentiated between the vignettes showing diagnosable depression versus those which did not. 67.5% of participants correctly diagnosed depression in the Emily vignette and 33.8% rated the Tony vignette as depressed.



The studies outlined above all use vignettes to stimulate responses from participants. The use of vignettes as stimuli is one way of prompting responses and avoids framing the behaviours described within the vignettes as mental illness from the outset. It serves as a strategy for investigating the extent to which respondents are able to identify a description which (according to researchers who composed them) is an objective and rightful depiction of mental illness and differentiate that description from others. This is somewhat akin to a 'spot the difference' type exercise and is not designed to give young people the opportunity to express their understandings of mental illness in their own terms.

Other studies begin with the phrase 'mental illness' or specific diagnostic labels as stimuli for responses (Adler & Wahl, 1998; Norman & Malla, 1983; Weiss, 1985; Weiss, 1986). One such study was carried out in the UK by Susan Bailey (Bailey, 1999). Bailey surveyed 106 young people aged 11-17, who completed a questionnaire immediately after listening to the Royal College of Psychiatry's Christmas lecture for children. The questionnaire asked respondents to answer questions such as "what causes mental illness?" and "what happens to people with mental illness?" and sought freely written answers to these questions. It is not stated in Bailey's article whether the respondents were given an explicit definition of 'mental illness' either at the beginning of the questionnaire or during the lecture they had been at prior to the completion of the questionnaire. Therefore exactly how each child completing the questionnaire conceives of the concept of 'mental illness' cannot be known. Bailey reports that the responses to questions tended to be quite diverse – a range of 13 different causes for mental illness were provided by respondents, ranging from stress (cited by 41% of the sample) to insecurity/ isolation (cited by 7% of the sample). Other frequently stated causes included genetics (27%) and bad experiences in childhood (26%). When asked what happens to people with mental illness, the young people responded across a number of different dimensions. Bailey reports responses as belonging to one of three categories: behaviour of individual; responses of members of the public and interventions. 12% of the young people surveyed said that people with mental illness would lose control, 9% reported that they may become neglected and 41% said they would go to a mental hospital.

Bailey's (1999) study, along with others which utilise terms such as 'mental illness,' 'mentally ill,' and 'mental disorder'(Adler & Wahl, 1998; Norman & Malla, 1983; Weiss, 1985; Weiss, 1986) does so without knowledge of the significance and meanings ascribed to these terms by the young people participating, which clearly poses problems with the face validity of the findings reported. Spitzer and Cameron (1995) carried out a study in the US in which children were asked directly what they understood by the term 'mental illness.' One of the aims of their

research was to investigate the impact of age on children's perceptions of mental illness, so for this reason they interviewed thirty children aged 6-7, thirty children aged 9-10 and thirty children aged 12-13. They reported that for most children, mental illness was an unknown term. In the youngest age group, none of the respondents claimed that they were familiar with the term mental illness. They were asked to give their best hunch as to what mental illness might be, and it was reported that the most common response was to define mental illness as very serious physical illness. Examples of comments from participants which illustrate this include "mental illness is when you are very very ill" and "mental illness is like AIDS. You can't catch it easily; it's like a bug that you can't get rid of" (Spitzer and Cameron 1995, p. 403). In the middle age group, the definition of mental illness as serious physical illness continued to be prevalent. One respondent in this age group commented, "mental illness is when you are very sick like having pneumonia or something." (p. 404). The researchers also reported that in this age group some children started to make links between mental illness and the brain or head, as illustrated by the comment "Mental illness is when you are sick in your brain but I do not know what it means." (p.404). In the oldest age group, fewer respondents defined mental illness as serious physical illness, although some did. The three most frequent definitions of mental illness provided by this age group were categorised as thinking problems, mental retardation and craziness. Comments included "you are not too together in your head. Something is wrong with the way you think," and "mental is with the brain; illness is sickness. So, mental illness is brain sick." (p. 404). Spitzer and Cameron conclude that older children were better able to connect mental illness to problems in thinking processes but that they did not understand mental illness fully.

The findings of these studies suggest that young people are able to recognise mental illness as depicted in vignette descriptions in the research studies. Furthermore, there is some evidence of children and young people being able to differentiate between different types of mental illness as well as demonstrating some awareness of its possible consequences and causes. When asked directly what mental illness is young people demonstrated considerable uncertainty. However, the findings of these studies may be somewhat hampered by various methodological limitations. The rendering of behaviours associated with mental illness in vignettes is rather different to the experience of meeting or talking to a real life person experiencing mental health problems. The majority of research conducted into young people's knowledge of mental illness has failed to properly investigate how children understand terminology used in the studies which undermines face validity.

One study took a more open approach to researching young people's understandings of mental illness (Secker, Hill & Armstrong, 1999). The 102 12- to 14-year olds who participated in the study took part in focus groups made up of six members, plus a researcher. Eighteen of the participants were also interviewed individually. The interviewers used a semi-structured interview schedule which covered themes relating to different aspects of mental illness. Each focus group began with the interviewers asking the young people to think of examples of behaviour which they found odd or unusual and to describe them. A series of five vignettes which described behaviour associated with particular mental illnesses was used to elicit further discussion. The groups were asked what they thought about the way the person concerned was acting; what name they would give to the behaviour described and how they would feel if the person in the vignette lived next door to them. If the young people in the group had not introduced the term 'mental illness' into the discussion by this point, the interviewer asked whether or not they thought the people in the vignette were mentally ill. Further questions were then asked to more deeply explore their understanding of the term.

Secker et al. reported that one of the most prominent themes to emerge from their data was the way in which participants appeared to make distinctions between what constituted mental illness and what did not. They found that the young people drew on their own experiences to separate behaviours with which they were familiar, regarding these as not mental illness, and those with which they had no experience, which were likely to be regarded as mentally ill. Amongst Secker et al.'s findings were some very interestingly nuanced discussions about depression. One of the vignettes used in the discussion presented the character of David, who is experiencing depression. Although many of the young people spontaneously described David's behaviour as being depressed, the great majority of them did not define this as mental illness. It is reported that the participants felt that behaviour described in the vignette was sufficiently accessible through their own experience that it was largely regarded as normal. One of the comments illustrating this was, "No, he's not mentally ill I just think he's got depression and he doesn't care about anything but I don't think he's mentally ill." (Secker et al. p. 734). Another of the vignettes used in the discussions represented Angela, a character with anorexia. Secker et al. report that the young people were grappling with categories in their attempts to make sense of what was going on in this vignette. On the one hand they found Angela's behaviour possible to understand in terms of experiences and people they could relate to, which led to reluctance to say that her behaviour was indicative of mental illness. This was coupled with a feeling that her behaviour, although within their experience, was somehow not 'normal.' Although a minority of participants did define anorexia as mental illness based on this, the majority resolved the dilemma through the creation of an additional

category of ‘psychological problems’, as illustrated by this comment: “I don’t think she’s mentally ill but she’s got a psychological problem with the way she feels about herself and the way she looks.” (p. 735). It is particularly interesting that the young people seem so keen to avoid labelling a character as mentally ill if they can possibly find a different explanation for the behaviour presented. This is not explored by the authors of the paper, but could be indicative of a deeply held evasion of the notion of mental illness, although not to the understandable behaviours which are regarded as mental illness by professionals. Two of the vignettes used in this study presented characters who hear voices – John, a 34-year old man, and Peter, a 15-year old boy. All of the participants unequivocally identified the behaviour of both of these characters as being mental illness. It was reported that the young people made no reference to experiences of their own in their explorations of what was going on for these two characters. They did, however, draw on media representations of mental illness as part of the process of constructing their viewpoints.

It is particularly interesting that when given the opportunity to explore what is going on in the vignettes through facilitated group discussions with peers, the young people demonstrated an understanding of the concept of mental illness which is significantly divergent from the psychiatric view described in the previous section. Their responses in the discussions show that hearing voices and psychotic experience delineate in their understandings as mental illness. Other experiences considered as mental illness by health professionals are seen differently – depression being regarded as a fact of life, part of normality, and anorexia being a type of ‘psychological problem’ but not mental illness *per se*. Secker et al.’s work is distinctly different from almost all other studies which have attempted to investigate young people’s understandings of mental illness in that group discussions were conducted, and although a degree of structure was imposed, conversations were allowed to evolve within that structure.

### **2.2.2 Young people’s attitudes to mental illness**

As well as knowledge, another focus for investigation has been young people’s attitudes towards mental illness. Some of the studies already described examined attitude to mental illness as well as knowledge about it. For example, Roberts et al. (1981) asked the participants in their study to rate the characters in the vignettes in terms of how attractive they would be as a playmate. The findings were that three of the characters were rated as being moderately attractive playmates, and that the one with the mild psychological disturbance (demonstrated by screaming and kicking other children) was the least attractive of all. This is not especially surprising given the aggressive behaviour depicted in that vignette, but is construed as an indicator of negative attitude towards mental illness. Wilkins and Velicer (1980) used a semantic differential technique to ascertain the attitudes of twenty children aged 8-12 towards

the concepts 'person,' 'crippled,' 'retarded,' and 'crazy.' They reported that the crazy person was rated less positively than any of the other concepts, as well as being more unpredictable and less understandable than the others. Half of the participants in the study ascribed dangerous behaviours to the crazy person. What children understand by 'crazy' cannot be taken for granted, however, and it is somewhat erroneous to assume that young people's responses to the phrase 'crazy person' are indicative of their attitudes to 'real' people with particular mental illness experience.

A more novel approach to the assessment of attitude towards mental illness was used in a study which utilised children's figure drawings and accompanying stories (Poster, Betz, McKenna, *et al*, 1986). 168 participants were included in the study, aged 8 to 12. Participants were asked to draw a picture of a person doing something and to write a short story about their picture. They were then shown vignettes which described behaviours associated with anxiety disorder, depression and schizophrenia. Finally, participants were asked to draw a picture of a 'crazy person' and again to write a story about the person they had drawn. The drawings were examined using scoring indicators for human figure drawings (such as line discontinuity and body shading) and it was reported that there were no differences between the drawings of normal versus crazy people. Differences were reported, however, in the stories which accompanied the drawings. The most frequent themes of the stories attached to the first (normal person) drawing-story combinations were to do with play and work, whereas themes of the second drawings/ stories (crazy person) were inappropriate behaviour, suicide and self abuse and hostile or aggressive actions. The researchers conclude that while the young people who took part in the study did not seem to attribute differences in physical characteristics to individuals with mental illness, they do associate mental illness with a variety of negative behaviours.

Watson et al. (2005) conducted a study involving 415 young people aged 14-18 in Chicago using the Attitudes Toward Serious Mental Illness Scale – Adolescent Version. They reported a perception amongst the sample that people with mental illness are violent and out of control and a tendency to exhibit what they call 'categorical thinking.' Items on the measurement instrument representing categorical thinking included "I can't see myself hanging out with a mentally ill person," and "If you become mentally ill your life is pretty much over." Researchers found that the female members of the sample exhibited less negative attitudes than the males. They also found that familiarity with mental illness was associated with more positive attitudes – respondents who had indicated that they had a family member with a mental illness were less likely to endorse statements related to categorical thinking. Also in

America, Chandra & Minkowitz (2007) conducted a study which involved carrying out in-depth interviews with 57 pupils aged 13-14 to investigate their perceptions of adult and peer attitudes to mental health services. Most participants in this study reported beliefs that people in their lives are uncomfortable with discussing mental health issues and some reported active disapproval towards mental health services. Chandra & Minkowitz's study was unlike most in that it engaged participants in one-on-one conversations in order to generate data, rather than relying on questionnaires and other paper based methods. However, the researchers did not use the opportunity to ask the participants directly about their own opinions, instead focusing on their perceptions of others' views.

In Scotland, Williams and Pow (2007) investigated gender differences in attitudes to people with mental health problems in a sample of 496 school pupils aged 15 and 16 using a questionnaire. They reported some evidence of relatively positive attitudes, including that 80% of those surveyed disagreed that people with mental health problems were largely to blame for their condition. However, they also found that 44% of respondents would not want other people knowing if they had a mental health problem. In terms of gender differences, Williams and Pow reported that there were significant differences on five items and in all cases boys exhibited more negative attitudes than their female counterparts, a finding which supports Watson et al.'s (2005) research from the US. The effect of gender on young people's attitudes to mental illness has been consistently reported in older as well as more recent studies and in all cases the attitudes of girls are more positive compared with those of boys (Cotton, Wright, Harris, *et al*, 2006; Khaton & Carrieria, 1972; Lopez, 1991; Olmstead & Smith, 1980). Marsden & Kalter (1976) found that girls tended to normalise the behaviour of a vignette character demonstrating psychotic behaviour to a much greater degree than boys.

The use of questionnaires, vignettes and social distance scales to investigate attitudes to mental illness are the most commonly used research methods and qualitative studies are rare. One qualitative study carried out in the UK was designed to allow young people to express what they thought about mental illness in a way which would not be constricted or constrained by attitude scales or vignettes (Rose, Thornicroft, Pinfold, *et al*, 2007). Participants were asked to respond freely in written format to the question, "what sorts of words or phrases might you use to describe someone who experiences mental health problems?" From the 400 14 year olds who responded to this question, 250 words and phrases describing people with mental health problems were produced. Rose et al. reported that 75% of these terms were strongly negative, with only 16% being neutral (such as medical diagnostic terms) and 9% being regarded as somewhat empathic or eliciting compassion (such as 'sad,' or 'isolated'). The

researchers identified five themes which the words and phrases belonged to. The first of these was 'popular derogatory terms,' which represented almost 50% of the total. These were, in effect, slang words and are a set of negative associations and judgements (e.g. screw loose; loony; freak). The other themes identified were negative emotional states (e.g. disturbed; confused; distressed); confusion between physical disabilities, learning difficulties and mental health problems (e.g. spastic; demented; dumb); violence (e.g. scary; violent), and sadness and isolation (e.g. loneliness). It is reported that the sheer range of words used showed a striking virtuosity amongst the young people surveyed, as well as a lack of precision in how adolescents expressed themselves when describing people with mental health problems.

Marc Weiss carried out an assessment of developmental differences in attitudes to mental illness in a series of studies by Marc Weiss throughout the 1980s and into the 1990s (Wahl, 2002). In his first study, Weiss (1985) looked at children's attitudes in relation to development, using the Opinions About Mental Illness questionnaire (Cohen & Struening, 1962) as a tool. 512 American children were included in the study, and those surveyed represented grades two, four, six, and eight, covering an age range of 7 to 14. Weiss reported that as children get older their attitudes towards those with mental illness seemed to improve. The questionnaire responses showed that with increasing age, children became less authoritarian, viewed those with mental illness as being more like themselves, and perceived the mentally ill as being less of a threat to society, being more in need of sympathy and support. The findings also suggested that the changes were most significant between grades two and four, with attitudes appearing to stabilise between grades six and eight.

Weiss went on to carry out a developmental analysis of children's attitudes towards mental illness using a social distance measure, adapted for use with children (Weiss, 1986). In this study, attitudes to mental illness were investigated in relation to attitudes to other stigmatised groups. 577 children were included, covering the age range 5 to 14. The participants in the study were presented with stick figures which represented seven 'attitude objects,' namely convict, mentally retarded person, normal person, mentally ill, crazy person, physically handicapped and emotionally disturbed. They were then asked to draw a stick figure representing themselves at a distance from the other person at which they would feel most comfortable. The drawings were analysed for the relative social distances represented. Results revealed that across all age groups, the convict and crazy person produced the most social distance and the physically handicapped and normal person the least. In terms evidence of a developmental trend, Weiss reported that the main change was that between grade six and grade eight, crazy person replaced convict as the most socially distanced.

Weiss also carried out an eight-year longitudinal study of children's attitudes to mental illness (Weiss, 1994) in which he found and re-examined thirty four of the sixty five kindergarten children (aged 5-6) who had participated in his 1986 study. These children, now aged 13 and 14 repeated the stick figure placement task designed to measure social distance described above. The main change over the time period was significantly reduced social distance from the 'mentally retarded' person – i.e. the children placed themselves closer to the mentally retarded person. Aside from this change, it was reported that that the results were strikingly similar to those obtained when the participants were much younger children. Weiss concludes from his results that they indicate that children's attitudes to the groups presented had developed and become stable early in their childhood. However, this is a somewhat bombastic claim given that the measurement tool used assumes that children individually and similarly understand what is meant by the terms provided.

Research into young people's attitudes towards people with mental illness demonstrates that children and adolescents frequently regard the mentally ill as different and unattractive, attributing antisocial, aggressive and violent behaviours to them. The studies suggest that young people often exhibit unwillingness to associate with people with mental illness and a propensity to use pejorative language to describe mental illness and people affected by it. However, it is important to consider whether some of these findings may reflect the methods used to research the topic. One problem is that if you ask closed questions, respondents have little scope to disclose nuances and ambiguities (Robson, 2002).

#### **2.2.4 The issue of mental illness in schools**

Teaching and learning explicitly about mental illness in schools is uncommon. A small number of published papers report on school based interventions which aim to increase awareness of mental illness with stigma reduction as a central focus.

The stigma reduction agenda is only one aspect of how mental health is dealt with in schools. In the past, mental health awareness education with stigma reduction as its central focus has tended to be delivered by experts from the psychiatric disciplines in experimental conditions. The literature suggests these types of intervention are rare, being delivered as one-offs for the purposes of conducting research. However, the issue of mental health and illness sometimes arises in schools' curricula without external experts intervening in order to conduct studies. There are currently opportunities for mental health issues to be covered in secondary schools within Personal Social and Health Education (PSHE) and Life Skills provision, although little is known about how many schools actively cover the topic, or what the emphasis of such



teaching might be. The National Healthy Schools Programme (NHSP) is a joint initiative between the Department of Health and the Department for Children Schools and Families which allows schools to apply for 'healthy school' status provided it meets certain criteria. NHSP includes a strand within its non-statutory framework on emotional health and wellbeing which addresses stigma and discrimination but this is an extremely small part of the framework (DfES, 2004). Attention has been drawn to emotional wellbeing in schools through the Social and Emotional Aspects of Learning (SEAL) initiative, but increasing understanding mental illness in society is not the explicit aim of SEAL, which focuses on related but different concerns to do with promoting social and emotional skills (DfES, 2007).

Furthermore, it is important to note that mental health problems amongst secondary school pupils appear to be both prevalent and on the increase (World Federation for Mental Health, 2003). Perhaps unsurprisingly, responding to mental health difficulties faced by pupils is happening more and more within school settings. Mental health professionals working with Child and Adolescent Mental Health Services (CAMHS) increasingly base themselves in schools. CAMHS policy identifies teachers as "Tier 1 CAMHS workers" which means that they have responsibility for noticing and responding to signs of mental illness in the pupils they teach (DCSF, 2010). Another recent initiative is Targeted Mental Health in Schools (TaMHS), which aims to build on the work of SEAL to respond to the needs of pupils identified as being at risk of developing mental health problems (DCSF, 2008). Although SEAL and TaMHS are built on the philosophy that an 'ecological' approach to developing whole school social and emotional wellbeing is necessary, mental health education with stigma reduction as its central focus is not an explicit aim (Weare & Markham, 2005).

The matter of mental illness, then, is an unavoidable feature of the school community and with young people in distress being identified and treated within the school setting, the social implications of this for the broader school community also need to be addressed. Because of the need to respond to those pupils who are currently experiencing mental health crises, it is understandable that attention is directed towards initiatives like TaMHS. However, with increasing numbers of pupils being identified as having specific mental health needs, it is inevitable that there will be social implications for them. It is important to consider what it does to a young person's social standing to be identified as needing specialist mental health support and to give consideration to how the rest of the school community responds to their peers in such a position. Given that mental health issues have become a feature of the landscape of the school environment, the need to promote greater understanding of mental illness in society becomes ever more pertinent. There is a growing body of evidence that there

is a place for mental health education (as distinct from mental health promotion) in adolescents' lives (Pinfold, 2003; Rickwood, Cavanagh, Curtise, *et al*, 2004) but currently there are no standardised mental health education programmes in the school curriculum in the UK, the US or in Canada (Pinfold, Toulmin, Thornicroft, *et al*, 2003; Pitre, Stewart, Adams, *et al*, 2007). Before such programmes are introduced, it would be advisable for further research to consider and evaluate different approaches.

### **2.2.5 School based stigma reduction initiatives**

Interest in whether school-based educational interventions may be effective in reducing the stigma of mental illness in children and adolescents has come largely from the health community rather than from educationalists. This is demonstrated by the journals in which relevant studies are published (*International Journal of Adolescent Medicine and Health; British Journal of Psychiatry; Journal of Mental Health; Psychiatric Bulletin; Psychiatric Rehabilitation Journal; Canadian Journal of Psychiatry; Schizophrenia Bulletin; Social Science and Medicine*). I was only able to locate one study describing a mental health education programme in a non medical or psychiatric journal (Esters 1998, published in *Adolescence*) and am not aware of any appearing in the education literature. For this reason, school-based programmes of this type tend to be one-off interventions, instigated by research teams primarily concerned with investigating the impact of the intervention on participants' knowledge and attitudes (Chan, Mak & Law, 2009; Essler, Arthur & Stickley, 2006; Esters, 1998; Lauria-Horner, Kutcher & Brooks, 2004; Meise, Sulzenbacher, Kemmler, *et al*, 2000; Naylor, Cowie, Walters, *et al*, 2009; Ng & Chan, 2002; Pejović-Milovancević, Lecić-Tosevski, Tenjović, *et al*, 2009; Pinfold, Toulmin, Thornicroft, *et al*, 2003; Pitre, Stewart, Adams, *et al*, 2007; Rickwood, Cavanagh, Curtise, *et al*, 2004; Schulze, Richter-Weling, Matschinger, *et al*, 2003; Shah, 2004; Spagnolo, Murphy & Librera, 2008; Stuart, 2006; Watson, Otey, Westbrook, *et al*, 2004). According to mental health professionals, one of the main problematic effects of mental illness being stigmatised is that people experiencing mental illness are less likely to seek help from mental health services as a result of it. The need to reduce stigma in order that barriers to seeking help from medical services be reduced is emphasised as a key aim of stigma reduction interventions including educational efforts in schools.

The published studies are inclined to give most attention to reporting the evaluation process, and very little to describing the content and form of the interventions themselves. None of the studies report carrying out detailed, qualitative investigations of how young people make sense of and understand mental health issues in order to inform the development of educational material. Interest focuses primarily on measurable impact of the programmes, in

terms of changes in knowledge, attitude, or behavioural intention (assessed by way of social distance measures). In seeking to assess the impact of mental health education programmes, no study reports conducting interviews or focus groups with participants – all measures are quantitative and survey based.

The majority of the educational efforts described in these evaluation studies took the form of brief, single opportunity interventions. Some interventions were as short as one hour (i.e. Spagnolo et al. 2008), others being more sustained - one example was delivered in fifty minute lessons over a period of six weeks (Naylor et al. 2009). The format and design of the interventions reported in the evaluations varies considerably. Most were brought in from outside the school and its curriculum, often being delivered by external ‘experts,’ with others being delivered by teachers using materials which were externally designed (Schachter, Girardi, Ly, *et al*, 2008). Some focused exclusively on schizophrenia (i.e. Schulze et al. 2003; Stuart 2006) whereas others dealt with mental illness more broadly (i.e. Watson et al. 2004; Pinfold et al. 2003). Most frequently, interventions are built around biogenetic explanations of mental illness, emphasising messages such as ‘mental illness is an illness like any other.’ Some have used creative means to deliver these messages, such as theatre (Essler, Arthur & Stickley, 2006) and puppets (Pitre, Stewart, Adams, *et al*, 2007). Others have acted on evidence that meeting people with lived experience of mental illness has the most profound destigmatising effect (Couture, 2006), delivering interventions which include direct contact (Schulze, Richter-Weling, Matschinger, *et al*, 2003; Spagnolo, Murphy & Librera, 2008) or video based contact (Chan, Mak & Law, 2009; Stuart, 2006).

Most of the evaluation studies report some positive change in knowledge and attitudes amongst participants following engagement in the programmes. Watson et al. (2004) describe the effects of a series of lessons called *The Science of Mental Illness*, delivered to 1556 American 11-14 year olds. They report improvements in knowledge and attitudes amongst students taking part, particularly in those students with more negative attitudes at baseline. This study did not incorporate a control group for comparison purposes. Ng & Chan’s (2002) study did include a control arm, and interestingly, the authors found that there was an increase in stigma amongst adolescents in this group. Stigma was assessed using the OMICC (Opinion about Mental Illness in Chinese Community Scale; Chu et al., as cited in Ng & Chan 2002) which measures a number of factors of stigmatisation. Those taking part in the education programme showed decreased scores on the Separatism and Stigmatisation factors, but also, unexpectedly increased scores on the Restrictiveness factor. Statements associated with this factor include “those who have been mentally ill should not have children.” The authors

suggest that cultural beliefs may have played a role and that participation in the study could have emphasised these beliefs. Essler et al. (2006) assessed the impact of an intervention delivered in collaboration with a theatre company using the *Mindout for Mental Health Quiz* (Department of Health, 2001). 104 year nine pupils participated and it was reported that the proportion of correct responses to items on the quiz increased following participation. 'Correct' responses to items on the *Mindout for Mental Health Quiz* were interpreted as evidence of positive attitudes. However, the use of the instrument in this way was not validated.

Schulze et al. (2003) report on a five day educational project on schizophrenia, designed for students aged 14-18. Ninety students from five different schools in Germany participated in the programme, and their attitudes to schizophrenia were assessed by way of a questionnaire. A control group also completed the questionnaire for comparison. The questionnaire focused on stereotypes of schizophrenia and social distance. Questionnaire results indicated that participation in the project led to a significant reduction of negative stereotypes and a positive trend on the social distance measures. These changes were not evident in the control group. The authors conclude that the results of their evaluation of the project support the assumption that targeting young people with interventions to reduce the stigma of schizophrenia is promising and that school-level interventions appear to be a good strategy for facilitating the equipment of future generations with more positive and open attitudes towards others with schizophrenia. Pinfold et al. (2003) investigated the impact of an educational intervention which consisted of two one hour workshops delivered to 472 year 10 pupils in the UK. Participants completed measures of attitude, knowledge and social distance at baseline, and two follow up time points - one week after the intervention and six months afterwards. At one week follow up, improvements were reported in attitude although social distance ratings did not change significantly. Knowledge is reported as having been improved following the intervention, although factual recall did not seem to be long lasting. At baseline, 1% of students provided correct answers for all of the factual statements. At one week follow up this increased to 24%, but this proportion fell to 6% after six months. It is possibly expectable that the impact of an intervention consisting of two one hour workshops would not still be felt six months after they were delivered.

Although positive attitude change is commonly reported, this cannot be assumed to have any bearing on the way people behave in their day to day lives. It may be that changes in attitudes amongst participants in educational interventions designed to reduce stigma are a reflection of participants' desire to be perceived as having more socially desirable attitudes as a result of the direct message being given that stigmatisation is undesirable (Haghighat, 2001).

Perhaps unsurprisingly, given the complexity and controversy surrounding mental illness, exactly what constitutes ‘knowledge’ regarding mental illness varies in how it is conceived of and measured in these studies. Stuart (2006) assessed the effectiveness of an education programme on schizophrenia through collecting knowledge scores derived from twelve true or false statements. These included “schizophrenia is caused by stress” (correct answer: false); “people with schizophrenia need medication” (correct answer: true); and “schizophrenia is a brain disease” (correct answer: true) (Stuart 2006: p.650). As demonstrated in section 2.1.1, the factual solidity of these statements cannot be taken for granted. There is considerable disagreement as to whether or not schizophrenia and other mental illness can ‘properly’ be regarded as diseases (Szasz, 1960). The role of medication is also contentious, and some people with schizophrenia argue it has done them more harm than good (Moncrieff, 2004). Furthermore, there is no conclusive evidence as to the causes of schizophrenia, and it seems that stress is likely to play a part in its onset even if it is not a sole cause (Bentall, 2003). So, the construction of these statements as ‘facts’ indicating level of knowledge represents a particular viewpoint and is not completely value-neutral.

The published studies describing educational interventions on mental illness are primarily interested in establishing their effectiveness in terms of stigma reduction. Very few of the studies solicited young people’s opinions about the interventions themselves. One exception was a Canadian study (Stuart 2006) which asked school pupils whether they would like to learn more about mental illness before and after participating in two lessons on schizophrenia. Interestingly, the percentage of those expressing interest in receiving education about mental illness dropped by 10% after taking part, which suggests that the particular intervention had a negative impact on interest in and enthusiasm for the topic. Another study sought evaluation from pupils participating by asking them how much they learnt about each topic covered by the programme, and how important they felt each topic was (Naylor, Cowie, Walters, *et al*, 2009). The teaching programme covered bullying, depression, stress, self harm and suicide, eating disorder and intellectual disabilities. Pupils’ ratings of how much they learnt were quite low (on a scale of 0-4, the overall mean was 2.19). The self harm and suicide topic was rated by young people as being the most important, with intellectual disabilities the least, but again, the importance rating was quite low (on a scale of 0-4, overall mean was 2.84). What this suggests is that where young people participating in interventions are given the opportunity to comment on them, their opinions fall a long way short of wholehearted endorsement.

This brief review of research investigating the effects of school-based anti-stigma education reveals a range of weaknesses. Many of the classic problems of pre-post research design using attitude measurement instruments apply (Oppenheim, 1992). For example, the limitations inherent in closed response attitude scaling techniques, and the fact that young people who have just participated in an intervention about mental health in a school setting may try to give ‘right’ answers regardless of their opinions. It seems to be the case that the majority of interventions reported here have attempted in various ways to simplify the issue of mental illness and the stigma associated with it. This simplification amounts to a sort of exclusion, wherein young people are not given the opportunity to fully engage in dialogue about the issues in their full complexity. A strength of this work is that it reveals that interventions can have the opposite effect to that which is intended, leading to young people being less interested in the topic of mental illness and leaving them feeling that they have not learnt very much. This highlights the extent to which the quality of the intervention can influence outcomes. It may therefore be desirable for the development of future interventions to take seriously young people’s own views, using an inclusive dialogue approach.

### **2.3 Rationale for the present study**

Section 2.1 demonstrated the multiplicity of ways in which mental illness is made sense of in society. The conflicts and confusions which characterise the professional discourse on mental illness are one exemplification of the inherent complexity of the topic. The ways in which mental illness is made sense of by members of the public are also diverse, further complicated by the biasing filters of the methods used by those who research and interpret those understandings. Although personal stories cannot be synthesised to provide a universal answer to the question ‘what is mental illness?’ individual experiences can be helpful in bringing an abstract concept to life. This diverse and complicated picture of what mental illness means indicates that the social world is rich with resources for making sense of and understanding it. These resources are available to young people and it would be naive to assume either that they do not have any awareness of them or that they do not have the capacity to draw on them. Equally, it would be presumptuous to suppose that young people use resources for understanding and making sense of mental illness in any particular way. Research is needed which will facilitate inclusive dialogue with young people to find out more about how they utilise these resources in their sense making about mental illness.

Section 2.2 showed that a body of work exists which examines young people’s knowledge and attitudes to mental illness. Findings of studies examining young people’s beliefs about mental illness are mainly interpreted in terms of degree of ‘literacy’ and evidence of ‘stigma.’ These findings have been interpreted as showing that young people generally have negative attitudes

to mental illness and are somewhat illiterate as regards mental health issues. This conclusion has been used to demonstrate the need for mental health education and anti-stigma work, and interventions have been developed to address this need. However, as we have seen, the ways in which 'knowledge' about mental illness has been researched are problematic, in that they tend to consider knowledge in terms of the extent to which people agree with the assumptions of biomedical views of mental illness. Similarly, the establishment of the existence of negative attitudes and stigma amongst young people has relied on methods which are reductive and require opinions to be expressed in terms which have been determined by researchers.

In-depth explorations of young people's views conducted on their own terms in their own language are incredibly sparse. The one study which did give small groups of young people the opportunity to talk together about mental illness found that they had quite sophisticated understandings, including a preference to describe most types of mental illness as anything other than 'mental illness'(Secker, Hill & Armstrong, 1999). This finding has potentially massive significance in terms of our understandings of 'stigma' and approaches which might be taken to develop educational strategies to address the issue of mental illness. However, Secker et al.'s research, which is now over ten years old, appears to have been overlooked by subsequent researchers and those devising educational interventions.

A growing body of work reports the effects of anti-stigma mental health interventions taking place in schools. The majority of these studies focussed on measuring the impact of the interventions they tested. In most cases it seems that little attention has been given to the development of the educational material to be used in the interventions. It may be that this is because of the reporting emphasis of the published research but it seems likely that there has been a tendency to overlook the importance of the pedagogical structure of anti-stigma education. There is a dearth of previous research exploring young people's existing understandings about mental illness to inform the development of educational material. Therefore, the central objective of the present research is to fill this gap.

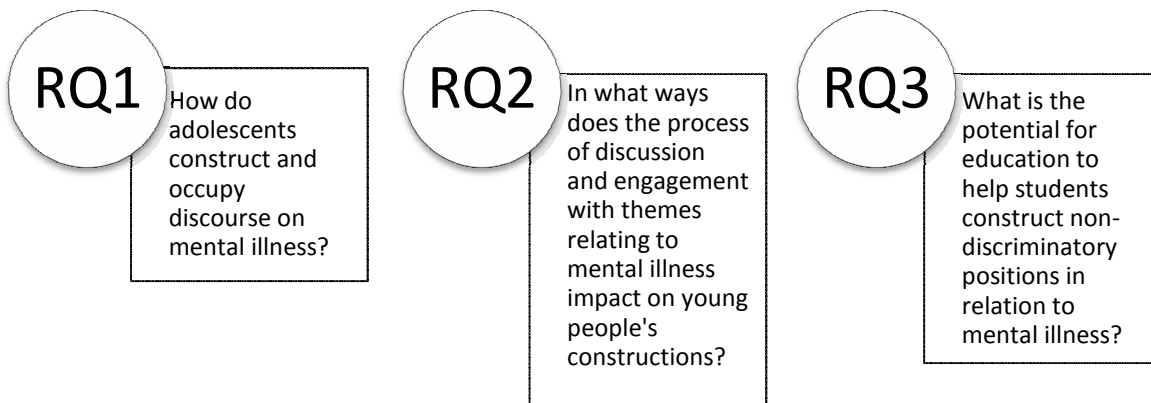
## Chapter 3: Methodology

*Assumptions ultimately mean choice, and the exploration of assumptions involves the exploration of choice.*

Gareth Morgan (1983)

### 3.1 Introduction

The aim of this chapter is to describe and justify the methodology used to develop, elaborate and investigate the research questions:



As will become clear, these questions did not precede the methodology but evolved as part of a broad process of exploration. The first section of the chapter introduces the approach underpinning the research, describing the ways in which this evolved and developed. The development of a research tool – photo-vignettes – is then described. Next, the method and procedures are described for the pilot phase of data generation and the main fieldwork. Issues relating to the trustworthiness of the data generated are reflected upon and finally, attention is given to ethical considerations.

### 3.2 Approach

In beginning a chapter on methodology, it is necessary to establish the ontological and epistemological assumptions upon which the research was predicated. I have chosen to be explicit about the fact that the need to address ontological and epistemological considerations came much later in the process of doing this research than did the interest in the topic itself. The impetus to research young people's understandings of mental illness discourse was stimulated by personal experience of the social phenomenon of discrimination against people with mental illness. So, at the beginning of this project, general ontological questions were not foremost, and my approach to the issue of discrimination against people with mental illness could be described in lay terms as rather naively pragmatic. For example, considering whether this type of discrimination can be regarded as something 'nominal' or



something ‘real’ were not really questions I spent much, if any, time thinking about when I began investigating it. As far as I was concerned, I had observed people with experience of mental illness being treated unfairly and I was interested in why that was and what could be done to change it, specifically through educative means. However, having undergone social science research training, and become immersed in the business of doing research, it became increasingly necessary to think about what kind of ‘truth’ it is possible to reach by undertaking the kind of research activity I was engaged in.

A common approach to broaching these issues within the context of a chapter on methodology for a social science PhD thesis is for the research student to find an ontological and epistemological framework which seems to best suit the work already undertaken, and apply a theoretical ‘retrofit,’ demonstrating how and why these particular assumptions are appropriate for the work in hand. I could have applied the theory *after* the fieldwork had already taken place, and presented the account in such a way as to make it appear as though the worked-through theoretical perspective was chosen because of its suitability for the research topic under investigation. I could have, for example, stated that this research was undertaken within a broadly social constructionist frame, and gone on to unpack exactly what the implications of such assumptions might be for the topic and research activity conducted to explore it. It would be possible to this, and to do it both sensibly and rationally. However, it would not be an accurate representation of the process of methodological ‘becoming’ which actually informed and produced the work reported in this thesis. Therefore, a different approach will be adopted in this chapter, and in setting out to expound the ontological and epistemological bedrock of the research, I will present an experiential narrative of how my understanding of these concerns ‘became.’ Because this was a process, it makes most sense to tell this story chronologically. There were three stages to the development of the methodological approach, which I will now describe.

### **3.2.1 Stage 1 – Attitude measurement and ‘proving’ effectiveness**

I was awarded a four year research studentship, which meant that having submitted a skeletal PhD research proposal, I undertook a research methods master’s degree. The aim of the research project I carried out for my MSc dissertation was to develop a questionnaire to measure adolescents’ attitudes to mental illness. During this year I was working closely with a theatre-in-education (TIE) company, Jest Theatre, and collaborated with them to devise and pilot a TIE workshop on mental health issues with the central aim of reducing stigma. The reason for developing the attitude measurement instrument was to have a tool which would be capable of capturing changes in the attitudes of young people who participated in the TIE

programme, thereby having some evidence of whether or not the programme ‘worked’. With hindsight, I can see that in seeking to develop this tool I was adopting a loosely positivist stance – assuming that if the point of the TIE intervention is to reduce stigma, then the point of the research must be to show to what extent the intervention was successful.

I carried out a review of existing measurement instruments which showed that none were specifically designed for use with young people, and furthermore that the statement items used were derived from ‘professional’ discourse rather than utilising the words and phrases of the people whose attitudes were being measured. With no suitable measurement instruments available to use, the need to develop a new one was clear, and I took the opportunity to take an approach which would identify participants’ own language for use as items in the questionnaire.

### **3.2.2 Stage 2 – The ‘richness’ issue**

I used a grounded theory approach to the generation of statements items to be used on the questionnaire by carrying out focus group discussion with groups of young people aged 11-18 in five contrasting settings. The construction of the questionnaire, coupled with the experience of carrying out group discussions with young people led me to critically consider what the questionnaire responses were actually capable of showing. My feeling was that while an analysis of young people’s responses to the questionnaire may be useful in terms of indicating general trends and patterns in respondents’ views, the instrument was also reductive. The content of the group discussions was rich and complex, with individuals frequently holding contradictory views and occupying ambiguous positions in relation to mental illness. The level of detail, nuance and subtlety which I observed during the focus groups could simply not be captured by a questionnaire using a bipolar response scale. Another limitation of attitude measurement techniques is that they force responses to be recorded as *either* positive or negative. It became clear through my discussions with young people that ambivalence and confusion were very genuine features of their understanding, which I deemed to be important and relevant, particularly when considering how best to approach the issue from an educational perspective. Taking seriously the significance of young people’s understandings even when they are messy and complicated is a crucial element of being committed to appreciating the student’s perspective. The starting point for a proper educational process needs to acknowledge the student’s current position and to recognise the need to take this into account in order to engage them in a truly educational process rather than a ‘brainwashing’ exercise which aims to implant ‘correct’ beliefs and opinions. This made me realise that it is necessary to carry out more detailed research which can take account of

the full range of complexities in how young people make sense of mental illness. It seemed to me that some of the comments and observations made by members of the focus groups were not only interesting in their own right, but also potentially of great value to developing educational processes which may be able to build on young people's existing knowledge and opinions in order to encourage non-discriminatory position taking. In terms of the contribution to knowledge that this thesis aspires to, I began to feel that the most meaningful input could be made through a detailed exploration of how young people occupy and construct mental illness discourse rather than through surveying their responses to a questionnaire on the topic.

### **3.2.3 Stage 3 – Group process, collective construction and inclusive dialogue**

This led me to the view that alternative means of researching young people's understandings of mental health issues were likely to have greater capacity to do justice to the ways in which the issues are really understood and negotiated. This represented an important stage in my process of ontological 'becoming,' and led to me leaving behind attitude measurement and moving towards a much more open, qualitative research design. Through having carried out the focus groups, I had also observed that the ways in which young people interacted during these discussions seemed to be of particular value. On occasions, group members disagreed with one another, or held related but slightly different views, and brought their own personal experiences and examples into the discussion seemed to facilitate a process of collective construction. This type of dialogue, with its Socratic flavour (Saran & Neisser, 2004), seemed to be especially productive and I felt that there was something distinct and advantageous about this which would be lost if I were to only interview young people individually. Therefore, I felt that working with young people in a small group was an important feature to maintain in the main fieldwork.

This meant that I planned a qualitative study, which would allow me to work intensively with a small group of year ten pupils (aged 14-15) over the course a term, with follow up sessions and individual interviews being carried out later in the academic year. Working with one small group, in one setting meant the study could be regarded as a case study, to which I would take a broadly phenomenological approach in which the idiographic accounts of participants would be central. Given these factors, it is fair to say that the research is grounded within the interpretivist paradigm.

### **3.2.4 Interpretivism**

The central tenet of the interpretivism in research is that reality is socially constructed (Mertens, 2009); hence the approach is sometimes referred to as social constructionism. Under this perspective, facts are regarded as subjective constructs rather than fixed and observable 'truths.' It is necessary to use more personal, interactive modes of data generation than might be considered appropriate under a positivist research design. Interpretivist research accepts that objectivity is very difficult to achieve in studies where one human researches other humans (Merriam, 1998), and being explicit about the influence and effect of one's own values and perspectives on the research being conducted is vital. Under this approach it is assumed that interpretations and outcomes are rooted in contexts which exist independently of the researcher, but which will inevitably be influenced by the individual researcher's particular reading of those contexts. Therefore, sensitive awareness of one's own influence in the research process is crucial.

### **3.3 Research tools: Development of photo-vignettes**

An important by-product of the work I carried out for my master's degree was an emerging tool-kit of resources for instigating discussions about mental illness with teenagers (Lindley, 2007). Although my primary aim had been to stimulate enough discussion to generate statement items for use within the questionnaire, I developed an elicitation tool (photo-vignettes) which had considerable capacity to precipitate detailed and reflective discussions about the topic in hand, as well as the potential to be further developed as an educational resource for helping to diminish discriminatory views.

The development of photo-vignettes came about as a result of experimentation with ways of stimulating young people to express their views on issues related to mental illness. I carried out a series of focus groups. The first of these rounds of focus groups was conducted with girls aged 11-13 who were participating in a youth drama group. I spoke to two groups of six girls, each for fifteen minutes. In these discussions I asked direct questions such as "What is mental illness?" I found that asking questions in this way was problematic for a number of reasons – one being that the participants ultimately wanted to be given a 'right' answer to the question posed. Because of this I decided to think about other ways of eliciting discussion and opinion on the topic.

A qualitative methods lecturer suggested to me that a creative strategy might be to find a way of using images to stimulate discussion. I did some research into using images as elicitation

tools, and then carried out an online search using the Google Images search engine. I used search terms such as “crazy; mad; psychiatric; lonely; screaming; desperate; excited; mental; depressed; suicidal; drunk; unhappy; psychotic.” The process of doing this felt uncomfortable and being aware of filtering out images of people who didn’t look ‘mad enough’ made me feel ill at ease and uncertain about taking this approach. It also occurred to me that there aren’t physical indicators of mental illness – a person dressed smartly carrying a briefcase is as likely to be suffering from depression as someone with holey jeans and unwashed hair. I assembled a group of images in spite of my discomfort and reservations, continuing to feel that do so was rather contrived. It has been argued that in a photo-elicitation interview, it is not the photograph itself which is of inherent or crucial interest, but rather that photographs act as a medium between researcher and interviewee, providing a springboard for discussion (Clark-Ibanez, 2004). I took some comfort from this, realising that the only way to find out whether these images had the capacity to operate as such a springboard was to use them in a discussion with young people. I collected 40 images which I felt demonstrated extreme emotion and which could provoke reactions from young people and saved them into a slide show. I then devised a list of questions to accompany the slide show.

I tested out the image slide show and accompanying questions with two more groups of six 11-13 year old girls from the youth drama group. The first thing I did was to show the group the images in succession, showing each image for a few seconds and to ask the members of the group to shout out whatever came into their heads as the images appeared. I then returned to certain images based on the responses the group called out and asked the group to consider these more carefully. This allowed the opportunity to follow up on particular statements and comments which had been made about an image. Focusing on the images which seemed to interest the group most, I asked participants to consider the people represented in these images and asked questions such as:

- What do you think the person in the photo is feeling?
- Why do you think they might be feeling that way?
- What, if anything, do you think is wrong with the person in the photo?
- Can you imagine being this person’s friend?
- Do you think this person is “normal?”
- Does anything make you think this person might be “ill?”

Although I had a prepared list, I did not stick to a fixed schedule of questions and instead allowed the discussion to take its own course. I was particularly interested in the language the

young people used when it related to mental illness, and encouraged them to explain what they meant when certain terms were used.

After reflecting on the results of this focus group and listening to a recording of the discussion, I decided to alter the technique for the next focus group. I compiled a smaller selection of the images, choosing those which had been of most interest or prompted strongest reactions in the previous group. I also composed a series of four vignettes which described individuals whose behaviour could be indicative of experiences associated with types of mental illness. Vignettes have been described as “Concrete examples of people and their behaviours on which participants can offer comment or opinion” (Hazel 1995:2, cited in Barter & Renold 2000). The vignettes I composed were based on personal experience of people I have known, as well as drawing on case study examples of behaviours associated with mental illness taken from first person accounts. I deliberately refrained from using the DSM-IV as a starting point for composing vignettes, and rather tried to compose vignettes which were vague enough to leave space for the young people to define and elaborate on the situations in their own terms. It has been argued that in the application of vignettes, fuzziness is strength and ambiguity productive (Finch, 1987). In this way, it is beneficial for vignettes to be vague enough that respondents need to provide additional factors which explain their judgement decisions in relation to them (Barter & Renold, 1999). This combination of sufficient detail to guide respondents to consider particular themes while leaving enough unsaid to encourage their contributions was what I was aiming for in the construction of vignettes.

I tested these approaches with a group of year 10 pupils at a rural secondary school in Yorkshire, and felt the young people responded well to the stimulus of the photographs and engaged enthusiastically with the vignettes. It occurred to me that the technique could be further refined and improved by combining an image with a vignette. In discussions about the images, it was common for participants to ask questions about the person depicted in the image – wanting to know more ‘biographical’ information about them with which to inform their responses. For this reason, attaching a vignette to the photo seemed to be a good idea. It also occurred to me that the addition of a photograph to a vignette would bring it to life somewhat, rendering the character represented as more believable and easy both to envisage and to empathise with. I reworked some of the vignettes I had already composed, and experimented with combining them with some of the photographs already used. An example of one of these early photo-vignettes is shown opposite.

### Photo-vignette 1



This is Julia. She's in the 6<sup>th</sup> form. Last year she was doing well at school at got Bs in her AS levels. She's pretty popular and has always been fun to be around. Over the last few months she's not been coming to school that much. When she does come she quite often forgets to bring things she needs like books and pens. She's stopped talking to people very much and sometimes when you do talk to her it seems like she's not really listening. One day last week she was in the toilets for a whole morning and when she came out she wouldn't talk to anyone and it looked like she'd been crying. Quite often she sits like this with her hands over her ears. She's done some strange things too, like coming to school wearing an evening dress with a pair of wellies.

## 3.4 PhD Pilot Work

### 3.4.1 Refining the photo-vignette technique

By the time I began pilot work, I had a set of four photo-vignettes which I had used in statement item generation discussions and felt were working effectively. I produced a further two photo-vignettes, and made small changes to the vignette elements of the existing ones, as well as replacing some of the images. I decided to produce a two-stage photo-vignette, in which the same character was depicted at different stages of his life – in the first he was a secondary school pupil, and in the second a middle aged man. I arranged to go into Pears Bank School to experiment with using the photo-vignette technique in discussions. On this occasion, I organised discussions with 6 groups of sixth form pupils. Three of the groups were all female, and three all male, and there were four participants in each group. On each occasion I began each session with very little in the way of introduction, instead presenting each group member with copies of the first photo-vignette and asking them what they thought was going on for the character represented. This proved to be a successful and effective way of instigating conversations and the participants appeared to find it easy and enjoyable to respond to the photo-vignette stimulus.

I carried out an additional round of photo-vignette based discussions as part of the pilot phase. This took place at Charleston High School and involved groups of year 9 and 10 pupils. I worked with 2 mixed groups of four children from each year group. Again, the responses to the photo-vignettes were lively and animated, with participants demonstrating a range of ways of engaging with the subject matter. The discussions about the people represented in the

photo-vignettes also led to broader conversations, including participants sharing their own personal experiences. By this stage I felt very confident in photo-vignettes as an elicitation tool and could see the potential for them to be further adapted and developed. A particular advantage of the photo-vignettes was that it allowed me to instigate conversations without beginning by either offering or asking for definitions of ‘mental illness.’ The photo-vignettes offered a way in to talking about people and their experiences which was free of the difficulties posed by trying to abbreviate what the phrase ‘mental illness’ actually refers to.

### **3.4.2 Research Bags**

During the pilot phase I also tested a technique I had devised which was intended to generate imaginative discussion about what a person with mental illness might be like. I compiled two research bags – one handbag and one rucksack. Each bag was filled with objects. The handbag contained items including a purse, a mirror, some dental floss, chewing gum, makeup, a mobile phone, a set of keys, a notebook, and a pen. The rucksack contained a wallet, keys, map, book of Sudoku puzzles, screwdriver, water bottle, tobacco tin, cigarette lighter. I planned an activity in which groups of young people would be presented with one of the bags and I would invite them to explore the contents. I would tell them that the bag belonged to a person with a mental illness. The idea behind this activity was to give group members a way into exploring the whole person, and to consider the things that might be important to that person through looking at their personal possessions. The bags were intended to be a representation of the interconnectedness of a person’s life, and to stimulate the young people to imagine and invent more narrative detail about the owner of the bag. I was also interested to see how young people would respond to the information that the person who owned the bag had a mental illness, and whether this would lead to particular interpretations of the objects included in the bags.

I arranged to spend a day at Pears Bank School in which I would meet groups of four year 10 pupils to trial the activity. Having invited the groups to explore the contents of one of the bags, I asked them to make up a life story for the owner of the bag, based on the information they had about them. In order to encourage responses from members of the group, I also used prompting questions to stimulate discussion. I repeated the process at Charleston High School, where I spent a day, and worked with eight groups of four year 10 pupils.

Although the discussions were interesting, and the young people who participated in this activity seemed to find it enjoyable and stimulating, I decided not to include this activity to generate data in the main fieldwork. This was mainly because of the fact that the exercise was



asking the young people to respond very imaginatively to the rather narrow and unspecific stimulus of the phrase ‘mental illness.’

### **3.5 Main Fieldwork Procedure**

The main fieldwork engaged a group of seven year 10 pupils. I wanted to facilitate the development of an ongoing process of construction with a group of young people who were socially comfortable with one another. I planned on engaging a group of six pupils, which would be a small enough group for discussions to be quite intimate and for a level of trust to develop but with sufficient members to bring diversity and contrast in terms of contributions. Given that the only example of previous research which engaged young people in group discussion did so only as a single opportunity (Secker, Hill & Armstrong, 1999), I felt that it would be valuable to investigate how a series of discussions held over a period of weeks would impact on the participants’ understandings and opinions. The potential advantages of a series of discussion sessions included that rapport would develop and that the young people may talk to one another or to others between meetings, or mull over issues discussed on their own. Having a series of discussions also meant that it would be possible to approach to topic from a variety of angles, and to use a range of different techniques to stimulate discussion. It would allow for relationships to develop and for a group dynamic to evolve which might mean more honesty and openness emerging as the series of discussions progressed. I also felt that holding a series of discussions over a period of time would increase the likelihood of the content of the discussions staying with the participants. It would also allow for my own relationship with the group to develop and for them to get to know me. I had considered the possibility of talking openly about my own diagnosis of bipolar disorder in the context of these discussions, and felt strongly that the ‘stigma reducing’ potential of this was greatest if the group had had the opportunity to get to know me and form opinions about the sort of person I was before learning this information. This would only be able to happen if a series of discussions was held.

#### **3.5.1 Sample selection and set up.**

The main fieldwork was carried out at Charleston High School. I had developed a relationship with the Life Skills coordinator at the school, Fliss Edwards, through visiting the school when Jest Theatre Company delivered their mental health drama workshop there as well as carrying out pilot work at the school. As a result of this relationship she was very accommodating and helpful in arranging regular access to a group of pupils at the school. I asked if it would be possible to work with a group of six year ten pupils. For practical reasons, the pupils would be selected from a Life Skills class taught by Fliss and would attend

discussion sessions with me during the time they would normally attend Life Skills. Fliss and I had a discussion about how to go about selecting members of the group. Because the intention was to work quite intensively with a small group, rather than to work quantitatively with a “representative sample” I did not have fixed requirements about the characteristics of the sample. I gave only two specific stipulations. These were that I would prefer not to be given a handpicked selection of very well behaved children and secondly that it would be beneficial to group discussion if pairs of friends were included (Mayall, 2000), or at least that the members of the group were likely to be relatively comfortable talking openly with one another. I also explained that I was really interested in getting the young people involved in talking freely, so including those individuals who were likely to enjoy contributing to a debate would be preferred over people who were apt to be very shy or unwilling to contribute to discussion for other reasons. Fliss suggested that she would approach members of the class who she felt would be interested in taking part and who met the criteria I had described. As a precaution against not having enough group members agree to take part, Fliss asked eight individuals if they would be interested. Of these, one said no. The other seven agreed in principal. I prepared some background information about the research to be given to potential participants along with a letter to go to their parents and asked for signed consent from both participants and parents before the research commenced. The information for participants is shown in Appendix 2.

In the first instance it was agreed that I would meet the whole group each week during the time they would usually be in a Life Skills class for a period of six weeks. This gave six one hour sessions in which to hold discussions. I also mentioned that I would like to interview each of the participants individually and it was agreed that they would be able to do this following the main discussion sessions each week. Fliss arranged for me to have use of the school’s careers library as a venue for the discussions to take place.

### **3.5.2 Approach to planning**

While I had prepared some activities and stimulus materials in advance, I did not have a comprehensive plan for the structure and content of each of the sessions before the discussions commenced. Part of the intended research strategy was to use progressive focussing analysis to inform the data generation process, meaning that responses contained within one week’s discussions would be analysed in order to inform the planned content for the succeeding session. I also wanted to maintain the possibility of allowing discussions to evolve and flow without being constrained by tightly planned session content. I went into

each session with resources such as photo-vignettes, personal stories, statistics and news stories available to draw on if, as and when it became appropriate.

### 3.5.3 Procedure

#### Session 1 - 8<sup>th</sup> October 2008.

I started the session by introducing myself as Emma and asked each member of the group to tell me their names. I then explained that I am a researcher from Manchester University. I made it clear that I am not a teacher. I said that we would be meeting each week for six weeks and throughout the sessions I would be interested in finding out what they think, feel and believe. I stressed that I would not be looking for right answers or for them to say what they think I might want them to say. I asked them to tell me what they knew already about what we would be doing. I then split them into two groups - a 3 and a 4 - and gave each group a large piece of paper. I asked one person in each group to write 'mental illness' in the middle of the paper. I then asked all of the group members to choose a pen and to write or draw whatever occurred to them as being associated with mental illness. I asked everyone to contribute, so there wasn't just one person writing in each group. After a few minutes, I suggested that the group think of words or phrases which people might use to describe a person with a mental illness. I said that it was ok to come up with terms which might be considered rude or offensive. Once the groups had both 'dried up' and had no more suggestions to make, I asked individuals to explain more about what they meant by some of the terms or phrases they had written on the pieces of paper. Photographs of the mind maps the two groups produced are shown in Appendix 3. Looking specifically at the terms to describe a person with a mental illness I asked the group to consider how it would feel to have those terms used about them and we had a discussion about that. One member of the group asked me what mental illness is, and I avoided answering the question directly, but reflected back some of the things they had written on their pieces of paper.

I then moved on to introduce the first of the photo-vignettes. *Sarah* is shown in Photo-vignette 2 overleaf.

Photo-vignette 2



This is Sarah. She's in your bunch of mates. She's always been quite quiet. Recently she's started getting angry at random times for no apparent reason and saying pretty nasty things to you and your friends, totally unprovoked. You found her in the toilets crying the other day and you've noticed she looks really tired and pale a lot of the time.

I had produced colour copies of the photo-vignettes for each of the group members and I handed everyone a copy of the 'Sarah' vignette. I read the vignette aloud and then waited to see if anyone said anything before asking, "What do you think is going on here?" The discussion flowed quite freely and naturally from this point so I did not go through a fixed schedule of questions, instead following up comments made by the group with additional prompts and probes. Following this discussion I passed each member of the group a copy of the 'Neighbour' vignette and repeated the process of asking the group what they thought was going on for the character represented and how they might respond to him. This is shown in Photo-vignette 3. At the end of the session I thanked the group for their contributions and said I would see them next week.

### Photo-vignette 3



Imagine this bloke lives across the street from you. You saw him pulling this face through the window recently. You know he lives on his own but the other day when you were walking past you heard him shouting, "No Johnny, No Johnny, No Johnny!" He doesn't have a job, and seems to come and go from his house at strange times of day, sometimes very late at night. He knocked on the door of your house at 7 o'clock in the morning once and asked your dad if he fancied a nice cup of tea.

### Session 2 – 15<sup>th</sup> October 2008

I had originally intended for the second session to be entirely devoted to photo-vignette based discussion. Given that we'd gone through two photo-vignettes last week, I felt it would be a good idea to bring something else to this discussion as well. It had occurred to me after last week that presenting the participants with some facts about mental illness and some information about discrimination against people with diagnoses of mental illness might be helpful, so I downloaded some of the information from the Time to Change<sup>1</sup> website and read it to them. This included statistics about the prevalence of mental illness, and some examples of the types of discrimination experienced by people with mental illness diagnoses. This led to a very rich discussion about risks associated with mental illness, professional roles which the young people felt might not be suitable for people with mental illness and why they had these views. There was some debate and disagreement around these issues. We also talked about the possibility of mental illness amounting to a lasting 'taint' on a person's character, which could amount to them being permanently regarded as unstable or untrustworthy. I went on to present the group with the *Simon 1* photo-vignette, which I read aloud to them. It is shown in Photo-vignette 4 below.

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<sup>1</sup> Time to Change is a national campaign which aims to end discrimination faced by people who experience mental health problems



Simon is 16. He's very brainy and always gets As in exams. He's brilliant at football and is on the United junior squad. He's a bit of a joker and makes people laugh all the time. One day he comes into school with 3 knives and starts juggling with them as he walks down the corridor. He's laughing really loud and he won't stop when people tell him to. Eventually he drops the knives and sits on the floor staring at his feet. He won't talk to anyone but starts muttering stuff under his breath. A teacher starts shouting at him but he just stares at the floor. Eventually he gets up, but he still won't talk properly, just under his breath to himself. His mum comes to get him from school. Then he doesn't come to school for ages.

This led to a very lively discussion about what might be going on for the character represented. One member of the group shared an experience from his own life which led to a rich discussion about 'possession' by evil spirits and the differences between this and psychotic illness. The group members engaged with this issue so I allowed this conversation to take its natural course.

### Session 3 – 22<sup>nd</sup> October 2008

For session three, I borrowed an idea from a Young Minds<sup>2</sup> resource pack on teaching about mental health issues. The exercise involved asking the young people to look through a selection of newspapers and magazines and to pick out photographs, phrases, stories or images which represented things which they felt could contribute to causing mental illnesses. I asked them to cut things out which had some meaning for them. Once everyone had selected a few items I asked them to talk about what they had chosen and why. These responses led to questions and comments from other group members and more detailed discussion about personal and social factors which can contribute to stress. When everyone had talked about the items they had selected, I made some comments about the common themes which had emerged from the things people had chosen. Some members of the group had questions about 'actual' causes of mental illness, so we discussed these. I tried to explain that there are

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<sup>2</sup> Young Minds is a national charity which aims to improve the mental health and emotional well-being of children and young people.

conflicting theories about the causes of mental illness and it is probable that a range of factors contribute to its onset, and I emphasised that even the experts don't know for sure.

I then handed out copies of another photo-vignette – *Simon 2*. I introduced the photo-vignette as a representation of *Simon 1* at a later stage of life. This is shown in Photo-vignette 5.

Photo-vignette 5



Simon is in his fifties. He lives on his own in a flat. Since his teens he has had periods of mental illness - an average of one month every two years when he has been unable to function. He's brilliant at football and loves to coach, but the local team won't let him work with children because of his history of mental health problems. He's very brainy, but didn't go to university or qualify in a profession. He used to work as a computer games designer but lost his job ten years ago after having to have time off when he was unwell. Now he works as a volunteer, helping to run a website about sports opportunities for young people. He has a great sense of humour and likes making people laugh but doesn't have many close friends.

I encouraged the group to reflect on how mental illness had affected the man's life and whether or not it was fair that he was prevented from carrying out certain activities on account of his mental health status.

#### Session 4 – 12<sup>th</sup> November 2008

I developed a narrative building game to use in session four. I prepared a selection of laminated cards, in several categories. These were:

- Short descriptions of mental illness experiences and behaviours
- Photographs of people
- Occupations
- Photographs of houses
- Family status
- Photographs of leisure activities/ interests
- Personality traits

I began the activity by reading out one of the descriptions of mental illness experience. I then asked the group to look through the photographs of the people and choose a person who they felt the description could be about. The next stage was to choose one card from each category, thereby building a set of characteristics about the person. I asked them to elaborate on the character profiles they had created, and to use their imaginations to invent more detailed narratives about each person. We repeated this process three times, using a different description of mental illness experience as the starting point on each occasion. The profiles that were created were laid out on the table and left in place. I then retold each story using some 'real' biographical information about the people shown in the photographs. After the stories were retold in this way, we repeated the original exercise twice more using new descriptions of mental illness as starting points. Images depicting an example of a group constructed profile alongside the retold 'real' story are shown in Appendix 4.

### **Session 5 – 19<sup>th</sup> November 2008**

I used a range of pieces of information as stimulus material for discussion. I began by reading out some of the symptoms listed in the DSM-IV for major depression, bipolar disorder and generalised anxiety disorder. I asked the group to comment on these and to consider how they related to their own life experiences. I explained in as simple terms as I could Szasz's arguments as to why mental illness is a myth and encouraged the group to explore what this might mean. Having read out the symptoms of bipolar disorder from the DSM-IV, I went on to read out a short life story taken from 'You don't have to be famous to have manic depression' (Thomas & Hughes, 2006). In the account a successful business woman explains how having manic depression helps her to be extra productive in her professional life and despite the difficulties that come with it she wouldn't have her life any other way. The group discussed this in some detail. I asked them whether if the narrator of the story were to walk into the room they would be able to tell that she had a mental illness and the group expressed a range of views about this.

The last twenty minutes of the session involved me sharing the fact that I myself have a diagnosis of bipolar disorder with the group, giving some basic narrative detail about the events which led to my diagnosis and some information about how the condition has affected my life. Members of the group expressed surprise and a range of other responses which we discussed.

During the session I noticed that Kamal was fiddling with the voice recorder. I asked him to stop and moved it away from him, but thought no more of it at the time. I later discovered that the recorder had been switched off about thirty minutes into the session. This meant that



I did not have a recording of the part of the discussion in which I made my disclosure. However, I did write a detailed account of the session in my research diary a few hours after the session had taken place.

### **Session 6 -3rd December 2008**

During the sixth session I asked the group to reflect on the previous discussion sessions. I asked them to tell me what they remembered particularly about the process, and what they liked and didn't like. I also asked them to talk to me about specific activities we had done in previous sessions and to reflect on what had worked well and what hadn't. We had a further discussion about what they thought they would remember about the discussion process in a year's time. One of the group members, Malik, said that he would remember "your bombshell, miss," referring to my disclosure of my own mental illness diagnosis. Another group member, Molly, had not been present in the previous week's session, so this led to other members of the group explaining what I had told them and another discussion about my experiences in which Molly asked a number of questions. I then reminded the group of the content of each of the previous sessions and asked them to comment on anything which still interested or puzzled them, as well as asking for feedback on how activities could be improved or changed. I thanked all of the members of the group for participating actively and fully in the discussion sessions.

#### **3.5.4 Individual follow-up interviews – phase one**

I carried out two phases of individual follow-up interviews. After the end of the main group discussion sessions, I arranged to go back to the school to interview each of the participants individually. I did this one month after the end of the series of group discussions. These conversations were relatively unstructured, and I asked participants to reflect on the process, to tell me about anything which stood out in their minds in particular. I also asked them to tell me what, if anything, they thought they would remember about the process, and how they would describe what we had done to a third party.

#### **3.5.5 Experimenting with attitude measurement instruments.**

I acquired a copy of Otto Wahl's attitude to mental illness questionnaire which aims to measure the degree of stigmatisation in adolescents' attitudes to others with mental illness diagnoses (Wahl, 2009). I arranged another discussion session with all seven members of the original group in the spring of 2009 and asked members of the group to complete the questionnaire. After they had completed it I asked what they thought about the process of

completing it, and how they understood some of the questions that had been asked of them. We had a lively discussion about the content and meaning of the questionnaire<sup>3</sup>.

### **3.5.6 Individual follow-up interviews – phase two**

The second phase of follow up interviews was carried out shortly after the group discussion about the questionnaire. In order to generate fruitful conversation and to kindle the memories of the participants, I prepared an activity to stimulate conversation as an alternative to asking questions from a schedule. I selected nine quotes from the transcripts from the group discussions and printed these onto cards. I placed them on a table and asked the interviewee to read through them all and then to choose the one which stood out or had most meaning for them. I then asked why they had chosen that particular quote and what it meant to them. I followed up their responses with comments and questions as appropriate. During these discussions I also asked other questions including whether there was anything which still puzzled or interested them about things we had discussed in the sessions. I also asked the interviewees how they would sum up the work we had done together in just one word. In order to get them to reflect in a different way, I asked them to recall the funniest moment and the most embarrassing moment. In an echo of the content of the first round of individual interviews, I also asked them to tell me how they would describe what we had done to someone else, and what, if anything they would particularly remember about the sessions. Each of these discussions panned out slightly differently from one participant to the next, and while I tried to cover similar material in all of the conversations, they each took on their own shape.

All of the group discussions and individual interviews were audio recorded using a digital voice recorder. They were transcribed in full.

## **3.6 Critiquing the value of data: trustworthiness**

It has been argued that *rigour* is one of the hallmarks of positivist research, and that demonstrable validity is an attribute that makes it both reliable and consistent (Robson, 2002). Interpretivist research has been criticised for being merely subjective, and impossible to replicate or generalise from (Mertens, 2009). Certainly, the ways in which one can argue for the trustworthiness of interpretive research are different to positivist evidence of validity (Lincoln & Guba, 1985) but that is not to say that trustworthiness is impossible either to achieve or to demonstrate. I will now consider the status of the data which comes out of the

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<sup>3</sup> It was beyond the scope of the present thesis to analyse this data.

process described above, and to address questions which relate to how trustworthy or otherwise is the data generated.

Attempts have been made to identify criteria by which the quality of qualitative research can be judged. For example, Lincoln & Guba (1985) propose four dimensions of trustworthiness in qualitative research, namely credibility, transferability, dependability and confirmability. These constructs address similar concerns to the criteria employed in positivist research to ascertain validity. Credibility is proposed in preference to internal validity; transferability as opposed to external validity/ generalisability; dependability as an alternative to reliability and confirmability in place of objectivity. Whether reframing positivist criteria for validity in order to make them applicable to the qualitative paradigm is appropriate, relevant and ultimately useful cannot be taken for granted (Hammersley, 2007). It has been claimed that attempts to apply any criteria to qualitative research inevitably results in misunderstanding and discrepancy because such criteria are fundamentally incompatible with the philosophical assumptions of this type of enquiry (Smith 1984, cited in Hammersley 2007). Furthermore, it has been suggested that overreliance on the idea of a universal system of rules for the assessment of quality in qualitative research may be damaging in that it overlooks the importance of the particular context of any given research enterprise (Hammersley 2007). Therefore it is necessary to bear criteria such as those proposed by Lincoln & Guba (1985) in mind, while maintaining flexible judgement about the particular research activity being undertaken. One of the crucial differences between the credibility of quantitative and qualitative research is that in the former, credibility depends on the strength of the instruments used to conduct the research. In the latter, the researcher *is* the instrument of the research (Golafshani, 2003), and in this sense it is much more complicated to reach an objective judgement about quality and credibility, especially if, as in the present case, it is necessary to apply this judgement to one's own research activity.

In the current study, the status of the data which was generated by the procedures adopted is firmly rooted in the methods used to engender it. The dynamic of the particular process that was facilitated, in which safe group engagement was sought, was uniquely created by the individuals who participated, including the facilitator/ researcher. Given that each individual in the group brought their own perspectives and understandings, and the synthesis of these created its own distinctive dynamic, it would be naive to imagine that a replication of the same process engaging a different set of individuals would result in similar results. The interaction between members of this discrete group was particular to the social context that was created by that group, and it is likely that a different set of individuals would relate differently,

bringing different understandings to bear. However, this does not impinge on the credibility of the data which has been generated by the process; rather, it highlights its idiosyncrasy and distinctiveness. Particular attention has been given to providing transparency and clarity in the description of this process, which should contribute both to the credibility and transferability of the work undertaken. Although the results which may emerge from repeating the same procedures with a different group of participants would be likely to be quite different from those reported here, they would nevertheless be valuable, meaningful and credible.

Despite the criticisms of Lincoln & Guba's (1985) criteria for establishing trustworthiness in qualitative research, it is nevertheless worthwhile to consider them in the relation to the present study. Credibility in qualitative research deals with the extent to which the findings of the research are congruent with reality (Shenton, 2004). There are number of steps which can be taken to ensure that the phenomena being researched have been accurately recorded. One of these strategies is to ensure that the research methods employed are well established and reputable. In this case, the main method of data generation was the group interview, with individual interviews also being carried out. Interviewing is one of the standard methods used frequently in qualitative research (Silverman, 2005) so the present study employed recognised methods. It is also helpful to note that the use of group discussion and interview was appropriate to the subject matter of the research. The fact that a 'thick description' of the procedures of data generation has been provided further contributes to the credibility of the resulting data. The background, qualifications and direct experience of the researcher is also highly relevant to the credibility of qualitative data (Patton, 1990). Given that the researcher is the primary instrument of the data generation and analysis, it is very important that that person is appropriately positioned as well as having the capacity for reflexive self-examination. My own personal experience of mental illness was certainly helpful here, along with my experience of drama youth work and my particular style and approach to conducting group discussions was a significant factor in the success of the process. Other ways in which credibility can be enhanced include ensuring frequent debriefing discussions with a colleague or superior are held throughout the data generation process (Shenton, 2004) - in this case the PhD supervisor. I met my supervisor soon after each of the group sessions in the six week series, and reflected on what had occurred and the development of my approach in the succeeding sessions.

Transferability in qualitative research is equivalent to the positivist notion of external validity. External validity is concerned with the extent to which the findings of one study can be applied to other situations. Because the findings of interpretivist research are specific to the

individuals participating and the environment in which it was conducted, it isn't possible to demonstrate external validity in the same way it would be for a quantitative study. However, transferability can be ensured by providing sufficient contextual information about the conduct of the study to enable others to make inferences about how transferable the work might be to another situation. Again, a detailed and precise 'thick description' of the research procedures adopted is crucial in order to enable readers to have as full an understanding of what took place as possible. The results generated by any qualitative study have to be understood in terms of the context in which the work took place, and this study is no exception. Inasmuch as it is ever possible to be confident of the transferability of a qualitative research project, it is possible here in that contextual information has been provided along with a thorough description of procedures employed.

The third of Lincoln & Guba's criteria for trustworthiness is dependability. This is derived from the idea of reliability in quantitative research. In a quantitative study, reliability describes the extent to which, were a study to be repeated using the same methods, in the same context, with the same participants the results would be the same. Given that one of the strengths of this study came out of the particular group dynamic which arose partly as a result of my own particular rapport with the participants, it is likely that if the study were repeated but carried out by a different researcher that the results would differ greatly. It is also likely that if I were to repeat the study, the results would not be identical on account of the fact that the participants would have already participated once and therefore their opinions, knowledge, beliefs and positions in relation to mental illness would have been affected. Lincoln & Guba (1985) make the point that in qualitative research there is a close relationship between dependability and credibility, and many of the steps taken to demonstrate credibility will similarly have the capacity to establish dependability. For example, dependability can be increased by providing a detailed and accurate description of the procedure and methods employed so that another researcher would be able to closely replicate the study if they so wished. The use of overlapping methods, for example using individual interviews in addition to focus group discussions is also recommended (Marshall & Rossman, 1999). Both of these are steps which have been taken in the present study.

The final criterion for trustworthiness proposed by Lincoln & Guba is confirmability. This is the qualitative research equivalent of objectivity. Objectivity is extremely difficult to achieve even in a positivist study because all research instruments are designed by humans and the incursion of researcher bias is therefore inevitable (Patton, 1990). However, that it is difficult to achieve does not mean that confirmability should not be strived for. The aim is to take

steps to make sure that the findings of the research report the experiences and viewpoints of the participants in the study rather than the preferences and interpretive bias of the researcher (Shenton, 2004). One of the key strategies for improving confirmability is for the researcher to be willing and able to disclose and reflect on their own predispositions and the potential for these to influence outcomes. An ongoing reflective commentary, which may well form an integral part of the 'thick description' provided in the analysis as well as methodology is one way of making sure that appropriate attention is given to this matter (Miles & Huberman, 1994). Given that my role in the study was very much embedded into the data generation process, an open and honest reflection of the impact of that is a necessary part of the analysis of the data which have emerged. Detailed description of exactly how the research was carried out has been provided and this, along with a serious attempt at reflecting on how my own beliefs and judgments are likely to have coloured this research should contribute to the confirmability of the work.

Trustworthiness in qualitative research is ultimately concerned with the extent to which the work can be considered to be academically sound. In order to convince a sceptical reader of the solidity and reliability of a piece of research it is necessary to be transparent about how data were generated and how analysis of those data was conducted. This is best done by providing a detailed and open account of what was done and the processes of thought which led to decisions being taken and conclusions drawn and this is one of the endeavours of this thesis. The degree to which this has been successful in the present case can only be judged by the reader.

### **3.7 Ethical Considerations**

The ethical considerations given to the conduct of the present research were both general (e.g. consent and confidentiality) and specifically related to the research methods used and the topic in hand. Informed consent for the current research was obtained both from the participants themselves as well as from their parents. Information about what would be involved in participation was provided and it was made clear that participants would have the right to withdraw at any stage and that anonymity and confidentiality would be ensured throughout. In addition, the possible uses of data were made clear and participants told they would be able to see any published material arising from the research if they so wished<sup>4</sup>.

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<sup>4</sup> A journal article was published in February 2009 which reported on the methodological development for this study, and this was shown to the participants. Media coverage of the publication of the article appeared in the *Times Educational Supplement* and *BBC Education Online* and these articles were also made available to the participants.

Ethical approval for the study was obtained from the School of Education ethics committee before commencement.

In addition to these general matters, a number of other ethical considerations arose in the planning and conduct of this research. It was important to be aware of the likelihood of the content of the discussions striking some personal resonance with members of the group. Mental illness is common and it would be naive to imagine that the participants in this study would not have family members or friends whose lives had been affected by it in some way, or indeed have concerns about their own mental health. Because of the potential for the issues to cause the young people to think about their own potentially troubling experiences it was important to consider how to respond in the event of emotional distress emerging and to ensure that appropriate mechanisms for support were in place. The teacher overseeing the research was also the form tutor of all of the participants. She agreed to take on pastoral responsibility for them during the research process and it was made clear to participants that she was available to discuss any concerns or difficulties arising as a result of the discussion groups. I agreed to report any concerns I had directly to her as soon as they emerged.

There was also a need to give due consideration to the ethical dimensions surrounding my intention to disclose my own diagnosis of mental illness with the group. I told the group about this during the fifth session, and one of the most striking responses was that group members apologised to me for negative comments they had made about people with mental illness in general prior to learning this information about me. It was evident that they felt they would have responded differently had they been party to this information from the outset. The need to avoid eliciting socially desirable or biased responses was one of the reasons that I chose to introduce the information in the latter stages of the discussion series. I also felt that allowing the group to get to know me first would increase the potential destigmatising power of the disclosure. From the participants' point of view, however, it became clear that they felt a little as though they had been lured into a trap – I'd encouraged them to speak freely and say things under the pretext that they and I shared the same perspective as people without diagnosis or experience of mental illness reflecting on the experiences of others. It had quite honestly not occurred to me that the young people would feel this way. I had assumed that they would be surprised by me disclosing my diagnosis, but I had not considered that withholding the information only to reveal it later would have the effect of making them feel manipulated. I responded to this reaction by encouraging the group to tell me more about how they felt, and to ask me any further questions. I also explained that I had not taken any of their comments personally and was in no way offended by the things they had said in earlier discussions prior

to them learning of my diagnosis. In this way I was able to demonstrate that I took their feelings on the matter seriously.

Statements about the ethical considerations in the conduct of research often focus largely on the question of how best to avoid causing harm to the participants as a result of engaging them in a research process. Questions around the positive ethic of setting up a particular research process are very often overlooked. It is useful, therefore, to reflect on what the potential benefits to the participants may have been of being involved in this research. In a sense, this was not purely a research process, but could also be regarded as an educational intervention in its own right. Although learning objectives and outcomes were not identified as a central aim of the discussion series, the process of sustained engagement in discussions about a particular topic is likely to have had an educational impact on those who took part. Mental illness is a topic which is largely overlooked within the mainstream curriculum, and while it is an issue of significance and interest to secondary school pupils, formal opportunities to discuss and explore it are rarely presented. The particular approach taken here, which was open and constructive rather than didactic and directive, allowed the participants to explore the issue in their own terms, using their own language. The benefits in terms of increased confidence in occupying discourse on mental illness, as well as learning to explore a complex and sensitive issue as a group should not be underestimated. The tone of the discussions was also quite different from standard classroom exchanges, and the aim was to avoid being patronising, moralising or purely instructive. Instead, an open process of exchange of ideas and exploration of understanding was the aim. In this way, the participants were treated as independent and autonomous adults, whose opinions were to be taken seriously. Clearly, my ability to offer 'objective' judgment on this positive ethic is clouded by my proximity to the research process, and my personal experiences of developing rapport with the individuals in the group. However, despite its subjectivity, I can comment that it was my strong impression that all of the members of the group felt their involvement in the discussions had been a positive experience which they benefited from.

### **3.8 Summary of methodology**

This chapter has given an account of the methodological considerations taken into account in the development and implementation of the present research study. It has outlined the evolution of the approach taken to the research and the emergence of one of the key research tools (photo-vignettes) used in the study. Activities undertaken in the pilot work phase were described, along with a precise description of the procedure followed in the set up and



execution of the main fieldwork. It has considered issues affecting the trustworthiness of the data and finally, the ethical considerations running throughout the study were discussed.

It is important to be explicit about the nature of the relationship between the theoretical framework underpinning the work and the practical procedures undertaken. Having established that mental illness is an essentially contested concept and that the dominant discourse is not the only way of construing the issue, it was clear that in order to investigate educational approaches to the topic it was important to find out first how young people already make sense of the issue. This is in line with constructivist educational strategy (Gale & Steffe 1995). Most previous work investigating young people's knowledge about mental illness has done so by assessing the extent to which young people appeared to be au fait with the biomedical perspective on mental illness (Wahl 2002). Therefore methods were needed which could explore understandings which might not be conceptualised or expressed in the language of the dominant discourse. Given that very little previous work had looked in detail at young people's understandings in their own terms, it was necessary to find an approach which would be sufficiently expansive and inclusive to be able to do this. Therefore, the most suitable methods to apply were qualitative. In order to fully explore the ways young people construct discourse on mental illness, it seemed most appropriate to engage them in group discussions with peers. The activities were designed to reveal what kinds of things they think about when they hear the phrase 'mental illness,' and how they made sense of accounts of individual experiences, which, from a biomedical perspective, could be regarded as mental illness. An approach was taken which avoided imposing the terms of the dominant discourse on the young people participating, and encouraged them to use their own idioms.

The need to maintain focus on the young people's own ways of expressing their interpretations of the topic of mental illness was also an important consideration in the analysis of the data. The strategies taken to attempt this are described in the following chapter.

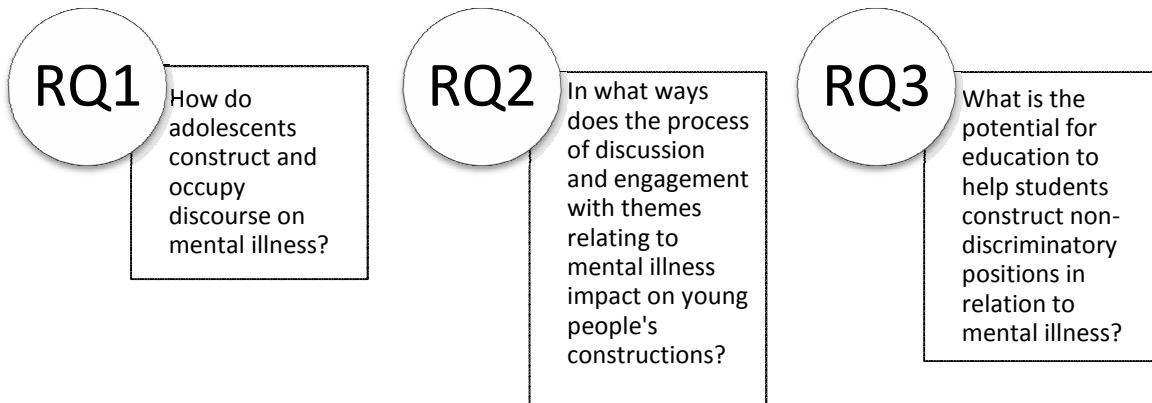
## Chapter 4: Analysis and Findings

*Because each qualitative study is unique, the analytical approach used will be unique.*

Michael Quinn Patton (2002)

### 4.1 Introduction

The aim of this chapter is to present the findings of the research process described in Chapter 3, and to consider them in relation to the research questions.



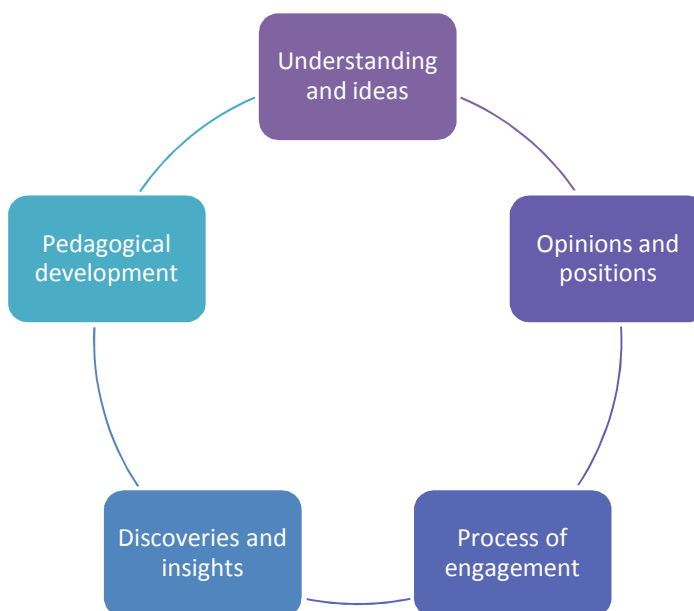
A second feature of the chapter will be to demonstrate how the findings emerged from the process of engaging with the data. The analytic process involved taking a grounded approach to considering the data in the first instance which, while being informed by an interest in the research questions, was also deliberately distanced from them. This first order analysis led to the identification of five categories of findings which were explored in detail using a coding procedure and fine grained analysis of the data. Before engaging directly with the research questions, this initial engagement with the data will be presented. The research questions will then be addressed, drawing on the data to demonstrate how answers have been reached.

There are three main sections within this chapter. Firstly, the analytic method which was employed in order to generate the findings will be described. Secondly, there will be a brief introduction to the research participants followed by a discussion of first order findings, and finally, a thorough exploration of the research questions will be presented.

## 4.2 Analytic strategy

The analytic strategy adopted for dealing with this data was eclectic and inductive, informed by some of the principles of grounded theory (Glaser & Strauss, 1967) and drawing on approaches used in content analysis (Weber, 1990) thematic analysis (Green & Thorogood, 2009), discourse analysis (Coyle, 1995), narrative analysis (Riessman, 1993) and interpretative phenomenological analysis (Smith, Flowers & Larkin, 2009). This amalgam approach evolved through the need to remain close to the data and to maximise the ways in which it could be used to answer the research questions. The analytic process began with writing detailed reflections on the transcripts and the experience of running the sessions. These reflections took the form of a chronological narrative account of the discussion sessions of which the core fieldwork was comprised, drawing on field notes and early analytic accounts written during the data generation phase. An extract from these accounts is included in Appendix 5. They described the shape of each of the sessions and aimed to draw out significant features and highlight critical incidents. Through a scrutiny of these reflections and a thorough discussion of their content with my supervisor, I began to identify categories of findings. At this stage I was looking for themes and in this sense this was a thematic analysis. However, it was necessary to take an interpretative approach to the data in order to generate the themes. These fell into five groups, shown in Diagram 1.

Diagram 1: Initial categories of findings



Firstly, there were findings about the knowledge and ideas that the participants contributed during discussions. Secondly, there was a set of findings which were to do with the opinions and positions demonstrated by participants during the discussion series. Thirdly, there was a

set of findings to do with the process of discussion and engagement with the issues in hand. Fourthly, there were a number of discoveries and insights made by the group during the period of engagement. Finally, there was a set of findings which related to pedagogical matters, including the participants own views on facilitated activities and the features of the series of discussions they had taken part in. These categories were deliberately generated without conscious reference to the research questions. The reason for taking this approach was to remain open to the unexpected and avoid being constrained by the need to answer the research questions. However, relationships did emerge between these categories and the research questions and these are shown in Diagram 2 on page 116. The identification of these categories of findings was based principally on intuitive observations and interpretations. While this approach is a legitimate and important element of the process of data analysis (Silverman, 2006), I felt that the robustness of the findings would be enhanced through employing a systematic approach to examining how the examples of each of these categories of findings played out within the data. Therefore, I decided to use a coding procedure to enable me to interrogate the data strategically. I used the five category headings to begin to construct a coding frame which would allow me to investigate how each of the themes appeared within the data. I explored the possibility of using a technically described system to do this, considering mapping my approach onto formal coding procedures as described by Saldana (2009). However, I decided it was more valuable to remain close both to what was actually going on in the data, as well as the interest in exploring the research questions which underpin this study. Therefore, it is most appropriate to describe the coding strategy I employed as interpretive (Mason, 2002).

Using the initial categories of findings, a coding frame was constructed, with specific codes under each of the five group headings. The transcripts from the six discussion sessions which made up the core fieldwork were then coded using this framework. This meant that it was possible to identify each instance of a particular phenomenon as it occurred. I began with the five group headings with several key codes under each of them. The process of coding the data in this way meant that I worked through all of the transcripts line by line in a fine grained analysis of the content. Engaging in this process meant that I noticed things going on which I had not necessarily given a great deal of attention to when writing the reflective summaries of the sessions. Therefore, it became necessary to add more codes in order to give due recognition to the range of phenomena I was observing. An example of a coded transcript is shown in Appendix 6. The final coding frame is shown in Table 2 on page 110.

The location of data corresponding to each code was recorded in a table so that each example of a particular coded phenomenon was easily identifiable. Once this table was complete, it was possible to see at a glance which phenomena were most prevalent in the data. It was also possible to identify patterns in when particular phenomena occurred during the discussion process. For example, it became apparent that discoveries and insights made by the participants were weighted towards the latter half of the discussion series. This table, showing the completed coding frame is shown in Appendix 7.

In order to further refine the first order findings, the first three categories of the coding frame were re-examined and synthesised, generating fewer codes. The original codes were thus rearranged into more logical categories. Reorganising the data in this way made it possible to present the findings under each category in a more streamlined and coherent way. It also represents an interpretive stage, changing the meaning of the five categories to some extent. The refined coding frame is shown in

Table 3 on page 111.

Table 2: Coding frame

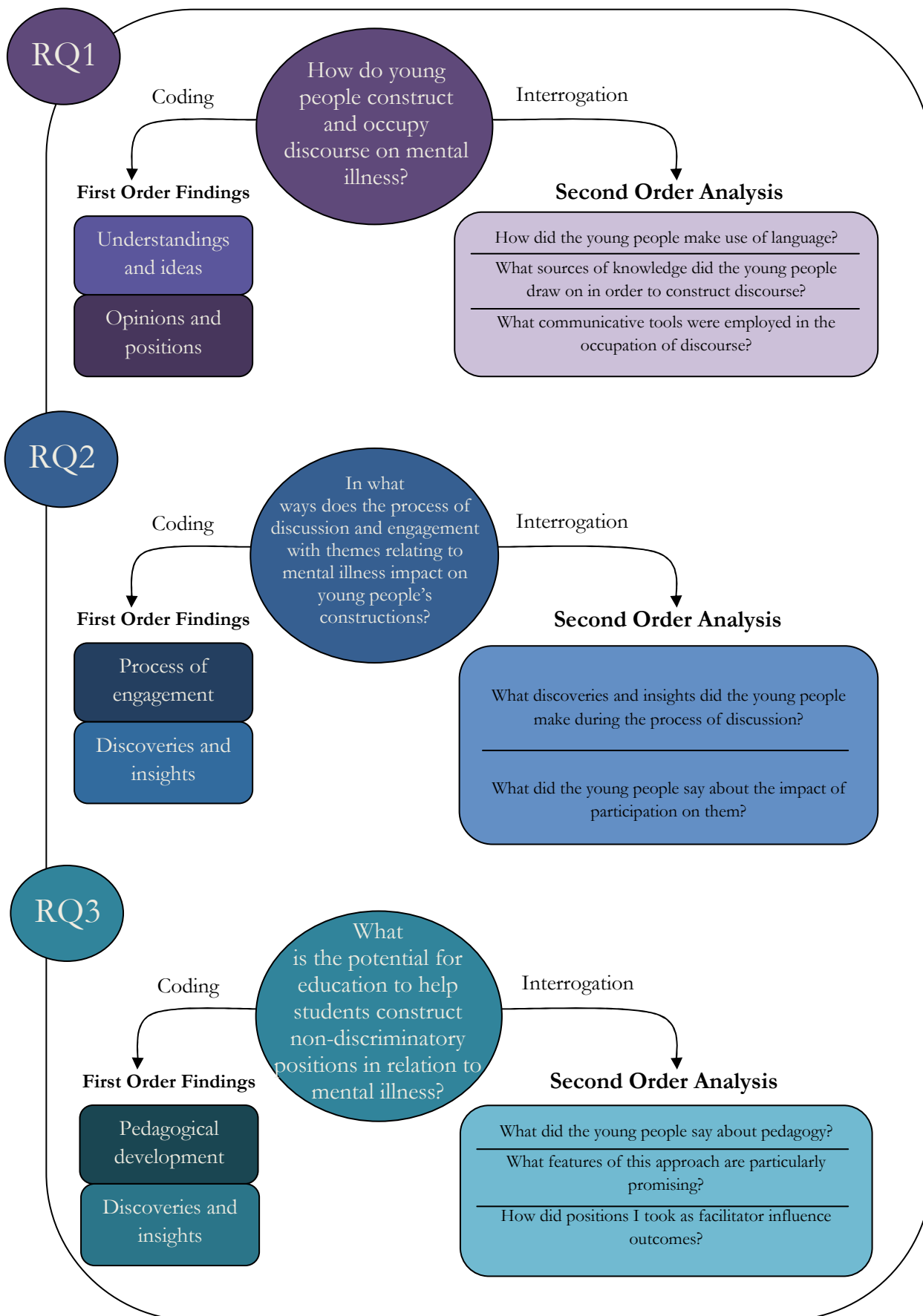
<b>Understandings and ideas</b>	
K1	Features of mental illness
K2	Firsthand experience
K3	Use of medical terminology
K4	Ideas about causality
K5	Uncertainty about normal responses to stress/ mild/ severe mental illness
K6	Vagueness about distinctions between m.i./ learning disability/ physical disability
K7	Use of vague slang terms
K8	Information from films/ television
K9	Suggestions for coping strategies/ responses
K10	Ownership of language
K11	Tendency to explain in psychosocial terms
K12	Ideas about genetics/ biology
K13	Unfamiliarity
K14	Individual predisposition
<b>Opinions/ Positions</b>	
O1	Risks means people with m.i. should be controlled
O2	Empathy
O3	Lack of empathy
O4	Pity
O5	Contradictory positions
O6	Fear
O7	Sympathy
O8	Ambivalence
O9	Respect
O10	Deficit view
O11	You shouldn't be judgemental
O12	Interest
O13	Acceptance
O14	Inevitability
O15	'Honest' reasons
O16	Dangerousness
<b>Process</b>	
P1	Collaborative meaning making
P2	Challenging each other's positions
P3	Questioning each other
P4	Digesting ideas
P5	Asking EL for clarification about 'facts'
P6	Asking EL for clarification about whether there are right answers
P7	Making associative leaps
P8	Visualising the vignettes/ characters
P9	Preserving group solidarity
P10	Politeness in expressing conflicting views
P11	Attempts to imagine others' experience
P12	Direct personal comments
P13	Surprise at each other's contributions
<b>Discoveries and insights</b>	
D1	You can't see mental illness
D2	Mental illness doesn't necessarily equal substandard living
D3	You can't know what it's like unless you've experienced it
D4	There can be positives associated with having mental illness
D5	Surprises and inversion of stereotypes
D6	You can get mental illness at any time
<b>Pedagogical process</b>	
G1	Effect of mind mapping exercise
G2	Effect of photo-vignettes
G3	Responses to newspapers exercise
G4	Effect of profile building exercise
G5	Importance of the small group

Table 3: Refined coding frame

<b>Understandings and ideas</b>	<b>What mental illness is</b>	Features of m.i.
		Firsthand experience
		Confusion/ vagueness/ lack of knowledge
		(Mis)information from films/ TV
	<b>Causality</b>	Psychosocial
		Supernatural
		Biological
		Drug induced
	<b>What to do about it</b>	Medical help, therapy
		Spiritual solutions
<b>Opinions and positions</b>	<b>Negative</b>	Scary/ weird
		Assumed to be dangerous
		Avoid contact
		Risky -should be controlled
		Pessimism/ deficit
		Lack of empathy
	<b>Positive</b>	Interested
		Respectful
		Showing empathy and understanding
		People shouldn't be judgmental
	<b>Ambivalent</b>	Scepticism
		Pity
		Contradictions/ oscillating positions
<b>Process of engagement</b>	<b>Getting their heads round it</b>	Visualising the protagonists
		Adding detail
		Attempts to imagine others' experience
		Making associative leaps
		Asking EL for facts
		Checking with EL re: right answers
	<b>Collaborative meaning making</b>	Questioning each other
		Challenging each other's views
		Digesting ideas
	<b>Preserving group solidarity</b>	Politeness when expressing
		Surprise at each other's contributions
		Direct personal comments

Once the first order findings had been analysed in this way, a second order analysis was conducted in order to thoroughly interrogate the research questions. Many of the first order findings were directly relevant to the research questions. However, I felt there was also a lot of untapped richness in the data, which would be valuable in reaching more thorough answers to the research questions. Therefore I devised sub-questions to enable a closer interrogation of each of the research questions, and in addressing those questions combined new analysis with an underpinning attentiveness to the first order findings. The analytic strategy is summarised in Diagram 2.

Diagram 2: Analytic Strategy





### 4.3 Introducing participants

Before discussing the first order findings in detail, I will provide some introduction to the individuals who made up the group. Because the main fieldwork engaged a small group of participants, and I worked with that group quite intensively over a period of time, it will be useful to the reader to have some sense of who's who. In this section I will provide a brief profile of each group member. The names of participants have been changed. The aim here is to give a sense of the personalities and dynamics between personalities within the group. I did not formally gather biographical information about each of the participants, but I did interview them each individually and during these discussions learnt more personal information about them. It is important to note that these are my own, unavoidably subjective observations and it is my perspective of the young people being presented here. I did not systematically ask each participant the same questions, so the content of each profile differs depending on what came up in conversations and group discussions.

#### **Molly**

Molly comes across as confident, articulate and bright. In the first session she demonstrated a concern for using 'appropriate' language and not causing offence to others. It seems that she is genuinely caring and thoughtful with a sincere desire to avoid saying or doing the wrong thing. In group discussion, she is capable of giving as good as she gets if challenged, and doesn't stand for any nonsense from the boys, although there was quite often banter between them. She is good friends with Rachel and they talked about the content of sessions in between meetings. Molly told me during a one on one conversation that her dad uses cannabis on a regular basis and she was interested in the link between cannabis use and mental illness. She did not want to share this information with the group but was very keen to talk about it with me. She felt that it would be embarrassing for others to know that her dad uses cannabis and she wouldn't want people making judgements about it. She also told me that her parents are separated and she lives with her dad.

#### **Rachel**

Rachel seemed to be really rather shy and unconfident at the beginning of the discussion series. In field notes written after session two I observed that she is "almost cripplingly quiet and socially awkward, so much so that when I looked her in the eye and addressed her directly she blushed very deeply and avoided looking up for some minutes afterwards. She seems to be quite intimidated by her peers and doesn't appear to have the confidence to speak up unless backed up in some way by Molly." Rachel spoke rarely in the early discussion sessions, but when she offers contributions they tended to be thoughtful and constructive. She made more contributions towards the end of the series, and it was my impression that she became more

self-assured as the sessions progressed. When I interviewed Rachel six months after the end of the discussion series her confidence seemed to have developed and she came across as being much more self-possessed than she had during our regular meetings. She made eye contact frequently throughout our conversation and seemed much more comfortable than she had in previous individual interviews. Throughout the whole process Rachel seemed to be interested and engaged in the discussions and to listen intently to what was going on even if she did not always make a lot of contributions.

### **Simone**

Simone comes across as being very mature and sensible. She seems quite self-assured and self-contained. She seems to be generally well-liked by everyone in the group. She has the respect of the boys and is friendly with the girls, although she doesn't seem to 'belong' to either of the bonded groups (Molly and Rachel/ Rahim, Farzan and Malik). My impression is that she has good-natured values and would always try to do, say and think the right thing in any given situation. I'm sure she would never deliberately insult or offend another person. She's bright, and obviously thinks about things quite carefully. She told me during a private discussion that her father died and she was aware that bereavement like this could contribute to mental health problems. She also told me that her family are closely involved with a church and she feels that the community support offered by the church is a positive, protective factor against mental illness.

### **Malik**

Malik seems less mature in some ways than the other boys. He's clearly good friends with Rahim and Farzan and, like both of them appears to have an agenda to do with impressing the others and displaying a certain amount of bravado. He joked around quite a lot, but unlike the other two, when it became necessary to 'get serious,' he seemed to me to find it more difficult to do so. In one on one conversation Malik genuinely found it difficult to comment on some issues, on one occasion saying "I don't know what to say." He told me that he has never had any direct experience of anyone with a mental health problem. He sometimes seemed a bit bewildered by the subject matter although he appeared to be interested in the discussions and made comments throughout which indicated he was engaged by the process.

### **Rahim**

Rahim is clearly very bright and was an interesting and sparky member of the group. He is good friends with Malik and Farzan His teacher had said to me before the work began that he was "a bit rough round the edges" and to keep an eye on him. Occasionally he would mess around and behave in ways which would likely be very irritating to a teacher I found this minimally intrusive and he was responsive to being asked to stop. In one to one conversation

Rahim was thoughtful and gave careful consideration to his answers. He was impressively honest, both in group discussion and on his own – for example being prepared to tell me that he would probably take the mickey out of a person with mental illness to join in with the group, but simultaneously feel sorry for that person and bad about his own actions. In some sessions Rahim seemed slightly withdrawn and I sometimes wondered whether he was unhappy or lacking confidence.

### **Farzan**

Farzan handled himself with confidence throughout the discussion series. He is good friends with Malik and Rahim. At times Farzan would play up to the role of the group joker and the laddish dynamic between him, Malik and Rahim would lead to all three of them appearing to try to impress one another. Despite this, Farzan was adept at switching out of the joker role and taking things seriously, being well able to comment and reflect when pushed to do so by others in the group as well as by me. Farzan's perspective on mental illness was interesting in that he felt it would be useful for him to understand the issues in more detail in case he ever needed to support his children through difficult times. He seemed to see himself in this role of responsibility and to not consider his own potential vulnerability to mental illness. This was in contrast with Molly, Kamal, Simone and possibly Rahim.

### **Kamal**

Kamal is not part of the friendship group of the other three boys and in some ways this made it more difficult for him to contribute fully to discussion. The other boys were sometimes somewhat scathing towards Kamal's responses, and it seemed to be difficult for him to know how to place himself in the face of this. He came across as being less mature than some of the other members of the group and was perhaps less engaged than some of the others. This may have been partly to do with being something of an outsider in the group. He was also absent from two of the sessions, and was not at school when the final follow up interviews were conducted. In one to one conversation Kamal told me that his dad had died and was interested in the link between bereavement and mental illness although he did not talk a great deal about this. He told me that he is half Moroccan and in Morocco mental illness is regarded quite differently.

## **4.4 First order findings**

In this section, the key aspects of each of the first three groups of first order findings which emerged through the coding exercise will be discussed. Extracts from the transcripts will be presented alongside discussion of them in order to provide illustration. The last two themes – discoveries and insights, and pedagogical development – will be discussed in section 4.4 alongside the research questions which they most closely relate to.

#### 4.4.1 Understandings and ideas

Young people’s understandings and ideas about mental illness was revealed in terms of what they said about what mental illness is, what they think causes it, and what sorts of things people do in response to it. The categories are shown in Table 4 below.

Table 4: Categories - Understandings and ideas

Understandings and ideas		
	What mental illness is	Features of mental illness
		Firsthand experience
		Confusion/ vagueness/ lack of knowledge
		Misinformation from films/ TV
	Causality	Psychosocial
		Supernatural
		Biological
		Drug induced
	What to do about it	Medical help, therapy
		Spiritual solutions

#### What mental illness is

An examination of the young people’s talk about specific features of mental illness showed some instances of accurate ideas about the nature of mental illness. For example, it was clear that the young people saw mental illness in terms of behaviour changes outside the normal range. Malik commented that “it makes you do stuff you wouldn’t normally do.” Isolation as an impact of mental illness was identified clearly, particularly by Simone. In addition there were a number of occasions in which the young people demonstrated the view that unpredictability in behaviour was a key feature of mental illness.

However, there was also a lot of vagueness about precisely what is and what isn’t a sign of mental illness. Some of the group members felt you would never be able to tell if a person had a mental illness by looking at them, whereas others felt there would be indicators in their behaviour and appearance which would make this possible.

The mind-mapping exercise conducted in the first session revealed considerable confusion about the distinctions between mental illness, learning disability and sometimes even physical disability. There was also significant confusion about the distinction between normal responses to difficult life events and signs of mental disorder. In terms of their first hand experience, the young people had far more experience of what seemed to be normal responses to stressful life situations than they did of people with mental disorders. Sometimes the young

people began to attribute medical interpretations to everyday stressed out behaviour. For example, when talking about one of their teachers becoming so stressed out that he swore, Farzan said “I wouldn’t be surprised if he ended up on the mental ward.”

It is also important to draw attention to absences in the young people’s discourse. They did not mention the classic distinction between neurosis and psychosis, for example.

### **The particular case of schizophrenia**

Talk about schizophrenia occurred on a range of occasions throughout the discussion series. When it came to knowing what schizophrenia is, there was quite a lot of confusion. One member of the group had latched onto a fairly uncommon symptom of schizophrenia portrayed in the soap opera *Hollyoaks* - having an imaginary friend. As a result of this influence Molly appeared to assume that that this is a defining feature of the condition, frequently mentioning having an imaginary friend in relation to schizophrenia.

Participants displayed differing dimensions of understanding about schizophrenia depending on the particular context. During the second session of the discussion series, Farzan talked to the group about a film he had recently seen which featured a character with schizophrenia. Farzan describes how the character with schizophrenia “rips her jaw off” during the film. It is interesting that the members of the group appear to be quite comfortable with this as an example of the type of behaviour or action that one might expect from a person with schizophrenia. This acceptance of the image is demonstrated in Excerpt 1:

#### **Excerpt 1**

*Farzan: It’s about this girl that goes crazy.*

*Emma: And what happens?*

*Farzan: When she was young she had like minor schizophrenia, innit, and she used to like have all these flashbacks and stuff and now she’s older and she becomes a nun but she was in this mental hospital and they couldn’t cure her because apparently she was seeing things in these mirrors and that made her go crazy.*

*Emma: Right, so what did you think of the film?*

*Farzan: I thought it was pretty scary. Yeah, the girl rips her jaw off.*

*Girls: Errrrrrrrrrrrrr!*

*Molly: Aw, that’s sick that.*

*Farzan: Yeah, there’s a part in it where she rips her jaw off.*

*Emma: Right, why does she do that?*

*Farzan: Well, because she's got schizophrenia. (S2, p2).*

Not only does Farzan state directly that the reason the girl rips her jaw off is because she has schizophrenia, but perhaps more importantly, no one else in the group questioned whether this was an accurate and appropriate representation of a person with schizophrenia. This suggests that exaggerated and tawdry images such as this one which appear in films are absorbed and accepted by the young people without difficulty. Dealing with images like this is perhaps part of the process of constructing an understanding of schizophrenia.

### **Causality**

The coding exercise showed that there were over forty instances in which the young people made remarks relating to the causes of mental illness. It is important to note that this is likely to be partly due to the nature of the activities that they were engaged in. Discussions about photo-vignettes, for example, often focused on what might have been going on in that person's life to bring about the circumstances described in the vignette. However, it was also evident that what brings mental illness about was an issue of particular interest and concern for the young people.

The principal explanatory framework used by the young people to make sense of the onset of mental illness was psychosocial. They always felt that there would be a life history explanation or element in a person becoming mentally ill. The outcome of the coding exercise suggests that the young people predominantly talked in terms of difficult life experiences as the cause of behaviour changes. Examples include being bullied, having problems at home, and getting abused. However, given the confusion between normal responses to life's difficulties and mental illness, this is not entirely surprising. The young people had much more experience of the former and therefore brought this experience to bear when discussing the photo-vignettes, even though the vignettes had been designed to be highly suggestive of depression and psychosis. Nonetheless, when asked to comment specifically on whether there might be a biological element to mental illness, they really didn't seem to have the knowledge or resources from which to form an opinion, giving responses like "Nah," "I dunno," "I'm confused," and "Not sure." It did emerge later that they had *some* ideas about fundamental differences between people, hinting at the possibility of there being a biological dimension to mental illness. For instance, they pointed out that you could go through lots of stressful life events and that this wouldn't necessarily lead to mental illness.

### Excerpt 2

*Molly: It **sort of depends** on you as a person, and events in your life... It's **always unique** to each person.*

*Farzan: Someone could just be mentally stronger than the next person... They might just like block it out, whereas someone else could just be like, it could take an effect on themselves. (S6, p9).*

These comments are tentative, and seem to be reaching towards a sense in which everyone is different, some being more prone to developing mental illness than others. Molly's view seems to be that the underlying reasons for this are as much about circumstances ("events in your life") as about temperament ("it sort of depends on you as a person").

Another possible explanation for behaviour changes proposed by members of the group was being on drugs.

### Excerpt 3

*Rahim: If you have too much alcohol you go tapped, and if you smoke too much booj, you get high and then you go tapped. (S1, p15)*

The vagueness of the term 'tapped' makes it difficult to be sure exactly what Rahim means here, but he seems to be using the word as being synonymous with 'crazy' or 'mental,' indicating his idea that alcohol and drugs can lead to mental health problems.

They also explored ideas about supernatural causation expressed in terms of ideas about a person getting 'possessed' by an evil spirit. When talking about the *Simon* vignette, the group were discussing various possibilities to explain Simon's behaviour. For the four boys in the group, all from non-Western backgrounds, spirit possession seemed to be as plausible an explanation as anything else. One of the boys told the story of an uncle who had dealt with what might otherwise be thought of as some sort of mental disorder through prayer and spiritual support at the mosque.

### Excerpt 4

*Farzan: I believe in black magic... One of my uncles, he got possessed... He just stayed in the mosque and they had to keep on praying on him. (S2, p10)*

*Malik: It's like a ghost that goes into someone else's body... and it makes you do stuff you don't wanna do. (S2, p10)*

The male members of the group showed intense interest in the idea of possession and it appeared that it was something they had thought about and talked about previously. They

seem familiar with idea of demonic or spirit possession being a state in which a person has been invaded by an external force to the extent that the person loses control of their actions and behaviour. I did not include a review of literature about spirit possession and mental illness in Chapter 2, so it is important to point out that this is something which is recognised as a common feature of many cultural and religious phenomena (Coons, 2003). Spirit possession as an explanation for strange behaviour also has much longer history than diagnostic categories such as psychosis and schizophrenia (Pereira, Bhui & Dein, 1995). That the boys introduce the idea is therefore no coincidence.

The similarities in descriptions of psychotic illness and a person who is possessed were clearly apparent to the young people in the group. After listening to the boys talk for a while, Molly commented, “But that’s like schizophrenia” (S2, p10). It was interesting that she made this link, demonstrating the flexibility of mind to be able to disagree with the group’s dominant explanation of particular behaviours at that point in the conversation. Molly’s comment also led to the discussion changing direction, and the boys stopped talking about possession and considered other potential explanations for Simon’s behaviour, including that he was under so much pressure that he was having “some sort of breakdown” (S2, p11).

This shows that the young people have ideas about a wide range of possible causes but are not very confident in the accuracy of any of them. Although their attempts to grapple with these issues are relatively ill-informed, there are certain parallels between the young people’s uncertainty about the cause of mental illness and the controversy which surrounds the professional discourse in this area. This will be explored further in Section 5.2.2.

### **What to do about it**

The young people’s ideas about possible responses to the people in the photo-vignettes give some indication of their notions about what to do about mental illness. In conversation about the *Sarah* vignette, the young people felt it would be helpful to be there for her as a friend, and be available to talk. However, there was also a sense in which getting the balance right between being supportive without being pressurising was important. Molly said “she wouldn’t want you asking like prying questions, like pressure to talk about what’s wrong with her.” (S1, p15). As well as being a good friend, there was a feeling that expert intervention might be helpful. Simone said, “what about doing, like, therapy sessions with her?” (S1, p.15). When discussing the *Neighbour* vignette they also felt intervention from medical professionals might be appropriate. They suggested calling an ambulance, contacting a doctor or to “phone some therapy for him”, but felt that they would need to be sure that there was really something serious wrong before getting involved in this way. In talking about the *Simon* vignette, the



young people considered what how they might respond if Simon was their classmate returning to school after the episode described in the vignette. Simone mused that “It might be weird for us, because he probably wouldn’t wanna go near anybody. He wouldn’t want anyone to speak to him so I’d say it’d be difficult to know how to talk to him. I’d be embarrassed.” (S2, p.13). This statement is evidence of Simone’s ability to reflect with honesty on how she might behave in a particular scenario.

#### 4.4.2 Opinions and positions

The young people in the group expressed a wide range of opinions and positions in relation to mental illness. Those that were identified in the coding frame were further sorted into sub-categories of negative, positive and ambivalent positions or stances. These are shown in Table 5: Categories - opinions and positions. Although the table might suggest that there were more negative opinions than positive or ambivalent ones, the predominant position taken by the young people was ambivalent.

Table 5: Categories - opinions and positions

<b>Negative</b>	Scary/ weird
	Assumed to be dangerous
	Avoid contact
	Risky -should be controlled
	Pessimism/ deficit
<b>Positive</b>	Lack of empathy
	Interested
	Respectful
	Showing empathy and understanding
<b>Ambivalent</b>	People shouldn’t be judgmental
	Scepticism
	Pity
	Contradictions/ oscillating positions

#### Negative opinions and positions

One of the negative positions taken by members of the group was to do with viewing people with mental illness as being scary and weird. On some occasions young people were able to articulate very clearly that they would feel frightened by a person experiencing mental illness. For example, talking about the *Neighbour* vignette, Rahim said “I’d be scared, so I wouldn’t talk to him.” (S1, p20). At other times the feeling of fear was more implicit in the young people’s statements. Talking about the *Simon* vignette, Rachel showed fear by saying “He could stab someone” (S2, p7). The supposition that having knives in his possession meant that Simon was likely to use them in a violent act demonstrated how quickly the young people assumed dangerousness. The feeling of fear seemed to lead to the young people drawing the conclusion that it was best to avoid contact with people who had a history of mental illness. In the profile

building exercise the prospect of seeing a doctor with a past history of drug-related psychosis led to Malik expressing the view “I’d... never, ever go to him” (S4, p16).

A closely related idea was the tendency amongst the group to regard people with experience of mental illness as posing a risk to others and therefore needing to be controlled. Discussions about photo-vignettes in Session 2 revealed a number of instances of this position as demonstrated in Excerpt 5.

#### Excerpt 5

*Simone: It’s for their safety that he can’t work with children. (S2, p16)*

*Molly: It could be putting everyone else in danger so even though he can’t help it and it’s really sad, you’ve got to think about other people and stop him from risking them. (S2, p18)*

*Molly: They’re not reliable employees. It’s not their fault, but you’ve got to think about the whole business, how it could affect the whole workplace and protect everyone else. (S2, p22)*

*Molly: It’s different if you’re putting other people at risk. I don’t have a problem with mental health, but I just think it’s dangerous if you’re going to put someone that used to be mentally ill into a situation where they’re putting other people at risk if they then have another breakdown. (S2, p25)*

In considering how mental illness might impact on the shape of a person’s life during the profile building exercise in Session 4, the young people revealed extremely pessimistic positions. They assumed that the characters presented in the exercise would be unemployed, would not have a partner or good friends, that they would live in unattractive accommodation and generally lead rather bleak lives. This view was similarly expressed in discussion in Session 5 where Malik assumed that someone with bipolar disorder would be “someone who has got no life.” (S5, p5).

It is perhaps not surprising given the range of negative positions taken by members of the group that lack of empathy for others with mental illness was also displayed. When discussing people who self harm, Farzan said “self harm themselves? That is just dumb!” (S1, p9). Malik showed a similar lack of empathy by saying “They’re just weirdoes” (S2, p5) and couldn’t imagine why anyone would want to cut themselves.

#### **Positive opinions and positions**

The young people also showed a range of positive opinions. One of the positives was that they generally seemed to find the topics of discussion to be interesting and all members of the group tended to remain engaged in discussion, contributing fully to what was going on. There were moments when their interest was especially intense. This happened when someone in the

group shared personal experience – for example Farzan talking about his uncle being possessed and me sharing my own experience of bipolar disorder. This heightened sense of interest also occurred when we discussed the second instalment of the *Simon* vignette which gave them a lot of additional information about Simon’s life story.

In Session 5, I read a young woman’s account of her bipolar disorder and in response to this the young people expressed respect for her ability to accept her illness and make the most of life. The young people’s capacity to respect people with mental illness also came across when they were reflecting on how I might feel about some of the negative language they had used before they discovered that I had a mental health condition. When asked how taking part in the discussion might change his view, Farzan said “Give them a bit more respect, like, if you’re going to judge them, get to know them first, then see what you might think of them. (S3, p19).

The young people expressed empathy and understanding towards the protagonists in the photo-vignettes who they saw as having a hard time due to difficult circumstances. Farzan said “You do feel like that sometimes, course you do.” (S6, p17). Making sense of what was going on by adding narrative detail, for example imagining that the *Neighbour* may have been bereaved, or that *Sarah* might be having difficulties at home and that *Simon* was struggling in the face of unmanageable pressure appeared to help in the forming of empathic positions. There was much less evidence of empathic understanding where they perceived people to be scary, dangerous and likely to be unpredictable.

Farzan expressed the view that one should not be judgemental when he described the effect on him of meeting me and discovering that I had a mental illness “Just not to be stereotypical in the way you think about mental illness and not to like judge people.” (S6, p14).

### **Ambivalent positions**

Members of the group frequently demonstrated ambivalent positions which were neither positive nor negative, or were oscillating. One way in which ambivalence was expressed was in the young people’s concern not to be taken in by what they saw as manipulative behaviour. For example when talking about self harm, Molly explained that sometimes people might be exaggerating behaviours for effect and took a negative view of this which she saw as illegitimate attention seeking. However she went on to say that “some people have honest reasons” for self harming (S2, p5).

Pity could lead to the young people taking positive, supportive positions, but could equally result in avoidance and negative views. Although others had suggested that it might be risking social opprobrium to stick up for a person with mental illness who was being taunted, Molly said “You don’t wanna leave that poor person there cos they’re going through a really rough time and these people are bullying them.” (S6, 10). In discussing the *Neighbour* vignette, Rahim expressed pity, “I’d just feel sorry for him to see him in that sort of state, but then again... I’d just be like, yeah I feel sorry for you, but I’m not gonna say nothing, I’d just put my head down.” (S1, p20). Rahim’s ability to be so self-aware as to recognise the contradiction between his gut feeling towards the neighbour and the unlikelihood of him being able to act on his sympathy is remarkable. I found it astounding that he is able to reflect in this way, and perhaps even more incredible that he is both able and prepared to articulate it to a group of peers. Rahim’s open frankness paves the way for Farzan to be able to communicate a similar position, also showing ambivalence in his pitying response as demonstrated in Excerpt 6.

#### Excerpt 6

*Rahim: I’d just feel sorry for him to see him in that sort of state, but then again... I’d just be like, yeah I feel sorry for you, but I’m not gonna say nothing, I’d just put my head down.*

*Farzan: I would feel sorry for him. But I’d be half and half if I’m gonna tell the truth. I’m not gonna... say to you that I would be nice and all that, cos I know I wouldn’t really. I’d probably just be laughing at him and all that.” (S1, 20).*

It is striking that both boys seem to be saying that they would feel pity and sympathy but that they would not be prepared to demonstrate this to others. It may be evidence of their need to preserve their own status as secure members of the in-group and the feeling that to reveal their compassion would be a threat to this. Their exceptionally lucid illustration of this is extremely helpful in terms of understanding the tensions inherent in being an adolescent with a range of conflicting concerns to negotiate.

Rahim and Farzan’s remarks about pity also illustrate the tension between the positive and negative positions that exist and suggest that the young people can flip from a positive to a negative view or vice versa. In discussing some scenarios the young people were struggling with the difficulty of deciding whether it is possible to view somebody as trustworthy given that they had had episodes of mental illness. Molly expresses this ambivalence in Excerpt 7.

#### Excerpt 7

*Molly: He is as a person but he isn’t when he gets this, cos even though it’s not his fault, that [the mental illness] makes him untrustworthy. (S2, p17).*

This further demonstrates how difficult the young people find it to reconcile broad feelings of supportiveness with underlying uncertainty, scepticism and concern.

The most important finding emerging from this section of the data was that the young people occupy different positions at different times depending on a number of factors. Context is extremely important. It is not the case that Farzan, who expressed the view that people with mental illness should be controlled when considering the *Simon (2)* vignette always held that view. In fact, he was quite liberal in discussion about politicians experiencing mental illness. Similarly, where Molly sometimes displayed empathy, sympathy and compassion, at other times her positions were dominated by fear, concerns about dangerousness and the need to control people with mental illness. Furthermore, it became clear that some members of the group held two or more opinions simultaneously and that these were sometimes, at least on the face of it, contradictory. The plurality of the young people’s positions is salient.

#### 4.4.3 Process of engagement

The secondary categorisation of the process of engagement theme led to the identification of three component categories. These are shown in Table 6.

Table 6: Categories - process of engagement

<b>Getting their heads round it</b>	Visualising the protagonists
	Adding detail
	Attempts to imagine others’ experience
	Making associative leaps
	Asking EL for facts
	Checking with EL re: right answers
<b>Collaborative meaning making</b>	Questioning each other
	Challenging each other’s views
	Digesting ideas
<b>Preserving group solidarity</b>	Politeness when expressing
	Surprise at each other’s contributions
	Direct personal comments

#### Getting their heads round it

The ways in which the young people tussled with ideas in order to get their heads round the topic of mental illness were manifold. Members of the group engaged effectively with characters presented in photo-vignettes, in the profile building exercise and in real-life examples. They sometimes expanded on the information they were provided with to further visualise the protagonists. In the case of the *Sarah* vignette, Simone looked closely at the photograph, commenting “The way you see it in her eyes, that something’s not right. I don’t

know what it is, whether she's going through this phase, or taking drugs or something. I can imagine her, with that look in her eyes, being on her own, not wanting to talk and stuff." (S1, p11). In conversation about the *Simon (2)* vignette I asked the group directly whether they envisaged him as a "goody or a baddy." The entire group responded by saying he was goody, one after the other. Farzan then offered a differing view, saying "Nah... He's a bit of a both because like.. he's like mental illness, but then he makes people laugh and all that and he's just like a normal person, but then he's got that side to him where he's a bit mental and he could do something dangerous to someone." (S2, p16). Not only does this represent an attempt to visualise the character in more detail, it also demonstrates the difficulty in reconciling mental illness as part of a person's whole personality without it having a detrimental effect on how they are viewed. The latter point is also relevant to Section 4.4.2.

Related to visualising the protagonists in more detail, the young people showed that they made attempts to imagine others' experience at various points in the discussion. This was demonstrated particularly clearly in a piece of discussion about self harm, shown in Excerpt 8.

#### Excerpt 8

*Simone: Maybe it's a way of getting relief. They go through the pain in their head and then have the pain in their body. Maybe they put themselves through that pain and then once the physical pain's gone, everything in their head is fine.*

*Molly: Or maybe they do it because they're so frustrated with themselves.*

*Malik: Pain gives them pleasure. (S2, p5)*

Simone and Molly seem to be trying really quite hard to imagine why a person might self harm, and they show concentrated attempts to do this. Malik's comment at the end of the above section is a somewhat droll summing up of the rather subtle point that Simone has tried to express but shows that he has processed the idea she was trying to communicate in spite of his tone.

Occasionally members of the group would also attempt to imagine others' experiences by envisaging what they would do if they found themselves in similar situations. When talking about the *Simon* vignette, Farzan said, "Personally I wouldn't wanna tell anyone about it. I'd just forget about it.. Any mental illness type thing, actually, I'd hide it." (S2, p19). Although this represents an attempt to imagine what coping strategies he might employ if experiencing similar mental health problems as Simon, Farzan's ideas about being able to hide it don't entirely harmonise with the content of the vignette – Simon is represented as having psychotic symptoms which are played out in a quite a public arena at school – hiding those symptoms

wouldn't really be a viable choice. However, Farzan's attempt to put himself in Simon's shoes is quite a brave move in terms of the way he engages in the discussion process. His comment also precipitated a very lively discussion about the benefits of openness versus keeping your problems to yourself.

On a few crucial occasions, the young people made what I have chosen to describe as 'associative leaps.' When I read the *Simon* vignette, Simone did not even wait for me to ask what they thought might be going on before saying "That's like that thing, um, the Columbine massacre." She went on describe the details of the Columbine massacre to the rest of the group. I was quite surprised by this association – the vignette represents a schoolboy in distress who juggles with knives in the corridor, and the Columbine massacre involved two pupils going into their school with a gun, murdering 12 people and injuring 21 others. This response suggests that Simone had latched onto the image of the knives in the vignette and based her associative leap on the significance this held for her, effectively ignoring all of the other narrative detail of the vignette. It is difficult to be sure of the effect of this associative leap on the conversation that followed, but immediately after this, the rest of the young people agreed that they regarded Simon as being dangerous.

Another associative leap was made during the profile building exercise in Session 4. The first character profile that the group constructed began with a description of a person who "finds it difficult to be around groups of people and gets stressed and anxious in social situations where they have to make small talk. The person has low self esteem, thinks they are worthless, boring and unlikeable and sometimes has panic attacks in unavoidable social situations." (S4 resource). After they had built a profile for this person, I asked the group if they would like to name the character. Almost instantly, Simone answered by saying "Rachel." It is impossible to know for sure whether Simone was reminded of the Rachel in the group by the description, or if she had simply chosen that name by complete coincidence. However, given the way in which the group responded to Simone naming the character Rachel, it is reasonable to assume there was at least an element of association going on. Excerpt 9 demonstrates this.

#### Excerpt 9

*Malik: What's the reason behind it? What's the reason Rachel came straight to your head?*

*Rahim: It's because she's quiet.*

*Simone: Noooo*

*Farzan: You think that's what Rachel's like*

*Rahim: Woooah Rachel, put some gloves on, man.*

*Simone: I didn't mean it to hurt though. Sorry Rachel. (S4, p6)*

Rahim's comment "It's because she's quiet" demonstrates that he regards Simone's naming the character Rachel as making a direct link to the Rachel in the group. However, there is quite a significant disparity between Rachel's shyness and the description of the person under consideration, and although other members of the group recognise that Simone has made a plausible association, it is also quite a leap. Simone's remark that she "didn't mean it to hurt" coupled with her direct apology is interesting. She doesn't say "I wasn't thinking of you," and it seems entirely likely that Simone was in fact reminded of Rachel by the description. It's also interesting to note the way other members of the group deal with, adjust and ameliorate in the face of the associative leap. For example, in Excerpt 9, Malik's question to Simone and Rahim's offer of an explanation show how the group are busy trying to make sense of what is going on, in the context of the social restraints of a group dynamic. It is notable that both of these associative leaps were made by Simone.

Other ways in which the young people demonstrated their attempts to get their heads around the subject matter included asking me questions. Quite frequently they would ask me for specific information or to provide them with facts. Examples of such questions include, "what do you mean by mental health, exactly?" or "Can you have anorexia mild and severe?" and "do you mean a bit of a breakdown or a proper mental disability?" My usual approach to these types of questions was to refrain from answering directly, but to use the question as a springboard for more discussion. As well as asking for more information, the members of the group also looked to me for clarifications about whether there were 'right' answers to the various scenarios we were discussing. The group showed a striking desire to know whether the stories we discussed in the various activities were true, and if the people in the scenarios were 'real.' As well as demonstrating their interest and engagement, this highlights the significance and importance of the real life narrative in discussing mental illness with young people.



## Collaborative meaning making

One of the most important features of the process of engagement which characterised the discussion sessions was the ways in which the group made meanings collaboratively. In discussing a particular subject, they would frequently question each other, challenge each other's views, try out different interpretations and in doing so, process and develop their understandings and positions. For example, in Excerpt 10 we see the group talking about factors which might influence the onset of anorexia.

### Excerpt 10

*Farzan: It all comes back to the parents, like, anorexia.*

*Molly: No, it doesn't always.*

*Farzan: Like, most of the time then.*

*Molly: No, because someone might turn anorexic because their friends call them fat, everyone at school calls them fat.*

*Farzan: Alright, friends and family, then.*

*Kamal: But most of it goes back to the parents.*

*Molly: I wouldn't say so.*

*Rachel: Quite a lot of it does.*

*Malik: You've gotta think about bullies as well, though.*

*Molly: You can have the most supportive parents in the world and still have mental health problems.*

*Rachel: Yeah, actually, you're right, it's not the parents. (S2, p.8)*

This exchange demonstrates how the group try out different understandings. Molly is very clear in her view that parents are not necessarily the cause of anorexia in their offspring and she stands her ground. During the exchange, Farzan moderates his position and Rachel appears to come round to Molly's view by the end of the extract.

After the group had cut out headlines, images and stories from magazines and newspapers in the Media exercise, I asked them to think about what linked the cuttings. The exchange of ideas that resulted showed the collaborative meaning making process in action, demonstrated in Excerpt 11.

### Excerpt 11

*Simone: They're all something to do with pressure.*

*Farzan: Peer pressure*

*Rachel: Like body pressure*

*Molly: Boyfriend pressure, like, relationship pressure*

*Rahim: And work pressure*

*Farzan: Everyone there is stressed.*

*Emma: It seems as though what you're saying is that stress could be the beginning of a mental illness.*

*Farzan: Yeah, cos stress is just like a mild part of it, and then...*

*Emma: And what do you think happens with stress, that kind of turns it into mental illness?*

*Molly: It gets out of hand.*

*Farzan: Yeah, it gets out of hand, like you can stress up to a certain level and then it's just like...*

*Emma: Like?*

*Rahim: Your mind just can't take it any more and it gets flooded or something.*

*Emma: Flooded?*

*Rahim: And you go over the edge. It makes you mental. (S3, p.15).*

This excerpt of discussion demonstrates how the young people collectively made sense of the link between the stories, headlines and images they selected. They go on to really explore the role of stress in the onset of mental illness. Simone's initial comment that all of the clippings were something to do with pressure led to others making specific comments about the types of pressure that the clippings illustrated. Members of the group came up with several examples of different types of pressure, including peer pressure, pressure to look good and pressure from work. I prompted the group to go a bit further in their thinking about stress and to explicitly relate it to the onset of mental illness. At this point, Molly commented that "it gets out of hand." Farzan expanded on this slightly by saying that "you can stress up to a certain level" at which point Rahim picked up the thread by saying that "your mind just can't take it any more and it gets flooded or something." This demonstrates how the process of constructing understanding is carried out collectively by the members of the group. It may be that any one of them could have explained the process on their own, but the way in which they seem to use each other's comments as stepping stones on which to build and explain their understanding appears to happen very smoothly and comfortably. In doing this, the

young people essentially describe a version of the ‘stress theory’ model described in Chapter 2. Rahim describes a person’s mind not being able to take it any more and getting ‘flooded.’ When I prompted him to explain what he meant by this, I was expecting him to expand by saying that he meant the brain would be flooded with certain chemicals which led to mental illness. He did not do this, but instead explained the effect of the “flooding” by saying “you go over the edge. It makes you mental.” This demonstrates an explanatory gap, in which Rahim is not able to articulate exactly what is going on to cause it, but has a sense of a person being under so much stress that their brain is overwhelmed and mental illness follows. While his expression of this idea has a somewhat naive flavour, the idea itself is not a million miles away from the types of explanations of mental illness which have been put forward by professionals (i.e. the diathesis-stress model). A significant feature of much of the discussion was that members of the group questioned and challenged each other, meaning that it was the individuals in the group driving the exploration of ideas rather than heavy handed facilitation from me. In Excerpt 12, Farzan says something quite challenging and negative about the impact of taking part in the sessions.

#### Excerpt 12

*Farzan: Miss can I tell you something?*

*Emma: Yeab*

*Farzan: When I was chatting before, to be honest, now, after doing this I would do something if someone was being bullied cos of mental health, but apart from that I ain’t gonna take nothing away from these sessions.*

*Molly: Oh, you’re just an idiot.*

*Farzan: Nab, right, you Malik – to be honest are you gonna take anything away from this?*

*Malik: Yeab.*

*Farzan: Be honest, man, no you’re not. You’re not. Don’t lie.*

*Malik: Yeab, I will.*

*Farzan: Why’re you lying? Don’t lie.*

*Molly: Why won’t you Farzan? What do you mean?*

*Farzan: Well, why would I? I’ll remember the stuff if something happens in my life, but I’m not gonna start talking about all the time or like think about it on a day to day basis.*

*Molly: It’s not about talking about it all the time, it’s about if you’re put in a situation you’ll remember it. It’s that remembering, not talking.*

*Farzan: Well, yeab, then, I probably would remember it if something happens and someone goes mental. (S6, p16)*

In making a critical comment, Farzan is immediately challenged by Molly, who demonstrates disapproval by calling him an idiot. When he looks to Malik for backup, he doesn't get it, and is clearly surprised by Malik's unwillingness to support him, illustrated by the way in which he pushes Malik for his concurrence three times. Molly then challenges Farzan directly, by asking him what he means. Farzan gives an explanation, which Molly then reframes and by the end of the exchange he has refined and further articulated his position, admitting that having taken part in the sessions probably will have some lasting impact on him. Part of what Farzan is doing here is working out what 'taking away' actually means. This process is all the more powerful because of the fact that the interactions happen between members of the group without me making any incursion into their talk, although my presence as a witness to the exchange certainly has an effect.

Another feature of the group's ability to collaborate productively was the way in which they collectively digested ideas. How this came about differed according to context. In the following example, the digestion process began with a striking admission of ignorance from Rahim, shown in Excerpt 13.

### Excerpt 13

*Rahim: What is schizophrenia? I don't even know what it is myself.*

*Molly: It's where you like hear voices, or have an imaginary friend or something.*

*Rachel: And the voices tell you to do stuff.*

*Molly: Like Newt on Hollyoaks.*

*Farzan: Hollyoaks do everything man!*

*Molly: He had this friend called Eli who used to be alive and now was dead.*

*Rahim: Ah yeah I think I saw that. Was then he was in a room and was like 'I don't like being ignored' or something?*

*Molly: He was in a care home and then this guy died in a fire and he was back and he was his imaginary friend and this guy, Eli's telling him what to do and telling him to burn things down and he stopped taking his schizophrenia pills and this dead guy's back.*

*Rachel: I don't think schizophrenia's always an imaginary friend. Some people just hear voices and stuff.*

*Farzan: Really none of us know because none of us have been through schizophrenia.*

*Emma: That's really interesting that you said none of us know because none of us have been through it.*

*Farzan: Yeah, we've never been through it, and even if there was someone here who'd had it, I can't say the word, but if they had it and even if they told you what it was like you wouldn't really know.*

*Molly: You can't know know but you can kind of get it a bit more by talking to someone who does know. (S1, p19)*

Rahim's question and comment demonstrates a very important moment of awareness which he is both able and willing to share with the rest of the group. He clearly articulates a lack of knowledge and draws attention to a blank space where a fuller understanding of the label 'schizophrenia' might be. Rahim could quite easily have said nothing, hiding his ignorance, or perhaps not even have noticed his own lack of knowledge. The fact that he identifies it, decides to share it and articulates it so clearly is evidence of the way in which the atmosphere of the group is conducive to this type of insight. Rahim's insight is very productive in terms of moving the discussion on. Molly has a go at describing her understanding of schizophrenia: "It's where you like hear voices, or have an imaginary friend or something." Rachel builds on this by saying, "and the voices tell you do stuff." Molly brings in another resource, saying "Like Newt in Hollyoaks." The group process this and between them mull over what they do know about schizophrenia. The collective digestion which was precipitated by Rahim's admission of ignorance is a very different process to one member producing an answer. Uncertainty is conveyed throughout, with the use of words and phrases such as 'like' and 'I don't think.' This sequence of conversation demonstrates how the group are entirely driving

the educative process. They are providing the resources for discussion, they're providing the questions to further the discussion and they're providing answers to those questions. In doing all of this they are processing ideas and digesting information. My role is purely facilitative.

### **Preserving group solidarity**

The success and fertility of the group's process of engagement didn't come about entirely by chance and all of the members of the group played a role in achieving and preserving group solidarity. This was played out in a number of different ways, one of them being the demonstration of politeness and sensitivity when expressing conflicting views. In discussion about the *Simon* vignette, there was some disagreement about whether Simon is likely to stab someone.

#### **Excerpt 14**

*Rachel: He could stab someone.*

*Emma: Do you think he's going to stab someone?*

*Molly: No.*

*Farzan: You never know.*

*Molly: I think he just thinks he's being cool.*

*Simone: Maybe someone's told him to do it. It comes back to whatever you said, the imaginary other... the imaginary friend, or summat. A voice in his head might have told him to do it.*

*Farzan: And he's brought in knives, maybe so people will fear him. (S2, p7)*

Molly, Simone and Farzan each propose different explanations for Simon bringing in the knives and their explanations are in some senses incompatible. Molly's suggestion that Simon thinks he's being cool implies that she does not necessarily regard his behaviour as a sign of mental illness. Simone, on the other hand, makes a link between the earlier discussions about schizophrenia, suggesting that Simon may have been hearing voices which told him to juggle with knives. Farzan's comment displays the view that bringing in knives is a deliberate act to make others feel intimidated. However, the three members of the group express their differing views with incredible courtesy. Simone begins her statement with "maybe" which allows Molly's suggestion to maintain credibility while introducing an alternative. That Farzan begins his statement with "And" has the effect of making it possible for his remark to act as a continuation of what both Simone and Molly have already said. This makes it feasible for all three statements to be regarded as being congruent even though this leads to an image of

Simon as someone who wants to be seen as cool, who may be hearing voices, and is also keen for others to fear him.

Another way in which the solidarity of the group was maintained was through the slightly risky business of making direct personal comments about one another. In Session 2, I introduced the widely quoted statistic that one in four people will experience a mental health problem at some time in their lives. I then asked them how many people were in the room, to which Molly answered that there were eight. I allowed the group to process this, and Simone then said “Well that means that two of us here is gonna get it.” This caused a degree of awkwardness amongst the group, which was dealt with initially through laughter. This awkward laughter lasted for a few seconds and Molly then said, “Rahim” with a slightly teasing tone of voice. Rahim responded to Molly’s comment by saying, “Kamal’s gone through it man,” which deflected attention away from him. Rahim’s comment is slightly stronger than Molly’s because he suggests that Kamal has *already* experienced mental illness whereas Molly, in simply mentioning Rahim’s name is implying just that he might be a candidate for it. Both of these comments suggest that in the conversational situation which has arisen, in which there is a strong suggestion that mental illness is real, direct and quite possibly going to feature in the lives of the people in the group, directly naming one another is an effective way of handling something quite uncomfortable. It also has the effect of sealing the members of the group in a joint appreciation of something quite threatening through a kind of camaraderie.

#### **4.4.6 Summary of first order findings**

The first order analytic process revealed that the members of the group brought some existing knowledge and ideas about mental illness to the discussions. These differed between individuals, but were inclined to be quite vague and partially formed, with a tendency to resort to stereotypes and crude images gained from films and television. The distinction between normal reactions to stressful life events and mental illness was unclear for most of the young people. They had plenty of ideas about what might lead to mental illness but didn’t appear to be very sure about whether they were accurate. The young people in the group demonstrated a wide range of differing opinions about mental illness, ranging from empathy and supportiveness to control, restrictiveness and fear. Opinions differed greatly according to context and the amount of information the group had about a particular individual. It was common for individual members of the group to display negative, positive and ambivalent positions and sometimes to occupy apparently contradictory positions simultaneously. The process of engagement which arose showed the young people collaborating in making meanings and digesting ideas. A sense of solidarity amongst members of the group developed

quite quickly and the way that individuals challenged and questioned each other was a striking advantage of the group dynamic.

The first order findings also included results about discoveries and insights and pedagogical development. These categories will be discussed in detail in 4.5.2 and 4.5.3 respectively. However, the findings for these categories can be summarised as follows. Members of the group made a number of significant discoveries and insights in the latter part of the discussion series. Largely, these discoveries signified individuals in the group making shifts away from pessimistic views about people with mental illness towards more empathic and propitious positions. The young people's explicitly expressed views about the pedagogical content of the discussion sessions were broadly positive. They showed particular approval for photo-vignettes and the profile building exercise and emphasised how important they felt it was to be able to have discussion in a small group setting with an informal atmosphere.

## **4.5 Second order analysis**

In this section I will focus on considering the data in relation to the research questions which the discussion series sought to address. The aim here is to provide substantiated answers to those questions. Many of the first order findings are directly relevant to answering the research questions. Although all of the five groups of data contribute in some way to exploring the three research questions, certain relationships between categories of data and research questions surface. These are shown in Diagram 2 on page 112.

### **4.5.1 RQ1: How do young people construct and occupy discourse on mental illness?**

Sections 4.3.1 and 4.3.2 demonstrate the content of the young people's discourse on mental illness. The substance of their knowledge, ideas, opinions and positions are all important components of the way they assemble and talk about their understandings of mental illness, and therefore very relevant to this question. Those findings revealed that the young people knew some things about mental illness and had ideas about its possible causes. They demonstrated a range of position-taking, sometimes negative, sometimes positive, and often ambivalent. This paints a picture of a complex collage of understandings and attitudes, which are in some ways inconsistent and incongruous. It is also important to consider not just what the young people think, feel and believe, but also *how* they negotiate the communication and expression of these. Section 4.3.3 showed some ways in which the young people did this and is also highly relevant to RQ1. Another way of considering how discourse is occupied by the young people is to examine the resources and communicative tools which they draw on in



order to express and explore their views. This will be the principal task of the present section, which will address RQ1 by addressing the following sub-questions:

- RQ1a: How did the young people make use of language?
- RQ1b: What sources of knowledge did the young people draw on in order to construct discourse on mental illness?
- RQ1c: What communicative tools were employed in the occupation of discourse?

### **RQ1a: How did the young people make use of language?**

Looking carefully at the language the young people use to describe mental illness is one way of getting a sense of how they make their way around the discourse. At the beginning of the first discussion of the series, the young people did a mind mapping exercise, in which I asked them to write 'mental illness' in the middle of a large piece of paper and for everyone to write or draw things which they associated with that phrase. The results of this exercise were extremely revealing in terms of showing what associations 'mental illness' had for the young people before they had become engaged in a process of discussion and exploration with me. I examined the responses to this exercise and categorised them. These are shown in Table 7.

Table 7: Words and phrases associated with mental illness

Category	Words and phrases associated with mental illness	Total
Medical terms	Anorexia Depression Schizophrenia	3
Descriptors	Crazy Stress head Muppet Spac Mad Spaz Moz Tapped Mentally disturbed Druggie Sick Mashed up Different Freak Bonkers Monged Wrong way round	17
Causes	War Midlife crisis Switched at birth Problems Death Stress Drugs Family breakdown Spirits and stuff	9
Symptoms	Nightmares Stress Unclear thinking Flashbacks Emotion Suicide Suicidal	7
Learning disability	Stupid Downer Idiot Syndrome Retarded Downs	6
Physical disability	Crippled Peg leg Disability	3

It is clear from these responses that the phrase ‘mental illness’ is one which is not unanimously understood by the group members and it clearly provokes a degree of confusion. Illness labels did not appear to be in the forefront of these young people’s minds when asked to respond to the phrase ‘mental illness,’ and the group gave only three examples of this type of term. The responses to this activity revealed an apparent tendency to muddle learning

disability and mental illness. The largest category was that of ‘descriptors.’ These are terms used to describe people – nearly all of them appear at face value to be terms of abuse or examples of derogatory language. The participants in the group did use two terms which could be said to be neutral or non-judgemental. These were ‘different’ and ‘mentally disturbed.’ Within the descriptors category, the majority of terms supplied were ambiguous and non-specific. It is difficult to be sure how the young people understand and use this language in daily life and some of the terms provided may or may not relate specifically to the mentally ill, for example, ‘Monged,’ ‘Spac,’ and ‘Moz,’ A third category of responses seemed to relate to life experiences which could be said to cause or contribute to the onset of mental illness. Some of these were vague – i.e. ‘problems,’ while others were quite specific – i.e. ‘war.’ The next category I identified was concerned with what could be described as symptoms of mental illness. A small number of examples of symptoms were provided by the young people, which included ‘nightmares’ and ‘unclear thinking.’ This indicated that the young people had some sense of how mental illness might affect a person, even if it was rather indistinct. Terms which related to both learning disability (i.e. ‘retarded’) and physical disability (i.e. ‘crippled’) also featured in the responses, and the inclusion of these words was an indicator of there being a degree of confusion amongst the young people about what mental illness actually is.

The content of the list of terms generated by this activity is fascinating. The terms themselves can tell us a certain amount about how young people occupy the discourse on mental illness and reveal that they do so with uncertainty and imprudence. To get closer to understanding how they *construct* this discourse it is important to focus more closely on how they came up with the responses they did. The discussion which accompanied the mind-mapping exercise reveals evidence of awareness of boundaries, taboos and the need to negotiate which language to use. Early in the discussion, Malik said “dyslexia.” The rest of the group responded by laughing at this and Molly said, “dyslexia’s not a mental illness.” The laughter with which the group responded indicates that dyslexia is being regarded as being a misfit – not an appropriate response to the mental illness stimulus. Molly clarified this position by saying “dyslexia’s not a mental illness” and Malik replied by saying, “I know, I was being silly.” It may be that he was genuinely ‘being silly’ but it is also possible that in saying this he was in fact covering up for having made a mistake. As a result of the rest of the group’s reaction, the term did not get written down on the final list. It is interesting to contrast the stridently expressed view that dyslexia does not belong in the overarching category of mental illness with the later inclusion of terms which describe other learning disabilities.

It is also interesting to consider how the terms in the largest category – that of descriptors – came up in the conversation accompanying the exercise. Rahim said the word, “tapped,” and there followed from this a quick fire collection of other terms from other members of the group – “mental, bonkers, weirdo, crazy.” The readiness to demonstrate this vocabulary amongst the group is noteworthy – it seems as though there were no barriers to using these words and the young people did not appear self-conscious in mentioning them. The next word to crop up in the sequence was, “retarded,” offered by Kamal. After he had said this, Molly turned to me and asked, “can you write retarded?” Despite the fact that I told her it was ok to write it down, she went on to refuse, saying, “you’re not putting ‘retarded’ down on this piece of paper.” Farzan commented that “saying retarded about someone is just snide.” The way in which this particular term is resisted is very interesting – Molly clearly sees the language as being unacceptable, crossing a boundary which she is uncomfortable with. Farzan shows that he agrees with Molly’s position in saying that use of the word is “snide.”

Immediately before this discussion, the word, ‘crazy’ had been written down. In discussing the word, ‘retarded,’ Farzan said, “well if you’re allowed to write ‘crazy,’ then what’s wrong with it?” to which Molly responded, “yeah but crazy’s not as harsh as retarded.” This shows that Molly sees a difference between the two words. It is significant that ‘retarded,’ which refers to learning disability is the word which triggers this censoring reaction, whereas the word ‘crazy,’ which might denote mental illness, is evidently much less problematic to use, and is regarded as being “less harsh.” This may indicate that the young people find it easier to use words which describe people with mental illness without self-consciousness or restraint in a way that does not apply to words relating to learning disability, or specifically the term ‘retarded.’ It is also interesting that none of the young people commented on the fact that ‘retarded’ is not a word which refers to mental illness. This may be further evidence of their uncertainty about the difference between mental illness and learning disability. Having made these observations, it is important to draw attention to the other terms relating to learning disability which the young people did write down. “Syndrome, downs, downer, idiot, stupid” were all included without being accompanied by comparable discussion questioning the acceptability of their usage. It may be that the word, ‘retarded’ acts as a hotspot amongst these young people and there is something about it in particular which causes them concern or discomfort.

The ways in which the group made use of language throughout the rest of the discussion series also revealed a great deal in terms of how they construct discourse on the topic of mental illness. A wider range of medical terms were used throughout the discussion series than the small number which were mentioned in the mind-mapping exercise. The way in which the group members used these terms was largely colloquial rather than technically

accurate. They talked loosely about paranoia and depression, for example, without demonstrating knowledge of how these terms are defined medically. The young people spontaneously mentioned a number of mental health conditions which appear in the DSM-IV. These were anorexia, self-harm, ADHD, depression, schizophrenia and OCD. In the case of ADHD and OCD, members of the group made links between particular behaviours and the diagnostic categories, demonstrating a basic knowledge of signs and symptoms associated with them. For example Molly said “ADHD, that’s anger issues.” (S1, p14). Given the descriptor “This person is very concerned about germs and dirt,” Farzan immediately said, “Ahh, this guy’s got OCD.” (S4, p6).

The slang terms which appeared in the mind-mapping exercise were observable throughout the entire discussion series. The use of slang seemed to serve quite specific purposes on certain occasions. For example, after a long discussion about a wide range of possible explanations for the behaviour described in the *Simon* vignette, the group changed the tone of the discussion by introducing slang. It seemed as though the language gave them a way out of continuing with a discussion which they were finding baffling and had maybe become tired of.

#### Excerpt 15

*Rahim: He’s just tapped in the head.*

*Kamal: He’s just a mong.*

*Farzan: He’s just doing it, just to do it. (S2, p12)*

It’s also notable that all three of the speakers in the above extract make their statements using the “He’s just...” construction, indicating a desire to sum up or close down this part of the conversation. This suggests that in occupying discourse on mental illness, when a difficult point of discussion arises with no clear resolution that the young people may need an escape route and are well able to collaborate in constructing such a route.

The young people’s frequent use of derogatory slang terms was notable. However, they were not using them without knowledge of their power to cause detriment. It emerged that they were well aware that many of the slang terms they use are pejorative and could be offensive. This is illustrated by Farzan’s comment in session 6:

#### Excerpt 16

*Farzan: we were just using them kind of words but if we’d known that you’d had a mental illness from the beginning we wouldn’t say it like that. We wouldn’t use them words. (S6, p3)*

Also reflecting on the language the group themselves had used throughout the discussion process, Molly said “it’s a bit like bullying or something” (S6, p3). In making this point she is drawing attention to the boundary between the normal members of an in-group and people whose abnormality puts them at risk of being relegated to a status of other or outsider. Further evidence comes from Farzan’s comment:

#### Excerpt 17

*Farzan: We were just being idiots at the start of it. We just didn’t really care and we were just being stereotypes about it. (S6, p3)*

These comments suggest that by the end of the discussion series the young people had developed an acute awareness of the power of language to distance themselves from an out-group and to denigrate its members.

The young people seemed to sometimes find it difficult to select which terms to use to talk about episodes of mental illness. For example, in a discussion about the *Simon* vignette, both Simone and Farzan demonstrate awkwardness in choosing the right word to describe Simon’s occasional periods of mental illness.

#### Excerpt 18

*Simone: Just have loads of backup but then again, he might have his... **thingy**... so you have to be, to think about others around instead of just thinking about him, cos he might be causing harm.*

*Farzan: The people that have hired him, then, if he hurts the kids then it’s their responsibility and you know people’ll be like, well why’ve you hired him to work with kids when you he’s got his **mental health**, I mean when you know he’s got **mental illness**. (S2, p17)*

*Farzan: He’s a bit of a both because like, **he’s, like, mental illness**, but then he makes people laugh and all that and he’s just like a normal person (S2, p16)*

This seems to be another indication of the unfamiliarity of the subject matter and the young people’s lack of experience of having negotiated these topics in conversation prior to involvement in these group discussions. The difficulty with which Simone and Farzan select terms to use to describe episodes of mental illness shows that they are beginning to appropriate a discourse which is new and appears to feel quite alien to them. That they stumble when trying to communicate within a new discourse may be an indicator of a lack of confidence in selecting and using what they imagine to be the proper language.

**RQ1b: What sources of knowledge did the young people draw on in order to construct discourse on mental illness?**

In order to occupy discourse on mental illness, the young people in the group used pre-existing knowledge and ideas as resources for making sense of the topic and contributing to discussions about it. Knowledge and ideas was one of the themes which arose from the first order analysis of the data, and I have already described the sorts of things the young people brought to this discussion. In considering RQ1, it is important also to ask what the sources of their knowledge and ideas were. It appeared that there were three primary sources of knowledge and ideas which I was able to identify. These were:

- first hand experience and the experience of salient others;
- information from films, television and printed media;
- cultural and religious instincts.

Each of these sources emerged within the coding exercise, and examples of them have been presented in 4.3.1. First hand experiences which young people drew on included Farzan describing his uncle becoming ‘possessed,’ and Simone and Kamal’s experiences of having been bereaved. Information from films and television included reference to the soap opera *Hollyoaks* and the films *Mirrors* and *Donnie Darko*. Cultural and religious instincts acted as a source of ideas, for example when the male members of the group were thinking about Farzan’s uncle, and demonstrated the possibility of responding to a particular type of distress through prayer. It is notable that learning gained from school or any other interventions did not appear to be a source of knowledge or ideas for the young people in the group. It is possible that their schooling has contributed to some of the positions they took – for example in relation to the unacceptability of using discriminatory language such as the word “retarded.” However, it isn’t possible to reliably trace the source of position taking such as this.

**RQ1c: What communicative tools were employed in the occupation of discourse?**

There were a number of identifiable communicative tools which helped members of the group to inhabit discourse on mental illness. The recognition and admission of ignorance was one such tool. For example, Rahim’s ability to tell the rest of the group that he didn’t know what schizophrenia is - as discussed in 4.3.3 - was important in that it allowed others in the group to explore what they did know and to collectively pool and explore their ideas. Similarly, Simone was able to identify and describe her lack of clarity about the concept of mental illness in asking the question “do you mean like a breakdown or do you mean a proper mental

disability?” (S2, p.1). Being able to articulate lack of knowledge and uncertainty was an important tool which facilitated the productive flow of discussion, allowing others to share what they did know, and for the group to explore their understandings together.

The use of a humour was another of the young people’s strategies for occupying discourse on mental illness. One of the reasons for needing humour may have been that the subject matter was alien and unfamiliar as well as being potentially quite threatening and challenging. During the mind-mapping exercise in Session 1, when members of the group were coming up with words which they associated with the phrase ‘mental illness,’ Malik said “pegleg.” All four male members of the group seemed to find this incredibly funny, laughing and saying, “Yo! Pegleg!” to one another. They may have found this funny because “pegleg” is pejorative term which applies to a physical disability rather than relating to mental illness, so it was deliberately divergent from the principle topic of the discussion and therefore funny on account of being anomalous. It may also have been that they found something inherently daft and entertaining about the word “pegleg.” In a way this could be regarded as just a moment of tangential silliness, but the word “pegleg” became something of a motif which ran throughout the rest of the discussion series, with members of the group mentioning it from time to time, particularly in moments of tension or as a way of altering the timbre of discussion. In the final individual follow-up interviews I asked each of the participants what they thought had been the funniest moment of the discussion series. Farzan said, “Ahh, pegleg, miss. That was so funny. It was stupid, but it was funny. Thing is, whenever I think about pegleg, I think about all that stuff we were talking about the insults people say about people with mental illness. I do think about it seriously as well.” (FF, p3). I asked him to tell me more about what he meant by thinking about it seriously and he explained how he perceives acceptable and unacceptable use of language in relation to mental illness. This seemed to suggest that for Farzan, the “pegleg” motif had stuck in his mind principally because it was funny, and perhaps because of it having become a running joke. Although the motif itself is in some ways extraneous to key content of the discussion, Farzan demonstrates how he used it as a hook on which he hung his understanding of some of the more consequential content of the work we had done during the discussion series. Humour, then, was a significant communicative and interpretative tool.

### **Summary, RQ1**

Occupying and constructing discourse on mental illness was managed in various ways by the young people in the group. The ways in which the members of the group used language throughout the discussion series showed that the topic was largely unfamiliar territory and they initially found it difficult to appropriate the terms of the discourse and use them with



confidence. They drew on various sources in order to make sense of the matters under discussion, including their own experiences, things they had gleaned from the media, and their cultural and religious instincts. Making their way around the issues wasn't always easy, and the young people dealt with this in a range of ways including being honest about their own ignorance, using humour and shifting the timbre of discussion by introducing slang terms. Although the analysis of how the young people negotiated the subject of mental illness shows that the topic was largely unfamiliar and at times uncomfortable, it was also the case that they found being involved in discussion about these issues was interesting and stimulating. Being interested and engaged was of crucial importance in terms of group members being able to get the most out of being involved in the discussions. The young people also demonstrated the ability to draw on experiences which were more familiar to them – for example, knowing that people sometimes have a hard time – in order to make sense of some of the scenarios involving mental illness which were under discussion.

#### **4.5.2 RQ2: In what ways does the process of discussion and engagement with themes relating to mental illness impact on young people's constructions?**

As was discussed in Chapter 3, it is not easy to confidently demonstrate the impact of participation in any educational process and it is important to remember the epistemological challenges in attempting to address an evaluative question. In order to answer RQ2, I used two strategies for drawing inferences about the way participation in the discussions affected the young people in the group. These were structured around the following sub-questions.

- RQ2a: What discoveries and insights did the young people make during the process of discussion?
- RQ2b: What did the young people explicitly say about the impact of participation on them?

#### **RQ2a: What discoveries and insights did the young people make during the process of discussion?**

The young people made a number of discoveries and insights during their engagement in the discussion process. I characterise a discovery or insight as a moment in which at least one individual in the group appeared to grasp or come to understand something in a new way. Sometimes this happened as a moment of realisation; at other times one group member's

articulation of something had the effect of seeming to cause others to make a shift in their comprehension. The discoveries are shown in Table 8.

**Table 8: Discoveries**

Discovery	
D1	You can't see mental illness
D2	Mental illness doesn't necessarily equal substandard living
D3	You can't know what it's like unless you've experienced it
D4	There can be positives associated with mental illness
D5	Surprises/ inversion of stereotypes

### **Discovery 1: You can't see mental illness.**

The use of photographs of people was a key feature of the photo-vignette and profile building exercises. This led to the young people in the group thinking quite carefully about what a person with a mental health problem might look like. Excerpt 19 and Excerpt 20 demonstrate how the young people came to the realisation that you can't identify mental illness from a person's appearance.

#### **Excerpt 19**

*Farzan: How can we know from looking at them? We should be saying no to all of them*

*Rahim: Yeah, it's impossible, from looking at pictures, to know if someone's got mental illness. (S4, p14)*

#### **Excerpt 20**

*Emma: What do you think she'd be like?*

*Rahim: Standard.*

*Farzan: Yeah cos you wouldn't really know, like, if she had a mental illness. Not from looking at her anyway.*

*Simone: In just every day things when you're in the street and you see all these people walking around in their business suits and everything, she could be one of them. She could be anybody and you still wouldn't notice but really deep down she's got this problem.*

*Molly: So you can't tell, you can't see it. (S5, p9)*

Looking at pictures of people and imagining what a person with a particular experience of mental illness might look like gave the young people the opportunity to think carefully about the relationship between appearance and mental illness. In doing this they discovered that it would be very difficult to tell, which seemed to help them take less discriminatory positions in relation to others with mental illness.

## **Discovery 2: Mental illness doesn't necessarily equal substandard living**

In the early stages of the discussion series, the young people tended to resort to fairly crude assumptions that having a mental illness would lead to a substandard quality of life. As the sessions progressed, and specifically through engaging in the profile building exercise, the young people came to the discovery that this wasn't necessarily always the case. The first stage of the profile building exercise led to the young people creating very deficient narratives. By the end of the exercise they had shifted their perspectives, coming to the insight that having a mental illness doesn't necessarily mean a person will have a substandard existence. This is demonstrated in Excerpt 21, Excerpt 22, and Excerpt 23 below.

### **Excerpt 21**

*Emma: So this person is actually a youth worker.*

*Molly: Ooh. She lives with her partner?*

*Emma: She lives with her partner.*

*Simone: That is surprising.*

*Farzan: Mmm.*

*Simone: We got it all wrong. (S4, p26)*

### **Excerpt 22**

*Emma: So, this is actually Rosie. She's a nurse.*

*Simone: Oh gosh!*

*Malik: She's the one who's concerned about germs and dirt.*

*Farzan: Yeah, is that why she's a nurse?*

*Simone: Well you can see why she'd be concerned cos she's seen a lot and has to deal with a lot of things so that's why she's washing her hands after everything.*

*Malik: Hm, so being a bit mentally OCD hasn't meant she can't do a proper job then. Nurse Rosie. (S4, p28)*

### **Excerpt 23**

*Rachel: The best thing we did was the one where you had to see the picture and then make a life story for them, because it was like, it just showed really well that anyone could have a mental health problem. (S6, p17).*

While the exercise itself may have been an invitation to rehearse stereotypes, the introduction of information which destabilised those stereotypes led to the young people being able to shift the way they made assumptions.

### **Discovery 3: You can't know what it's like unless you've experienced it.**

In talking about what schizophrenia is, the young people made the discovery that you can't really understand what it means to have schizophrenia without having experienced it yourself.

#### **Excerpt 24**

*Farzan: Really none of us know because none of us have been through schizophrenia.*

*Emma: That's really interesting that you said none of us know because none of us have been through it.*

*Farzan: Yeah, we've never been through it, and even if there was someone here who'd had it, I can't say the word, but if they had it and even if they told you what it was like you wouldn't really know.*

*Molly: You can't know know but you can kind of get it a bit more by talking to someone who does know. (S1, p19)*

The mutually worked through discovery that you can't really know what mental illness is like unless you've experienced it represented quite a sophisticated and subtle type of empathy. A psychiatrist diagnosing schizophrenia might claim to know exactly what the symptoms of the condition are, and to have confidence in their knowledge of what it is. However, the insider experience will always be completely different from the abstract interpretation of it, and the way the young people reflected on the 'unknowability' of experiences they haven't had was quite astounding.

### **Discovery 4: There can be positives associated with mental illness.**

Through exploring personal narratives detailing people's lives with mental illness, the young people came to realise that mental illness doesn't necessarily amount to an exclusively negative experience.

#### **Excerpt 25**

*Malik: Well, she's even kind of happy she's got a mental illness.*

*Emma: What do you think about that?*

*Malik: I am surprised, to be honest.*

*Simone: Yeah, but it's come out for the better for her.*

*Kamal: She's alive.*

*Malik: And she wants to be.*

*Farzan: She knows what she's got and she's dealing with it her own way. She's taking her illness and making...*

*Malik: Making it better, making into a good thing. (S5, p8).*

#### Excerpt 26

*Emma: What did you think about the profile building exercise?*

*Rachel: I think that was good because, I don't know really, cos it was like showing you that you might say that person gonna be doing nothing cos of a mental health problem but then actually they don't have to be that affected by it. Or they can even make something good out of it. (S6, p8).*

While this discovery was genuinely surprising for some members of the group, they also demonstrated a readiness and willingness to accept and process the possibility of there being positive aspects to living with and through mental health difficulties.

#### Discovery 5: Inversion of stereotypes

The group's astonishment at my own disclosure of having experienced bipolar disorder brought with it the realisation that the stereotypes they associated with mental illness at the beginning of the process were less accurate and extant than they had imagined.

#### Excerpt 27

*Emma: So, if you've got a stereotype of what a person with a mental illness might be like...*

*Molly: Well it's not you! Definitely not.*

*Rahim: Nah, miss is clock on.*

*Simone: I would never, ever have guessed you'd had a mental thing. It was a big surprise. (S6, p3)*

#### Excerpt 28

*Emma: Yeah, so I'd like you to think about the whole process of having these discussions, and I wonder if there's anything in particular you think you'll remember... something that maybe had an impact on you.*

*Malik: That you said you had a mental illness. I'll never forget that cos I just didn't expect it at all.*

*Emma: And what sort of effect did that have on you?*

*Malik: Obviously I was shocked, man, because you're ordinary and not, I dunno, just, well, yeah, I dunno, like how I thought mental would be. (S6, p14)*

The impact of my disclosure was something that most of the participants discussed with me in their final follow up interviews, and their comments will be considered in greater detail in the discussion of RQ2b.

Most of the discoveries the young people made seemed to represent shifts being made away from deficient views of people with mental illness being strange and different and towards more open, empathic stances.

The five discoveries and insights identified here are those that I felt confident occurred as a result of the engagement in this particular discussion process and which fitted the way in which I characterised a discovery for the purposes of the coding framework. There were other less clear-cut instances of discovery-type moments. For example, the realisation that the subject matter was actually quite interesting, and the recognition of the huge range of life experiences which are categorised as mental illness.

An inspection of the completed coding framework (see Appendix 7) shows that the discoveries and insights made by the young people took place largely in sessions 4, 5 and 6. This suggests that there was something about the series of discussions which meant that the discoveries happened later in the process. An implication of this is that it would not be possible to deliver a quick fix, one off intervention and expect to have the same effect in terms of young people constructing their own meaningful discoveries.

### **RQ2b: What did the young people explicitly say about the impact of participation on them?**

In the final follow-up interviews, conducted 7 months after the end of the primary discussion series, I asked the group members to reflect on various aspects of their participation. The comments they made during these conversations are a helpful way of getting some sense of the sorts of ways in which being involved in the process affected members of the group. There were some themes in the ways the young people described the influence of participation, as well as some responses which were idiosyncratic and particularised. The themes I identified were:

- Confidence in talking about it
- Responding to others in distress
- Knowledge and understanding
- Increased empathy
- Impact of my disclosure
- Surprise at each other's contributions

Each of these themes will now be discussed with illustrative examples from the data, mainly taken from the individual final follow up interviews.

#### **Confidence in talking about it**

One of the impacts mentioned by several group members was that being involved in the process had increased their confidence in being able to talk about mental illness. Rachel was

very clear about this: “It’s made me feel more comfortable to talk about it now and to, like, discuss it with other people.” (RF p2). She explained further that “before, you’d never really talk about it cos you wouldn’t really know what to say or what words to use or something, but when you get to know a bit more about it, it’s like, you can talk about it cos you know what you’re talking about.” (RF, p.2). Her comments suggest that participation in the discussions gave her the feeling of having a vocabulary for talking about mental health issues which she didn’t have before, as well as the confidence of feeling that she knew what she was talking about. Molly also expressed how her confidence in talking about mental health issues had been enhanced. “Now I sort of understand it a bit more, at least enough to be able to talk about it better. Like, when me and Rachel speak with our friends they have no idea about it at all, and we’ve got a much better idea than them because we’ve talked about it and thought about why people get mental illness and what happens when they do.” (MF, p.3). Rahim also explained how taking part in the group discussions had equipped him to talk more confidently about mental illness “We wouldn’t talk about these things normally. Not at all. And, cos of doing this, I have actually talked to Eamonn about it and to Farzan and Malik as well, but you know, I just wouldn’t have done before.” (RhF, p4). It’s interesting that Rahim reports actually having had conversations about mental illness with a friend from outside the group – demonstrating that he feels more able to talk about the topic and has acted on this.

### **Responding to others in distress**

Another of the effects described by several of the group members was the way in which being in the group had made them feel that they would know how to respond if someone they knew developed a mental health problem. It is particularly interesting that they reported this as being an impact of participation, given that discussing practical ways of responding to others in mental distress was something that was barely covered in the sessions. Simone explained “I’m really glad this session has been happening, because, you never know what might happen, and now I feel I would know what to do if I someone I cared about got mentally ill. I wouldn’t have known before. So, this would be really useful later in life.” (SF, p.2). Rachel expressed a similar sentiment, “If my friend got a mental health problem before we’d done this then I wouldn’t even really know what it was about, or what to do, or what to say to them, but now I feel that I would be able to deal with all of that and I could be a better friend cos I wouldn’t be scared.” (RF, p3). It’s interesting that Simone imagines her knowledge of mental health issues becoming useful “later in life” whereas Rachel’s tone suggests that she imagines being able to apply her knowledge at any time. Like Simone, Farzan seems to feel that knowledge of mental illness would become most useful in the future “It is useful because, like in the future, god forbid I had a kid that was mentally ill, then it’s like, well, I knew

nothing about it before but now I do so yeah I think it's good to have a general idea about these things so you know what to do if you need to." (S3, p19). Given that we didn't talk in detail about the best ways of responding to another's mental distress during the discussion sessions, it is in some ways surprising that members of the group said they felt they would know what to do. Rachel's comment that this was because she wouldn't be scared perhaps points to an explanation for this. Perhaps having explored the topic and come to feel more comfortable in using the terms of the discourse, as well as having met a person (me) who subverted their stereotypes of what mental illness means combined to make the young people feel that mental illness is not such a scary thing. It may be that this demystification has the effect of making the young people feel as though they would have the resources to respond confidently if they were to encounter a person experiencing mental illness in the future, even if they did not have a cast-iron plan of action.

### **Knowledge and understanding**

Gaining knowledge was another impact of participation which the several of the young people identified. Rachel expressed this very simply, "I got to know a lot more about something I didn't really know anything about before." (RF, p.1). Farzan echoed this, "Before I met you I didn't know *nothing* about mental illnesses. I'd never talked about it, at all. And now I feel like I know quite a bit." (FF, p2). Malik also described the change in his comprehension of mental illness: "I never knew about what mental illness even was, and I've never met anyone who'd had it. Well, I don't think I had. So, now I do know what it is and I know that it doesn't make you a freak or anything. You can be just normal." (MaF, p.1). Simone also felt that participating had impacted on her knowledge and understanding. "I think it's helped me to understand what a mental illness is, and that it can be a variety of different things and people can still be normal with it. It's kind of hard to explain but I understand so much more than what I did before." (SF, p.2). Simone's statement that "it's kind of hard to explain" suggests that her new knowledge is not completely secure, or that there are things which still puzzle her to some degree. Molly described a similar experience of feeling she had come to know more, while simultaneously maintaining some uncertainty. "Now I understand it a lot more. But I still don't know exactly what it means, cos there isn't actually one defined thing that is mental illness, but I've got a better idea than I did and it sort of means I can understand it enough to see the reasons why people might become mentally ill." (MF, p.3). This range of comments indicates that the participants in the group felt that they had gained knowledge and come to understand mental illness much more than they had prior to taking part in the group.



## **Increased Empathy**

Another impact which emerged from the young people's comments was that they seemed to have an increased sense of empathy for others with mental health problems. Molly demonstrated this by saying "I've sort of come to see that people have sometimes actually got a real problem and they're not just being attention seeking. I get that it's more complicated now." (MF, p.4). Farzan also showed that he had started to think more empathically: "I know I'll remember it. I know that. More or less that mental illness is like, the people who have them, that they're still just people, you know. Like anyone, but they've got stuff to deal with." (FF, p.3). Simone also demonstrated how she had come to be more empathic in Session 6: "We've learnt it's part of life isn't it? I mean, I'm sure everyone here has felt rubbish, felt depressed at some time." Farzan showed his agreement by saying, "You do feel like that sometimes, course you do." (S6, p.17).

## **Impact of my disclosure**

The fact that I told the group about my experience of having bipolar disorder clearly had an impact on how they felt about the whole discussion series. The fact that they had spent five sessions getting to know and forming opinions about me before discovering this information seemed to add to their surprise at the discovery. The responses from the group at the time of my disclosure were recorded in my research diary as follows:

### **Diary extract 1**

Everyone in the group seemed extremely surprised, shocked even. When I said "I have a diagnosis of bipolar disorder myself," there were gasps of "woooooah!" and "no way!" After I'd told them some details, Rahim said 'you're still clocked on though,' by which I think he meant he thinks I'm sorted, together, sound, safe, generally an alright person in spite of it. Simone asked if I minded talking about it and asked me whether it was upsetting to go over it. Farzan said, "well what's happened has happened and she's just getting on with it."

I remember that Rachel and Malik said less than the others, but that they both seemed as surprised as the rest of the group. Molly was absent from Session 5, but at the beginning of Session 6, it emerged that she had heard about my disclosure via Rachel, who had also talked about to another classmate, Isabel. The fact that Rachel had talked to another friend who was not part of the group suggests that the discussion had been both interesting and significant to her.

In the final follow up interviews, all of the group members talked about my disclosure. Malik said he was sure he would remember the sessions in later life. When I asked what he would

remember in particular his response was, “Your bombshell, miss.” (MaF, p.3). His use of the word “bombshell” demonstrates how massively surprising my disclosure had been. Other members of the group also highlighted the significance of my having told them about my own experience. Simone said “Well, when you told us about you it kind of made me think that there must be other people who’ve had it who you think of as being really together but maybe they don’t tell people about it.” (SF, p.2). Molly said, “Well, obviously knowing now that you have had it and you’re so, well, normal, but not just normal, you know, you’re pretty cool and everything – that’s just made me think that mental illness isn’t what everyone assumes it to be.” (MF, p.4). Rachel also articulated her feelings about this: “It was kind of embarrassing when you told us about you, because of everything we’d already said, but then that was good in a way, for us to feel embarrassed. You telling us that kind of made it all seem a bit different somehow.” (RF, p.3) Rahim also explained his perspective. “Because, like, you explain it to us and obviously we can believe what you said because you’ve had it yourself, so it’s not like you’ve just heard it, or read about it, or whatever and are just telling us. It’s different when you’ve been through it. When I found that out it made me think differently about all the stuff we’d talked about before.” (RhF, p.7). Kamal also expressed how “You telling us what you told us about you, that’s what I’ll remember most, because it was a shock. Just shows mental illness isn’t what you think it is.” (KE, p.2). All of the young people in the group made comments about the influence of my disclosure, and it seems likely that the ‘bombshell’ will leave a lasting impression.

### **Surprise at each other’s contributions**

Most of this section has focused on the impact of participation in relation to the young people’s thoughts and feelings about mental illness. However, I also observed that the process of being involved in the discussion group had some bearing on individuals in the group in other ways besides how they made sense of mental illness. For example, the members of the group learnt things about each other which were unanticipated and surprising. In a one-to-one conversation carried out at the end of Session 2, Rahim explained his incredulity at the ways in which Farzan and Malik behaved in the group. This is shown in Excerpt 29.

#### Excerpt 29

*Emma: Do you think it's interesting?*

*Rahim: It's interesting what other people think about it.*

*Emma: What, the other people in the group?*

*Rahim: Yeah, it's interesting what they say.*

*Emma: What in particular, then?*

*Rahim: I thought like Farzan and Malik would be just empty really, and I thought they would've just made a joke out of all of this cos that's how they are. They take the piss. But they are being serious about it and that's like, well, I wasn't expecting that.*

*Emma: Why not?*

*Rahim: Cos I've just not seen that side of them. I didn't think they were like that, you know, like serious. But now I've seen they can be serious when it's time to. (S2, p.29)*

It was interesting how Rahim's comment about the way others were contributing to discussion came about. I asked him "Do you think it's interesting?" meaning the sessions in general. He answered by saying that he found what others think to be interesting, suggesting perhaps that his observations of others was the *most* interesting thing going on for him in the group at that time. This indicates that seeing his peers being able to deal with the subject of mental illness seriously was a particularly important discovery for Rahim, perhaps enabling him to legitimate his own interest in the topic – if they can take it seriously, then so could he.

Similarly in a one-to-one conversation with Farzan, at the end of Session 3, Farzan explained how surprised he was by Rahim's contributions in discussion.

#### Excerpt 30

*Emma: So, what's it been like in the group?*

*Farzan: Well, Rahim's surprised me because usually he's like 'nah nah nah' yeah. Us boys, me Malik and Rahim, we'd never chat about mental illness and all that because we'd always be making jokes about all this stuff, and just calling each other tapped and everything, so it's like, weird how come they've been talking about it seriously. I didn't think they'd think about it like that, you know, like, properly think about it. To be honest, it's impressed on me, that. That they're deeper than I thought. (S3, p19).*

It's clear that the boys found something very surprising in seeing each other engaging in discussion in what they call a 'serious' way. There was significant value in this surprise, and it seemed possible that it had an emancipatory effect, allowing them to feel ok about themselves approaching the subject matter seriously.

## **RQ2 Summary**

The process of discussion and engagement impacted on young people's constructions in a variety of ways. They discovered a number of things which they had not previously understood, including that there can be positive aspects to having experienced mental illness, and that having a mental health problem doesn't necessarily mean a person will have a substandard life. The experience of being told by me that I have a diagnosis of bipolar disorder came as a great surprise to the group and they felt that I was definitely not the kind of person they imagined as having a mental illness. Perhaps because of the very personal and immediate nature of this, the young people seemed to be quite profoundly affected by it. When asked directly how participation had impacted on them, the young people reported that they had become more confident and comfortable in being able to talk about issues relating to mental illness. They felt that they would be less scared if faced with a friend or family member experiencing mental illness in the future and that they would have the resources to know how to respond. They also reported increases in knowledge and understanding as a result of taking part in the discussions, along with more resources to be able to empathise with the experience of mental illness.

### **4.5.3 RQ3: What is the potential for education to help students construct non-discriminatory positions in relation to mental illness?**

In considering the potential for education to help students construct non-discriminatory positions in relation to mental illness, it will be beneficial to address the issue from various angles. The first approach I take is to consider what the young people themselves said about the content of the activities they participated in during the discussion series. By drawing together the findings discussed under RQ1 and RQ2, it is possible to suggest particular features which may be especially promising in terms of developing anti-discrimination pedagogy on mental illness. It is also important to consider how my role as facilitator may have influenced young people's position taking in relation to mental illness. In light of these concerns, this section will be structured around the following sub-questions:

- RQ3a: What did the young people say about pedagogy?
- RQ3b: What features of this approach are particularly promising?
- RQ3c: How did positions I took as facilitator influence the discussion and outcomes?

#### **RQ3a: What did the young people say about pedagogy?**

While the structure of the discussion sessions was principally a research process rather than having been overtly designed as an educational intervention, there were some features of the

work carried out which are pedagogically significant. The sessions were generally quite fluid, often being shaped by the young people's contributions, but I also experimented with a number of facilitated exercises. It is useful to reflect on the ways in which the young people responded to the exercises. I will do this by looking at the young people's explicit comments about and criticisms of the exercises we did, thereby identifying primary feedback.

During the course of the discussion series the young people occasionally made comments which indicated their views on the content of the activities they were engaged in. Molly and Rachel lingered to talk to me at the end of the first session and fortunately I had left the voice recorder switched on. Their comments are shown in Excerpt 31.

#### Excerpt 31

*Molly: That was really good. It was really interesting.*

*Rachel: Yeah, much better than the lesson we would've been in.*

*Emma: What would you have been doing in Life Skills?*

*Molly: Doing, like, working from a book or whatever.*

*Rachel: Yeah, you don't learn much.*

*Molly: I don't like just writing in books on your own. I like discussing things. It makes you think more, cos of what other people say as well as saying stuff yourself.*

*Rachel: Yeah, I think with this, like mental health and stuff, discussions are best.*

*Molly: And like you do it, where we can say what we want, with not that many of us. (S1, p22)*

Molly and Rachel express a clear preference for small group discussion over individual desk based working. They also make some crucial points about the particular features of the discussion they had just taken part in. Molly's statement that discussion "makes you think more, cos of what other people say as well as saying stuff yourself" highlights the value she feels in hearing other people's views as well as articulating her own. This implies that having the forum for her own views to be heard by others gives her a more meaningful educational experience than expressing her opinions in an individual writing exercise. This is supported by the examples given demonstrating the impact of discussion on Molly's perspective in the discussion of RQ2c. Rachel makes the point that having discussions is particularly appropriate when it comes to the topic of mental illness, and it appears that she has found this approach to be beneficial. Molly elaborates, pointing out that there were specific features of this discussion which were important to her. The feeling of being able to speak freely was clearly key, as well as having the discussion as part of a relatively small group. Her comment "like you

do it” also points to there being a something in particular about the feel of the session facilitated by me which she feels is important.

Kamal made an explicit comment in which he showed how reflecting on the mind-mapping activity carried out in the first session helped him see how his own thinking had developed and changed:

**Excerpt 32**

*Kamal: You know in the first session where we were writing everything on the posters, we were thinking of mental people like that, all those bad stereotypes and everything. But now you've got to know more about them a bit more, sort of, now, I would see it from their point of view more. (S4, p29)*

His comment “you’ve got to know more about them” draws attention to the way in which by the fourth session in the series, he is thinking about and imagining fleshed out characters rather than abstract sketches of “mental people”. This demonstrates clearly how identification with personal narratives has enabled him to move from “bad stereotypes” to seeing “it from their point of view.”

In the final session of the core series, I encouraged the group to reflect back on the whole process, reminding them of the activities and discussions that we had had in the previous five sessions. Therefore I explicitly sought comments from them on what they thought about the content of facilitated exercises I had presented them with and as a result of this quite a number of explicit comments were made during this session. When I asked the group what they felt about the mind-mapping exercise in Session 1, the feedback from Molly was positive.

**Excerpt 33**

*Molly: That was quite good cos it sort of made you get sort of into the right frame of mind to think about it and sort of gave us an idea of what we knew. What we didn't know! (S6, p4)*

With her comment “What we didn’t know!” Molly indicates that thinking back on the exercise from her current vantage point, she feels there is a difference between what the group knew then and what they know now, which in turn implies that she feels their understandings have developed.

The group gave a range of positive comments about the use of photo-vignettes in discussions.

#### Excerpt 34

*Rachel: The photos going with stories made them seem more real.*

*Molly: With the Simon one it made you think a lot more when you saw the two different pictures of the same guy and seeing how he'd changed and everything.*

*Malik: You got more into it by seeing the person when you read about them too. (S6, p.7)*

These comments indicate that the young people generally liked the photo-vignette format, and being able to see a picture of the person represented in the vignette helped them to see them as being more authentic. The discussions and responses which took place around the photo-vignette discussions were clear evidence of the technique's effectiveness (see Excerpts).

The group's feelings about the media exercise, in which they looked for symbols of causes of mental illness in newspapers and magazines, were more mixed.

#### Excerpt 35

*Farzan: It wasn't that helpful at all. You were just cutting out pictures of people that were stressed or something, and reading about it. (S6, p9)*

*Molly: In a way it was good cos it sort of made you realise that you don't really think about it or realise it but mental health stuff is everywhere you look. And there's so much pressure on everyone that it's not surprising they get mentally ill sometimes.*

Farzan's critical comment shows that while he didn't find the exercise helpful, he did remember the details of it. Molly displays a more positive opinion in saying "in a way it was good." It may be that the tentativeness of her comment is serving to preserve group solidarity and to gently express a different view without completely rejecting Farzan's opinion. Her feeling that the exercise was useful in demonstrating the previously unnoticed prevalence of "mental health stuff" suggests that it was effective in contributing to Molly's (if not others' in the group) normalising of mental illness.

The group's comments about the profile building exercise were especially positive.

#### Excerpt 36

*Rachel: I think that was really good because it was like showing you that you might say that person's gonna be doing nothing cos of a mental health problem but then they actually don't have to be that affected by it.*

*Molly: Or it made you feel like who you'd assume had mental health problems actually aren't and then the people you might not necessarily think it would affect are actually the ones going through it. Sort of thing. (S6, p8)*

*Rachel: The best thing we did was that one where you had to see the picture and then make a life story for them. Because it was like it just showed really well that anyone can have a mental health problem. (S6, p17)*

These comments demonstrate how the activity was linked to the discoveries that you can't see mental illness (see Excerpt 19 and Excerpt 20), and that having a mental illness doesn't necessarily equal substandard living (see Excerpt 21 and Excerpt 22). Rachel was particularly enthusiastic about the impact of this exercise, both in group discussions, as illustrated in Excerpt 36, as well as in individual interviews.

As well as comments about the specific facilitated activities, members of the group made remarks about the significance of working together in a small group.

#### Excerpt 37

*Farzan: I don't think you can like teach a whole class about mental illness all together. I think it's better to take out small groups and do it like this. You couldn't teach it as a class, it just wouldn't work. But you can have good discussions in small groups like this, and really learn stuff.*

*Emma: What do other people think about that?*

*Molly: Yeah, cos teaching it in a big class people aren't gonna pay attention properly or take it as seriously cos they're gonna try to impress others or whatever. They'd be uptight cos big classes isn't as easy to talk in as a small group. (S6, p.19).*

Excerpt 37 demonstrates that the young people felt explicitly positive about working in a small group, and that it enabled them to “really learn stuff.” Just as importantly, they displayed a clear view that trying to emulate a similar process in a whole class “just wouldn't work.”

The comments made by members of the group in the final session suggest that they found most of the facilitated activities to be interesting and enjoyable. They also show that they felt that taking part in the activities had an impact on the way they were thinking about issues relating to mental illness, broadening their perspectives and deepening their understandings. It appears that members of the group found the photo-vignettes and profile building exercise to be particularly stimulating and they were able to identify how taking part in these activities had an impact on them. The mind-mapping exercise and the media activity may have been slightly less engaging, but nevertheless remained in young people's memories at the end of the process. The young people fervently expressed the view that carrying out this type of work is not only best suited to a small group setting but also unsuitable for whole class working.

#### **RQ3b: What features of this approach are particularly promising?**

The analysis and findings which have already been presented point to a range of particular features which seem to be especially promising in terms of the development of meaningful mental health education which can counter discrimination. The young people themselves were clear that they felt working in a small group with an informal participatory feel was particularly valuable for exploring the topic of mental illness.



The preceding analysis indicates that personal narratives, including photographs, biographical information and details which helped the young people to empathise with the protagonists of those narratives were powerful educational tools. The inclusion of my own personal narrative and disclosure of first-hand experience of mental illness appeared to operate as a potent vehicle for subverting stereotypes. The profile building exercise seemed to be a compelling activity which shifted the young people away from automatically assuming that mental illness will amount to deficiency of some sort.

Another important feature was that the sessions were flexibly structured, with plenty of space for the members of the group to take charge of the direction the discussion took, introducing humour at times and using their own language throughout. This would not be possible to achieve with a very tightly defined lesson plan structured around didactic outcomes. The coding exercise revealed that most of the really dazzling discoveries made by the young people happened in the latter stages of the discussion process. This suggests that there was something about holding the discussions on a regular basis over a period of weeks which was beneficial. I do not believe it would have been possible to reach a comparable end-point in only one session, even if lasted for half a day or even a full day. The establishment and development of a dynamic and fertile rapport in the group was an important element, and something which could only happen over a period of time.

In summary, promising features of this approach to mental health education include:

- Working in small groups
- Meeting regularly over a period of time
- Encouraging discussion and exploration
- Introducing a range of resources to consider
- Presenting personal narratives
- Using photo-vignettes
- Using profile-building
- First hand disclosure of mental illness experience

### **RQ3c: How did positions I took as facilitator influence the discussion and outcomes?**

In considering the potential for education to positively influence young people's position-taking on mental illness through an analysis of the present data, it is necessary to interrogate the role I played in the group. The findings so far suggest that the group discussion process was fertile and productive and that the young people who took part made significant gains in

terms of their appreciation of the meaning of mental illness and of the experiences of people with it. It seems unlikely that the fertility which characterised the process of engagement came about simply because of the planned activities and pedagogical content of the discussion sessions. I suspect that the dynamic of the group and the way in which interaction took place within it was a key factor in the process, and this was likely to have come about partly as a result of the position taking of the facilitator.

In order to assess the influence of my own role in the process, I conducted a further coding exercise. Because of the need to maintain trustworthiness, I aimed to approach the data as dispassionately as possible, using an inductive analytic method, grounded in the data (Lincoln & Guba, 1985). I examined each of my own contributions in the transcripts and attempted to determine the function or effect of them. This initial analysis led to the generation of twenty six codes. I then analysed the thematic relationships between the codes to come up with four themes which described the functions I was carrying out as facilitator. These were: establishing rapport and group building; probing; directing and challenging. Having identified these themes, I then went back to code all six of the transcripts with instances demonstrating the themes. I will now discuss each of these functions, providing examples from the data of them in practice and considering how they were influencing the discussions.

### **Establishing Rapport and Group Building**

Establishing rapport and group building was the first theme I identified from the coding exercise. The two components are slightly different but I have decided to deal with them as one category because they are closely related and there is a lot of overlap between them. A range of features are covered by this category including: establishing and maintaining a healthy group dynamic; allowing humour to play out; encouraging participation from all the group members; allowing members of the group to take charge of the conversation; giving space for tangential talking to unfold; and giving affirmation to contributions from individual group members. Taking seriously the contributions of group members and adopting an open, receptive stance in relation to all contributions were also important elements of establishing rapport and group building.

The way in which I introduced myself to the group will have had some influence on their impressions of me. The first few lines of the transcript from the first session are shown in Excerpt 38. It should be noted that the first few lines of the transcript do not represent the absolute beginning of my first encounter with the young people. Before I started recording the conversation, I'd already talked to them for a couple of minutes, collected consent forms and explained the recording procedure to them.

### Excerpt 38

*Emma: I'm Emma. I'm a researcher from Manchester university and **we're** going to be meeting every week for a while.*

*Farzan: **Alright mate.***

*Emma: **(laughs). Alright. So,** I want to stress that I'm a researcher, I'm not a teacher. **So,** I'm interested in what you guys think and what your kind of feelings and thoughts and ideas are on the stuff we're gonna talk about. I'm not trying to teach you anything or looking for right answers, so I'd really like you to be totally honest in everything we do and don't try and say what you think I might want you to say. (S1, p1)*

In my first sentence, I tell the group that “we’re going to be meeting every week.” My use of the collective pronoun is a discreet indicator of my perspective of the group and me being equals. The meaning of the statement would have been subtly but significantly different had I phrased it “I’m going to be meeting you,” or “you’re going to be meeting me.” Either of these phrasings would have emphasised a difference between me and the rest of the group, as well as having connotations about who was in control, whereas the structure I opted for avoided doing this.

The way in which Farzan interjects by saying “alright mate” suggests either that he already feels comfortable enough to interrupt me and to use vernacular language, or that he is testing the water to see how such a comment will go down. My response to this was relaxed – I laughed, and then echoed his greeting, before carrying on with my introduction. This small conversational move may have helped to establish rapport in that it validates and accepts Farzan’s comment on its own terms. An alternative, perhaps more ‘teacherly’ response might have been to give a disapproving look or to have answered more formally with “Hello Farzan.” In laughing lightly, and returning the greeting in Farzan’s idiom, I am making it clear that what he said was ok by me. Having made my acceptance clear, I then show that I intend to take control and would like the group to give me their attention by starting my next sentence with “So.” I emphasise this, by also starting the next statement with “So.” In taking these two low-key conversational positions, I have demonstrated to the group that I’m open to them talking freely, that I do not expect to conduct the discussions formally, but that I also have an agenda which includes them listening and focussing.

A crucial part of ongoing rapport preservation was to create and maintain a safe space for discussing a topic which could be quite unsafe for the young people in the group. Setting boundaries and showing that I was going to take control of the discussion may have contributed to creating a safe space. My being at ease with the subject matter allowed them to feel more at ease with it than they otherwise might have. Although it was obviously particularly important in the first session, the establishment and maintenance of rapport was

embedded throughout the entirety of the discussion series. As we've seen in 4.5.2, it appeared that much of the collaborative processes in the group contributed to a considerable amount of development and learning. I suspect that this would not have happened had the rapport between the facilitator and the individuals in the group not been secure. The group working together so productively was partly as a result of feeling safe in the group and their being able to trust that the discussions were overseen by a relaxed and composed facilitator.

It is important to consider whether positive rapport between me and the group may have influenced or swayed the young people's reporting of the impact of participation on them. We had a good relationship, and I had the sense that members of the group enjoyed the group discussion sessions and also liked me personally. Because they liked me, it may be that they wanted to say nice things about the work we'd done, by way of complimenting me. This effect may have been heightened following my disclosure of my own personal experience of mental illness. This issue will be discussed in more detail later in the section on Challenging.

### **Probing**

Probing was a feature of facilitation which was a product of the discussion series being primarily a research process. Its purpose was to encourage the young people to say more, to clarify their ideas and go deeper into the emerging issues. Probing techniques included: reflecting back; answering questions with questions; using questioning to push discussion; refocusing; resisting giving answers; keeping my responses vague; and staying out of the discussion. It may be that much less probing would take place in a mental health education intervention which did not have an underlying research agenda. However, I had a strong feeling that the frequency and regularity of probing throughout the discussion series actually had educationally valuable outcomes, in that it encouraged the young people to explore the limits of their own understandings and positions. Examples of probing techniques are shown below.

#### Answering questions with questions

##### **Excerpt 39**

*Kamal: Miss can people get mental health problems from like the stress of GCSEs?*

*Emma: Well, what does everyone think about that? (S2, p.4)*

#### Using questioning to push discussion

#### Excerpt 40

*Malik: They're just weirdoes* (talking about people who self harm).

*Emma: Why do you think people would do it? What would make you do it?* (S2, p.5)

#### Refocusing

##### Excerpt 41

*Farzan: One man kills ten and then shoots himself* (reading headline)

*Emma: And how does that relate to mental illness?*

*Farzan: I suppose he could be depressed or mental.* (S3, p.5)

##### Excerpt 42

*Emma: So, you've said loads of things, but what links them? What's the overriding issue?*

*Molly: It's all about pressure.* (S3, p.15)

Probing techniques may have influenced the young people's contributions in certain ways. For example, it might be that through nudging them to elaborate and expand on what they had already offered I was making the young people feel as though there must be more to say. In this way it is possible that some of their responses might have become contrived. However, from the timbre of most of the discussion, I do not feel that this was a serious problem. When members of the group had had enough of talking about something, they usually deployed strategies to make this clear (for an example see Excerpt 15).

#### Directing

Directing refers to the interventions I made in order to keep the discussion relevant both to the research agenda, and educationally valuable. There were times during the discussion series when conversation went entirely off-topic, but it was essential to remain on-topic for enough time to meet the purposes of holding the discussion series. Part of the facilitation role was to have some sense of when to allow the group to 'go off' and when to 'pull them back.' Keeping the reins loose and generally allowing fluidity were so important for successful rapport building that I sometimes prioritised them over tight directing.

Directing includes inputs such as reminding group members to stay on track; bringing the discussion back after a tangent has been explored; summarising/ feeding back; moving discussion on by shifting focus; reminding the group of their previous contributions, making suggestions and clarifying purpose or details. Examples of these functions are shown in the Excerpts overleaf.

Reminding group members to stay on track

**Excerpt 43**

*Emma: Remember, we're not just thinking of any old insulting term. (S1, p.5)*

Bringing the discussion back after a tangent has been explored

**Excerpt 44**

*Emma: So, going back to your thoughts about schizophrenia. (S1, p.19)*

Summarising/ feeding back

**Excerpt 45**

*Emma: So, it seems to me that you've come up with different groups of things. Some of this is about causes of mental illness, some of it's about what mental illnesses are called, and some of it is kind of associated things, like how people might feel if they had a mental illness, and then you've come up with words we might use to talk about mental illness. Let's have a closer look at what you've written down. (S1, p.6)*

Slowing down/ focussing

**Excerpt 46**

*Emma: Ok... rewind! So, my question is what do you think is going on? You dived straight in and said you think she's taking drugs and getting abused at home and then everyone started talking at once. If we can speak one at once, that would be good. So... (S1, p.10)*

Moving discussion on by changing tack

**Excerpt 47**

*Emma: So, do you think she's mentally healthy? (S1, p.13)*

## **Challenging**

Challenging the group to think or rethink was a facilitative technique which I used sparingly. It included supplying information; offering suggestions or examples; being suggestive or leading; and making the discussion personal, either by asking members of the group about themselves or by talking about my own personal experiences. Giving the group relatively small amounts of information usually gave them enough stimulus material to talk productively about a theme or topic. One example of challenging by supplying information came in Session 2, in which I presented the group with the widely quoted statistic that one in four people will experience a mental health problem at some time in their lives. I then asked them how many people were in the room, to which Molly answered that there were eight. I allowed the group to process this, and Simone then said "Well that means that two of us here is gonna get it." Although Simone's comment shows a misunderstanding of how statistics work, her comment led to a rich and intense exchange in which the group really engaged with the idea of mental illness being tangible, real, and possibly personally relevant to them. The information functioned as a challenge which led to this type of thinking and discussion. The group's active engagement

with the information given was crucial, and it is notable how little I needed to do in terms of facilitation at this point.

On some occasions which I identified through the coding exercise, there were moments when my challenging inputs may have erred towards me being suggestive or leading. Examining these moments is especially important in order to consider how they may have influenced the impacts on young people's educational experience. The following four excerpts all come from discussion about the two *Simon* vignettes. In Excerpt 48, I respond to Simone having likened the *Simon* photo-vignette to the Columbine massacre.

#### Excerpt 48

*Emma: Ok, let's think about Simon then. What do you think's going on here? He's juggling with knives. Is he dangerous?*

*Farzan: Yeah, obviously.*

*Simone: Ye-ab (S2, p.7)*

I placed particular emphasis on the word “juggling” and in doing so might imply through my tone that Simon is ‘only juggling,’ which could perhaps serve to lead the young people to say he was not as dangerous as they first thought. However, the responses which followed suggest that my emphasis on this occasion had not influenced the group significantly.

Later we discussed the *Simon 2* photo-vignette and, Farzan made the comment that Simon “could do something dangerous.” The exchange is shown in Excerpt 49.

#### Excerpt 49

*Farzan: He's like mental, but then he makes people laugh and all that and he's just a normal person, but then he's got that side to him where he's a bit mental and he **could do something dangerous** to someone, you know what I'm saying?*

*Emma: Do you think... do you think he **would** do something dangerous?*

*Kamal: Probably.*

*Farzan: Yeah, if he doesn't get help.*

*Molly: No.*

*Malik: I don't know actually. (S2, p.16)*

The way in which I reflect Farzan's comment back, asking “do you think he would do something dangerous?” does two things. It changes the meaning, from possibility (could) to likelihood (would). In one sense this is a straightforward probe. However, it could also be seen as being slightly leading, in that I am giving Farzan the opportunity to elaborate, and opening

up a path for others to offer alternative judgements about Simon's dangerousness. Kamal and Farzan do not respond by saying "no, Simon wouldn't do something dangerous" but instead continue to express the views they were expressing prior to my comment. Molly is clear that she does not think Simon would do something dangerous, and it is impossible to know whether she was influenced by my possibly slightly leading position-taking. Malik's contribution suggests the possibility that it might be hard to tell whether someone is likely to be dangerous or not. The range of views expressed shows that the position-taking displayed by the young people in this particular exchange is similar to how it appears at times in the discussion when I had not made potentially leading comments.

A little later in the same conversation, I make a comment which more obviously contains a degree of suggestion.

**Excerpt 50**

*Molly: That's gonna really freak out the kids, it's a danger to everyone and it's just...*

*Farzan: And it's like he'd be influencing knives on them.*

*Emma: **But he did that thing with knives when he was sixteen.***

*Malik: Has he lost it or is he alright now or...?*

*Emma: How it is with him is that he's alright most of the time but about every couple of years or so he has an episode where he loses it a bit, and isn't himself. (S2, p.16)*

In Excerpt 50 I display overt sympathy for Simon, and my comment effectively implores the group to see that it isn't fair to judge a man in his fifties on the basis of something he did when he was a teenager. This leads to Malik asking for more information, presumably with the purpose of finding out more so as to be more informed as to whether or not it is fair to judge Simon based on the knife juggling incident. This suggests that rather than directly influencing the young people's positions, my sympathetic statement acts as a probe, pushing Malik to think about Simon from a different angle.

The most significant challenge I gave the young people who participated was to talk to them directly about my own experience of mental illness. This had striking effects, both in terms of the educational value and research benefits. The impact of my disclosure resulted in the young people leaving the discussion series with the view that a person can experience mental illness and still be a 'normal' person, and it seemed that the experience of working with me was one which they would remember. As a result of my having told the group about my own experience, it became clear how acutely aware they were that the language they had used in earlier sessions was pejorative. The male members of the group all apologised to me for saying



the things they'd said once they heard about my diagnosis, as they thought their comments might have been personally offensive to me. This was an important finding which came about directly as a result of my disclosure.

However, my disclosure inevitably changed things in the group, and may well have had some impact on how the group related to me. Some members of the group had been apologetic about comments made about mental illness early in the discussion series because, on discovering I had a mental illness diagnosis myself, they were concerned I could have been offended. The feeling of having caused me offence combined with their general liking for me might have led to them feeling that they needed to compensate in some way. This raises a question about whether all the positive things they said following my disclosure were coloured by this. It is not possible to establish with any certainty whether this was happening through interrogating the data I have. It may have been possible to triangulate for this by conducting evaluative interviews or group discussions carried out by a third party, but this was not practical in this case. Although young people's comments to me informed some of the conclusions drawn about the educational effectiveness of participation, much of the evidence for it comes from examining the content of the discussions themselves. So, even if their positivity is tainted by an underlying desire to say nice things to me, it is possible to observe active learning, exploratory position taking and developing thinking throughout the transcripts, before my disclosure. For these reasons, I feel that the influence of my disclosure on statements made about the value of engaging in the process was not of sufficient magnitude to render the findings untrustworthy.

### **RQ3 Summary**

The analysis of this data suggests that there is obvious potential for educative strategies to be effectively put to work in order to help young people better understand mental illness in all its complexity, and in doing so to construct non-discriminatory positions. The data also suggests that there are certain ways of approaching such education which are especially effective. My own role in facilitating the discussion series was inevitably a factor in the outcomes which have been reported. It may be that the group members' concern to compensate for possibly having caused me offence was an influential factor in their giving positive feedback about the impact of participation on them at the end of the process. It is not possible to be sure of this from analysis of the present data, but reasonable confidence can be had in the trustworthiness of the findings that participation:

- improved confidence in talking about mental illness
- increased confidence in their ability to respond to others with mental illness

- increased empathy towards others with mental health problems
- resulted in the recognition that people with experience of mental illness can be ‘normal’
- raised awareness of discriminatory language and behaviour towards others with mental illness experience.

#### 4.6 Summary of analysis and findings

I took a grounded, interpretative approach to data analysis and organised the findings initially around a first order coding structure, and subsequently in relation to the three research questions which underpinned this research. The analysis showed that young people’s knowledge and ideas about mental illness were somewhat erratic, and they began the discussion series with some confusion about what mental illness is. Their opinions and positions varied enormously according to context, with individual members oscillating between being sometimes quite fearful and controlling, and at other times open, supportive and empathic. The way in which the members of the group collaborated to make meanings, pool understandings and negotiate controversial subject matter was generally sophisticated and impressive. The young people’s occupation of discourse on mental illness was handled in a variety of ways, with communicative tools such as humour being used in order to help them navigate the discussions as a group. The process of being engaged in the discussions appeared to influence group members in a number of ways, including that they felt they knew more, were more comfortable in talking about mental illness and that they would be more confident in knowing how to respond if they encountered mental illness in someone they knew. The potential for education to positively influence the ways in which young people make sense of mental illness is illustrated by these findings. The experience of the members of this group suggests that for such education to work most effectively it should be carried out in small group settings with a participatory and informal flavour. The use of figurative narrative detail in bringing the meaning of mental illness to life is absolutely key to making mental health education meaningful to young people. Taking a constructivist, exploratory approach is also vital if education is to meet young people where they already are and enable them to build on their existing understandings and beliefs in the most resonant way.

The following chapter will explore the implications of these findings in their wider context.

## Chapter 5: Discussion and implications

*Truth is something which can't be told in a few words. Those who simplify the universe only reduce the expansion of meaning.*  
Anais Nin (1985)

### 5.1 Introduction

The aim of this chapter is to consider the findings of the study in their wider context and in doing so to discuss the implications of the findings in practical terms. There are a number of angles from which I will approach the discussion. Firstly, I will consider the relationships between the research reported in this thesis and the literature discussed in Chapter 2. This discussion will be structured around the following three themes which arose from the present data:

- Young people's understandings and ideas about mental illness
- Young people's positions in relation to mental illness
- Stigma and discrimination

The implications of these findings will be considered in relation to other research conducted about these topics. This discussion leads to the presentation of a new conceptual approach to knowledge and attitudes about mental illness and its stigma. I will then illustrate the relevance of the approach to education policy and anti-stigma practice. I will go on to highlight the need for further research which arises as a result of the findings of the present study. I will then discuss some of the lessons learned from the conduct of the study; examining the limitations of the work and considering what I would differently was I to conduct the study again. Finally, the chapter will be summarised, and some conclusions offered.

### 5.2 Relationships between present findings and previous research

There is a powerful relationship between the ways in which young people's knowledge about mental illness and their attitudes towards it are theorised and researched and the approach taken to 'enhance' knowledge and 'improve' attitude. Through taking an innovative approach to finding out more about how young people make sense of mental illness, this study sheds light on the problems which come about as a result of this relationship. The first section of this chapter will illustrate this by revisiting the main findings of the present study and examining them in relation to previous literature.

#### **The need to hesitate in making a distinction between 'knowledge' and 'attitude'**

As demonstrated in Chapter 2.2.1, most previous research into how young people make sense of mental illness is framed in terms of their knowledge of and attitudes about it and has been conducted by researchers from within the mental health field. Previous research into what young people and (adult) laypeople think about mental illness therefore assumes a distinction

between knowledge and attitude, with the constructs being researched as though are discrete. The findings of my study show that what other researchers call ‘knowledge’ and ‘attitudes’ are highly interdependent amongst the young people who participated in this research. Rather than being fixed and stable, they explored these things collaboratively, slipping around in a messy process of sense making. One of the features of this process was that beliefs and feelings informed ideas and ideas were furthered through exploring emotional reactions to them. Although my own analysis considered young people’s understandings and ideas separately from their positions and opinions, it does not tally with the social reality to regard them as being distinct. The evidence from this study suggests that what people know and understand about mental illness is inseparably enmeshed with what they feel and believe. This brings us to a place where it longer makes sense to separate and distinguish attitudes from knowledge when considering how people make sense of the topic of mental illness.

Furthermore, the way in which the relationship between knowledge and attitude has informed the development of anti-stigma education has significant implications. If one takes a mental health literacy approach to young people’s knowledge about mental illness, assuming that the more literate they are under this framework, then the less stigmatising they will be in their attitudes, the danger is that important features of young people’s sense making are overlooked. In addition, the essentially contested nature of mental illness is left out of such a framework, which leaves difficult questions unanswered which may fuel the fire of stigmatisation rather than serve to extinguish it.

### **5.2.2 Young people’s understandings and ideas about mental illness**

The way in which the present study relates to previous work investigating young people’s knowledge of mental illness is not straightforward, in part because the epistemological foundations and emphasis of the research are fundamentally different. The majority of studies reported in 2.2.1 investigated individual young people’s knowledge of mental illness from the literacy perspective, using quantitative measures, at a single moment in time. In contrast, the present work engaged a group of young people in discussion which took place over a period of time, during which their understandings and opinions shifted and changed.

In order to discuss the relationships between the findings of the present research and those of previous studies, I will begin by summarising the findings about knowledge and ideas from the present study. I will then compare and contrast these findings with those of previous studies. I go on to include a consideration of how the present findings would be interpreted under the mental health literacy framework. The discussion will be drawn together with a consideration

of how young people's 'knowledge' about mental illness has been constructed and what has been overlooked as a result of this construction.

The present study's main findings about young people's understandings and ideas about mental illness were as follows:

- Understandings were vague
- The young people were unclear about the meanings of diagnostic labels and didn't make much use of them.
- They saw causality in mainly psychosocial terms but also considered spirit possession. While recognising that some people might be more vulnerable than others, they didn't see this as being biologically based.
- Where behaviour was understandable in terms of their own experiences they were less likely to see a person as mentally ill. Behaviour outside the normal range of their experience was associated with mental illness.

### **Understandings were vague**

I found that the young people's understandings of mental illness were vague and patchy. The mind-mapping exercise carried out in the first discussion session gave an insight into the kinds of associations the young people made with the phrase 'mental illness,' thereby shedding some light on what they thought it was. The results of the exercise demonstrated that the young people's knowledge about mental illness was nebulous and uncertain. They were unclear about the distinctions between mental illness and learning disability, and sometimes even physical disability. There are notable overlaps between these findings and those of other researchers who have investigated young people's knowledge of mental illness. For example, Spitzer and Cameron's (1995) study asked children what they understand by the phrase 'mental illness' and found that the respondents were extremely uncertain about the answer. Spitzer & Cameron's research involved three age groups; the eldest being aged 12-13. In drawing comparisons, it only really makes sense to compare this age group with the responses of the members of the discussion group in the present study as the other age groups in Spitzer & Cameron's study were significantly younger. The three most frequent definitions of mental illness offered by the 12-13 year olds in Spitzer & Cameron's study were thinking (mind/brain) problems, learning disability and craziness. The young people who took part in the present study did not include 'thinking problems' in their responses to the mind-mapping exercise. They did, however, provide responses which showed they made strong associations between the phrase 'mental illness' and learning disability, as well as madness, or as Spitzer & Cameron call it,

‘craziness’. In these two domains, there were clear similarities between the results of Spitzer & Cameron’s work and the present research.

Spitzer & Cameron’s is the only study I was able to identify to have explicitly asked young people what they understand by the phrase ‘mental illness.’ Other research reveals data about young people’s interpretations of behaviour described in vignettes and concludes that they are able to distinguish between disordered and ‘normal’ behaviour (Burns, 2006; Coie & Pennington, 1976; Marsden & Kalter, 1976; Novak, 1974; Poster, 1992).

By the end of the discussion process conducted for the present research, young people’s ‘knowledge’ about mental illness was still quite vague. However, the findings of this study showed that the young people had a tremendous capacity for engaging with, processing and making sense of personal narratives of mental illness which developed throughout the discussion series. Molly expressed this lucidly in her final follow up interview “I still don’t know what it is *exactly* but I kind of do. Well, I know how to talk about it now.” Although they did not end up with terse, decisively expressed understandings of what mental illness is, they did leave the process with increased resources for making sense of, and occupying a discourse which is inherently complicated and messy. Personal representations of the experience of mental illness were presented in Chapter 2.1.3, offering a particularised answer to the question ‘what is mental illness?’ Given that each and every individual narrative of mental illness is different, taking account of personal stories doesn’t necessarily lead to a crisp, concise answer to that question. This research shows that personal stories of the experience of mental illness really resonate with young people, and that they have the capacity to comprehend the possibility of ambiguous and multifarious manifestations of mental illness. It was the process of engaging with personal perspectives, rather than being furnished with abstract, technical information which allowed this to happen. So, although understandings at a personal level do not necessarily equate to concurrence with any of the models of mental illness described in Chapter 2.1.1, they do seem to make sense to young people in terms of getting a handle on the experience of mental illness. Previous research has not approached the study of young people’s knowledge in such a way as to be able to take account of this complexity.

### **Diagnostic labels were rarely utilised**

The use of diagnostic labels and clinical language was sparse in the discussion series conducted for the present research and it was evident that the young people were uncertain about the meanings of some technical terms. Previous studies have revealed similar findings. For example, Burns & Rapee’s (2006) study investigated young people’s knowledge of depression, concluding that adolescents’ ability to correctly identify and label behaviour as depression was

unreliable. Roberts et al.s (1981) research also found that children's explanations for behaviour designed to represent mental illness did not utilise diagnostic language, with responses being framed in terms of circumstantial reasons for behaviour rather than the application of clinical language. Similarly, one of the main findings from Poster's (1992) study, which investigated young people's knowledge of mental illness, was that less than a third of respondents assigned mental illness labels to behaviour described in vignettes designed to depict particular diagnoses of mental illness.

The infrequent use of diagnostic labels in young people's discourse can be interpreted in a variety of ways. Other researchers commonly report that it is evidence of poor mental health literacy, i.e. that young people do not understand the meanings of diagnostic labels and therefore cannot assign the correct label to behaviour which is associated with that diagnosis. An alternative interpretation is that young people have some awareness of diagnostic language but are reticent to use technical terms which they are uncertain of the meanings of. A further possible interpretive approach might regard young people's infrequent use of diagnostic language as evidence of their not making links between particular behaviours and clinical diagnoses. For example, that two thirds of respondents 'failed' to label a vignette character as suffering from depression in Burns & Rapee's (2006) study may be evidence that they do not regard the behaviour as (clinical) depression rather than that they don't fully understand the meaning of the term. While the infrequent use of diagnostic labels is significant, it is important to remain open to the possibility of a variety of explanatory factors underpinning it rather than to assume that it is a straightforward indicator of 'ignorance.' Previous studies have not done this in their interpretation of results.

### **Causality was seen in mainly psychosocial terms**

During the discussion series conducted in the present study, talk about causality was frequent, both in relation to the individuals presented in photo-vignettes, and as part of unstructured discussion which took place around facilitated activities. In contrast, Bailey's (1999) study investigated young people's understandings about mental illness by soliciting responses to a questionnaire. The 11-17 year olds who responded were asked to produce freely written answers to the question 'what causes mental illness?' In Bailey's study, the most commonly cited cause for mental illness was stress. Bad experiences in childhood were mentioned by 26% of the sample as a cause, and genetics by 27%. The idea of stress was one which featured prominently in the way the young people in the present study talked about the causes of mental illness (See Excerpt 11). Bad experiences, both in childhood and in later life were also talked about. The present group did mention the possibility of genetics being a factor but with

considerable uncertainty (See Excerpt 2). They also explored the role of parents, friends and family in affecting a person's mental health (see Excerpt 10). The findings of Bailey's study, in common with those of the present research point to the multifariousness of young people's ideas about where mental illness comes from.

The young people in the present study also raised the possibility that some 'mental illness' may not in fact be mental illness at all, but rather that a person has become possessed by a demonic spirit, thus losing control of their actions and behaviour. Bailey's study made no mention of spirit possession. However, there is a sizeable body of literature which addresses transcultural interpretations of deviant behaviour, and the notion of spirit possession as an explanation for 'psychosis' is commonplace in many cultures (Dein, Alexander & Napier, 2008; McCabe & Priebe, 2004; Redko, 2003) as well as amongst Christian clergy in the UK (Leavey, 2010). Those who hold medically informed views of psychosis may be quick to dismiss spiritual perspectives as absurd and perhaps as a result of this, the spirit possession as an explanatory possibility appears to have been left out of questionnaires investigating young people's knowledge about mental illness. However, the present data indicate clearly that, for some young people, the idea of spirit possession is as plausible an explanation for strange behaviour as anything else.

As we saw in Chapter 2, modern psychiatry is built on Kraepelin's assumption that biological and genetic factors are the primary determinants of mental illness. Although this assumption has never been proven, biological psychiatry continues to dominate formal understandings of mental illness in contemporary western society. It is striking, therefore, that the young people who took part in this research showed virtually no signs of giving credence to the idea of biological factors contributing to mental illness, nearly always resorting to life-history and psychosocial factors to explain the presence of mentally ill behaviour. When I gave them the opportunity to comment directly on whether there may be biological or genetic factors involved, they were doubtful and hesitant, only ever hinting at the possibility of there being fundamental or innate differences between people who develop mental illness and those who don't. This is demonstrated in Excerpt 2.

The young people's views on the causes of mental illness were more in line with psychological and sociological models than those offered by the medical model. For example, one of the assumptions of clinical psychology is that mental normality and abnormality are continuous (Peterson 1999) rather than discrete. It appeared that the young people regarded mental illness in this way at various points in the discussion series. The view was demonstrated explicitly in



Excerpt 11. Here, members of the group explained how they regard mental illness as starting with stress, then getting out of hand “until your mind can’t take it any more.”

The young people in the discussion group frequently demonstrated the view that environmental factors were significant in the onset of mental illness. Sociological explanations for mental illness place emphasis on external, environmental factors rather than individual, internal ones, and in this way the young people’s views could be said to resonate to some degree with Stress Theory (Thoits 1999), as described in Chapter 2.1. The way in which they constructed economically disadvantaged profiles in the first stage of the profile building exercise suggests that they saw a connection between mental illness, unemployment and poverty. This could be interpreted as a rudimentary version of Structural Strain Theory, which proposes that economic disadvantage is itself a risk factor for mental illness.

One of the most important things which emerges from section 2.1 is that the very idea of mental illness is heavily contested, and for good reason. The philosophical nuance of the arguments proposed by figures in the anti-psychiatry movement is unsurprisingly lacking from the discourse occupied by the young people who took part in this research. However, Thomas Szasz’s idea of “problems of living” as opposed to biologically based mental illness (Szasz 1960) seems to sit more comfortably with the young people’s ‘natural’ way of making sense of what causes mental illness than the biological explanations offered by the medical model. Laing’s concern with taking seriously the individual profile in order to make sense of madness (Laing 1960) also seems to resonate with the way in which the young people in the present research found it possible to empathise with and understand personal stories of mental distress. Young people’s diverse ideas about causality could be interpreted as evidence of confusion and lack of confidence about what the causes of mental illness are. However, given the controversy and lack of evidence as to the causes of mental illness which are prominent features of the professional discourse in this area, it could equally well be interpreted as a reverberation of this. The experts have lots of ideas but few proven answers, and the treatment of mental illness in films and other media often reflects this, so it is perhaps unsurprising that young people’s positions are also very diverse.

**Where behaviour was understandable in terms of their own experiences they were less likely to see a person as mentally ill.**

In the present study, it emerged that where the young people could understand behaviour in terms of their own experiences, they were less likely to see a person as being mentally ill. Behaviour which was outside the young people’s range of experience was more likely to be

regarded by them as mental illness. This reveals a noteworthy difference in the way behaviour is labelled as mental illness by medical professionals and how it is regarded by young people. Behaviours presented in the photo-vignettes which would be likely to be interpreted by psychiatrists as symptoms of clinical conditions were rarely identified by the young people as mental illness. Instead, they related these things to the circumstances of a person's life, imagining scenarios which would lead a person's behaviour to change as a result of them feeling sad, anxious or stressed. (See Excerpt 10). The exception to this was in the case of the *Neighbour* vignette, which the young people felt fairly sure depicted a person who was mentally ill, although they were not entirely confident what specific type of mental illness. This tendency for young people to identify 'clinically disordered' behaviour not as illness, but instead as normally explicable is further evidence of the young people's uncertainty about how to describe behaviour which psychiatrists consider to indicate mental illness.

Previous research has revealed a similar trend in young people's sense making. For example, the children who took part in Poster's (1992) study gave psychiatric labels to the vignette character with schizophrenia much more readily than they did to the characters with other disorders. In the context of Poster's reporting of the research, this is regarded as evidence of lack of knowledge. The pattern of responding, in which psychotic behaviour is labelled as mental illness and other behaviour not being considered to be mental illness echoes the way the young people responded to the photo-vignettes in the present research.

Rogers & Pilgrim's (2005) suggestion that the public spontaneously associate mental illness with psychotic or unintelligible behaviour is relevant here, as are Secker et al.'s (1999) findings about young people's reticence in labelling behaviour they have experience of as mental illness. Secker et al.'s (1999) study concluded that young people were likely to label behaviour with which they were familiar through their own experience as *not* mental illness. Behaviour which the young people in the study found difficult to account for in terms of their own experience was more likely to be described as mental illness. In the present study, the young people responded to the *Neighbour* vignette, which describes distinctly odd behaviour, by making an immediate link with mental illness and tentatively labelling it as schizophrenia. In responding to the other vignettes, in which the behaviours represented are less unintelligible, the young people hesitated in or saw no need to use the language of mental illness. The findings of this study harmonise with those of Secker et al. and it seems that young people find it easier and more comfortable to think in terms of difficult life experiences than mental illness and diagnostic labels.

## **Mental health literacy considered**

The majority of previous research into young people's understandings of mental illness is predicated on the mental health literacy paradigm, aiming to establish young people's ability to recognise and identify mental disorders and to distinguish between normal and disordered behaviour (i.e. Marsden & Kalter 1976; Coie & Pennington 1976; Norman & Malla 1983; Roberts et al. 1983; Poster 1992; Burns & Rapee 2006). While such questions were not the explicit focus of this research, the data this study generated can be considered from the standpoint of mental health literacy research. The young people's responses to the photo-vignettes which were used as loci for discussion can easily be examined in the terms of mental health literacy, for example. If this approach were to be taken to the present data, it would undoubtedly be reported that the young people who participated in the present research displayed low levels of mental health literacy. In the case of the *Sarah* vignette, the young people talked about a variety of possible explanations for what was going in her life, but they did not identify her behaviour as being indicative of depression. Although one member of the group mentioned anorexia within the broader discussion about *Sarah*, the vignette did not contain details which would be congruent with such a diagnosis, so this response would also be considered incorrect and 'illiterate' if approached from the mental health literacy standpoint. Similarly, the *Simon* vignette presented a character displaying symptoms which were, in clinical terms, indicative of a first episode of psychosis, but the young people did not conclusively identify the behaviour in this way. Instead, they approached the character in terms of psychological and social factors which might have led to him behaving uncharacteristically. While they did talk about the role of stress in Simon's predicament, and explored the possibilities of spirit possession or mental illness generally, they were not confident in assigning a diagnosis. The word 'psychosis' was not mentioned once by the young people during the entire discussion series and I am doubtful that they would have been able to provide a definition of it if asked. Again, under the literacy paradigm, this is evidence of unfamiliarity with psychiatric terms and poor mental health literacy. In the case of the *Neighbour* vignette, the young people were much more confident in asserting that the character presented was mentally ill, tentatively ascribing the label of schizophrenia to describe the behaviour represented. However, there was some disagreement amongst group members as to whether this labelling was correct. The behaviour described in the vignette would correspond to a clinical diagnosis of schizophrenia so in this instance the young people's response may be interpreted as more literate than their other responses.

The mental health literacy approach would regard the young people who were engaged in the present research as being relatively 'illiterate.' My analysis of their responses is different.

Rather than being 'wrong,' I interpret their knowledge as being vague and imprecise which is not to say that they don't have legitimate ideas. The mental health literacy standpoint would consider that young people's unconfident use of diagnostic language is strong evidence of their illiteracy. I suggest that the reasons for their reticence in using this vocabulary should not be assumed to be a straightforward sign of 'ignorance.' It is possible that their uncertainty about the meanings and appropriateness of medical labels to describe behaviours is an explanation for the terms not being readily employed. Their ideas about causality are various and do not concur with the biomedical model of mental illness, and therefore could be seen as 'illiterate.' I propose that they nevertheless represent serious attempts to understand the range of psychological, social and environmental factors which may be involved.

This research, along with a number of earlier research studies, has shown that young people are reticent to describe behaviour with which they are familiar as mental illness. Where they can make sense of behaviour changes indicating psychological and emotional distress in terms of their own experience, they tend not to regard it as mental illness. However, psychotic, unintelligible behaviour which violates the social norms of young people's own experience does tend to be regarded by them as mental illness. With the exception of Secker et al.'s (1999) study, the studies making this finding have interpreted it as evidence of young people having little knowledge of mental illness, and poor mental health literacy. As a result of these findings being cast in that light, a proper analysis of their significance has not been worked through. When considered in relation to the ontological controversies surrounding mental illness, young people's hesitancy in labelling behaviour as mental illness might reasonably be seen as an instinctive rejection of the medical model. That young people seem to have a preference for understanding emotional and psychological distress holistically, in terms of the social context and psychological landscape of a person's life, rather than as something somatic has previously been regarded as evidence of ignorance. However, given that the scientific basis of the assumptions of medical psychiatry is so flimsy, it is unwarranted to account for their perspectives only in this way. The construction of the mental health literacy concept is itself a way of legitimising the medical model of mental illness, using professional power to sideline views which are oppositional by framing them as illiterate. Laypeople in general are prey to being derided in this way, but young people especially so because of assumptions about their naïveté and immaturity.

However, it is possible to take seriously the views of young people in their own right. Doing so allows the opportunity to avoid dismissing perspectives which contradict a constructed orthodoxy as illiterate and instead to consider alternative explanations for their sense making.

That a group of year 10 pupils with no educationally constructed knowledge on the subject hold views which run counter to the psychiatric orthodoxy should not automatically be considered as evidence of their ignorance. We should at least consider the possibility that as people with no acquaintance with the ontological difficulties posed by the very concept of mental illness, their responses to it could instead be regarded as unsullied, genuine and worth reflecting on properly. Instead of being cast aside as illiterate, young people's conceptions could be considered as resonating with the arguments of classical anti-psychiatrists such as Szasz and Laing, in which mental illness is better regarded as "problems of living" and the individual experience of distress is always idiosyncratic, and as such unsuitable for the narrow categorisation imposed by diagnostic labelling. Much previous research investigating young people's knowledge of mental illness has failed to critically engage with how what is considered to constitute 'knowledge' in relation to mental illness has been constructed. The problems which arise from this have significant implications for anti-stigma enterprise and mental health education. These will be discussed in more detail in 5.5.

### **5.2.3 Young people's positions in relation to mental illness**

As demonstrated in section 2.2.2, previous research investigating young people's attitudes tends to report that young people stigmatise mental illness and are socially distancing towards people who experience it. Most previous research reported sought to capture young people's attitudes to mental illness at a single point in time, whereas the present study engaged a group of young people over a period of time in which they displayed a range of changing opinions. Furthermore, the vast majority of prior attitude studies have used questionnaire rather than discussion-based methods to elicit the views of young people. This study was not primarily concerned with investigating young people's attitudes to mental illness, but rather set out to investigate how young people make sense of the issue and construct their positions in relation to it. In conducting the study, data emerged which were able to give some indications as to young people's opinions and feelings about mental illness, but very much as part of a broader discussion process rather than as a result of a direct attempt to ascertain attitude. It is important to bear these matters in mind when making comparisons between findings from the present study and those of previous research studies.

The main findings about young people's positions in relation to mental illness from the present study can be summarised as follows:

- Position taking is plural
- The default position is ambivalence

- Position taking is context specific
- Position taking is influenced by collaboration

These findings will first be considered in relation to the findings of the attitude research studies reported in section 2.2.2. Haslam's model of Folk Psychiatry will then be considered in light of the discussion so far.

### **Position taking is plural**

A major finding of the present research is that position taking about mental illness amongst young people is plural and fluctuating. None of the young people who took part in the discussion series demonstrated a consistent unidimensional view about people with mental illness. Individuals would sometimes exhibit optimistic and positive views, and at other times display pessimism and negativity. Previous research into young people's attitudes about mental illness can be summarised as principally reporting negative attitudinal trends and have not reported plurality or fluctuation (Wahl, 2002). The findings of the present study paint a much more complex picture than the results of these studies. This is undoubtedly in part due to methodological factors. Responses to questionnaire items which use attitude response scales can only be provided within the terms of the questionnaire. It is the nature of attitude measurement studies that they aim to measure attitude in terms of the degree of positive or negative affect in relation to a statement (Himmelfarb, 1993; Oppenheim, 1992). Consider, for example, the questionnaire item "People with mental illness are dangerous," inviting respondents to agree or disagree. The questionnaire item leaves no space for nuance or complexity either in the response or in the interpretation of the response. The process of open discussion which characterised the present research was a process which allowed and indeed encouraged much more complex responding than is made possible by the research design of the attitude studies reported in 2.2.2. Similarly, the strategies for analysis in the present study sought to make sense of this complexity rather than to consider young people's attitudes in terms of purely positive or purely negative responding. The unearthing of this complexity is a finding which has significance for how stigma is understood and responded to.

### **The default position is ambivalence**

The young people in the present study displayed position taking which was sometimes negative, sometimes positive, but predominantly ambivalent. This is in contrast to the findings of questionnaire-based attitude studies reported in 2.2.2 which report broadly negative attitudinal trends and do not report ambivalence as being a feature. That ambivalence has not

been a finding of previous research studies may in part be due to the limitations of using bipolar response scales in questionnaire based studies which aim to measure attitude in terms of degree of positive or negative affect and therefore do not have an adequate mechanism for recognising ambivalence.

Although ambivalence was central, the young people in the present study did display distinctly negative opinions about people with mental illness and it was clear that the risk of a person with a mental health problem causing harm or disturbance was a very real concern for them (See Excerpt 5). That they expressed these sorts of views could be regarded as evidence supporting findings from attitude measurement studies that young people stigmatise mental illness (i.e. Watson et al. 2005; Chandra & Minkowitz 2007; Williams & Pow 2007). However, the picture painted by the findings of the present research is much more intricate than this and it would be reductive to make this point and stop there. A very important outcome of the present study is the evidence that negativity, while being a component of young people's position taking in relation to mental illness, is not a fixed dimension. The young people in the present study sometimes seemed to flip between negative and positive positions, (see Excerpt 6 and Excerpt 7) demonstrating that their feelings about the issue of mental illness are inherently complex. The fact that the same individuals who sometimes displayed negative opinions based on stereotypes also displayed positive and open positions on other occasions further demonstrates their underlying ambivalence and uncertainty. Therefore, other studies which report negative attitudes and stigma are missing an important component of young people's position taking which it is crucial not to overlook, particularly in relation to anti-stigma education. This constitutes a challenge to the concept of stigma

### **Position taking is context specific**

Through the research process conducted in the present study, it emerged that whether young people displayed ambivalent, positive or negative positions was dependent in part on the influence of contextual factors, such as the type of mental illness, and the biographical details of a character with a mental health problem. Context-specific position taking has not been a finding of previous research studies. One reason for this may be that previous studies have not made it possible to investigate the influence of contextual factors on young people's attitudes. These findings suggest that young people's feelings about mental illness, like their knowledge of it, are not rigid, and are very much dependent on details which lie beyond the sense that can be made of the ideas that spring to mind when presented with the phrase 'mental illness.'

### **Position taking is influenced by collaboration**

A further finding of the present study was that through the process of talking to each other, the young people reflected on their opinions and feelings, sometimes moderating and altering them as a result of considering others' views (see Excerpt 10, Excerpt 12, and Excerpt 31). This is further evidence of the fluid, shifting and contextually dependent nature of young people's position taking in relation to mental illness. It makes sense that people's opinions would be influenced by those of others, given the fundamentally social nature of the matter in hand. However, this is an important finding which has not been revealed by questionnaire based studies. This is likely to be partly down to the fact that traditional attitude measurement methods only look at respondents' individual responses in isolation and therefore cannot capture the interplay between individuals. While questionnaire based approaches are convenient for research purposes, the results cannot reflect the socially constructed and enacted basis of phenomena such as how people respond to others with mental health problems.

### **Folk psychiatry considered**

The folk psychiatry model described in 2.1.2 presents a schema for understanding how laypeople think about mental illness (Haslam, 2003; Haslam, 2005). At this point, I will consider how the present findings relate to the folk psychiatry model. The model suggests that the first stage of laypeople's cognition about mental illness is 'pathologising,' whereby people identify behaviour as being not within the normal range and in so doing establish the presence of mental illness. The folk psychiatry model goes on to propose that once pathologising has taken place, laypeople opt for one of three explanatory possibilities for the out of the ordinary behaviour. These are 'medicalising', 'moralising' and 'psychologising'. In other words, people either explain mental illness in terms of something being wrong with the body, something being wrong with a person's moral conduct, or something being wrong with their psychology. Haslam states that what is distinctive about his model is its cognitivism – i.e. that it focuses on the thought processes which lead people to draw conclusions about what is going on when someone is mentally ill. Because of this, one might regard the model as being more about knowledge than it is about attitude. However, the response dimensions which Haslam identifies involve distinctly 'attitudinal' domains – whether one moralises or medicalises is not based solely on a person's knowledge base, but also very much depends on their opinions and feelings. In the same way as I have already argued, it does not make sense to consider knowledge and attitude as being discrete. In relation to the organisation of my own findings, Folk Psychiatry speaks to both understandings and ideas and positions and opinions.



As we have seen, the young people's understandings and ideas about mental illness were vague. They rarely utilised diagnostic labels and saw causality in psychosocial terms. Where they were able to understand behaviour within the terms of their own experience, they did not regard it as being mental illness. Their position taking in relation to mental illness was plural, characterised by ambivalence, context-specific, and influenced by collaboration. At face value, this picture does not correspond with the Folk Psychiatry perspective at all. It's clear that a formal model of this kind isn't designed to reflect the complexities of real life, but rather to assist in unravelling and analysing them. Therefore it is not surprising that the concomitant multiplicity of young people's sense making does not fit neatly into a model which suggests that people opt for one of a limited number of explanatory positions. Despite this outward discord, it may be that there are elements of the folk psychiatry dimensions within the knotty mishmash which characterises young people's approach to mental illness. The question is whether the model is able to capture some of what goes on.

A closer appraisal of the Folk Psychiatry model in relation to the present study's findings reveals both substantial discrepancies and elements of harmony. To illustrate, I will now consider each dimension of the model in relation to the present findings. We have already seen that the process of labelling behaviour as mental illness is fraught with difficulty for young people, and if they can possibly explain it in other terms, they will do so. When behaviour is not otherwise explicable, young people do identify it as mental illness, so it is fair to say that 'pathologising' is something that they sometimes do. However, the strong resistance to pathologise is important to re-emphasise, in particular because of its consequences for stigma. Because of the fact that young people seem to prefer to normalise rather than pathologise, it may be that the remainder of the dimensions of Haslam's model are not appropriate to apply to the ways young people make sense of what is going on when someone is, as they see it, having a hard time rather than, as seen by psychiatry, experiencing a mental illness. However, on the occasions when pathologising has clearly taken place – for example in the young people's responses to the *Neighbour* vignette – a consideration of whether their responses are indicative of cognising along the dimensions identified in the model is valid and worthwhile.

So, are medicalising, moralising or psychologising observable aspects of what the young people did in their handling of mental illness? Haslam explains that the 'medicalising' dimension of the folk psychiatry model does not simply represent laypeople's internalisation of the biomedical view as expressed by psychiatry. It also incorporates essentialist thinking, whereby mental illness is regarded as being a 'natural kind,' innate and immutable. The present

data gives scant evidence of this type of essentialist thinking. Although the young people did consider the possibility of some people being “mentally stronger” than others, and therefore less prey to mental illness, they also felt that it depended on “events in your life” (see Excerpt 2). The sense of one person being mentally stronger than the next represents a touch of essentialist thinking, but it is cautiously expressed, tempered by the perception of the potential significance of environmental factors. As we saw in 5.2.2, young people were extremely wary and uncertain about the role of biological factors in mental illness, and evidence of their considering mental illness to be somatically rooted is basically non-existent in the present data. The idea of mental illness as ‘disease’ simply did not appear in their discourse. So, although there was a hint of essentialism in terms of there being a feeling that people are different, some more susceptible to mental illness than others, the medicalising dimension did not appear to be a prominent feature of young people’s expressed cognition.

Haslam suggests that ‘moralising’ involves making an appraisal as to whether a person’s behaviour is intentional or not – moralising occurs where a person is deemed to have displayed deviant behaviour as a result of their own volition. There was some oscillation in whether or not the young people regarded behaviour as within an individual’s control. In some discussions they expressed the view that whatever was going on was not the person’s fault, and that they couldn’t control it. Molly, for example said about *Simon 2* “it’s not his fault that he’s like that” (see Excerpt 7). However, on other occasions, there were indicators that the young people might feel that some behaviours were within individuals’ volitional control. Examples include talking in general terms about self harm (see Excerpt 40), and when the possibility that *Simon 1* was being deliberately attention seeking was raised. The tendency to moralise, then, was certainly an element of the young people’s thinking about mental illness. However, it was highly context specific, and seemed to be related to the degree to which they felt empathy for a person, as well as how much they identified with them.

Given the ways in which young people saw mental illness in largely psychosocial terms, it might seem at face value that the ‘psychologising’ dimension would be likely to be the most concurrent with young people’s sense making. A closer analysis of what Haslam means by ‘psychologising’ is needed in order to establish whether application of the dimension can be assigned to what young people actually do. Haslam states that psychologising involves explanation in terms of *causes*, by which he means unintentional behaviour, carried out neither consciously nor rationally. As compared to the moralising dimension, which assumes intentionality, psychologising does not. This equates to distinctions in explanation along the internal versus external or person versus situation dichotomies. Psychologising is certainly an

observable explanatory strategy adopted by the young people in the present study. However, it rarely exists in isolation – sometimes occurring, perhaps seemingly paradoxically, at the same time as the moralising dimension. The role of life events and environmental factors is extremely important in young people’s sense making, and quite where such features fit in the folk psychiatry model is not immediately clear.

Some of the dimensions identified in the folk psychiatry model are observable in the ways the young people in the present study occupied discourse on mental illness. However, they do not appear as bounded and discrete explanatory strategies, and combining two or more of the folk psychiatry dimensions in one explanation is more common than exhibiting one in isolation. The folk psychiatry model also does not give space for the possibility that people’s position taking might happen collaboratively. The ways in which the young people in the present research used each other’s contributions as stepping stones to work towards developing understandings were multiple. Rather than having pre-formed explanatory strategies for and ‘attitudinal’ responses to mental illness behaviour, they negotiated and constructed them collectively, according to context. This harmonises with the suggestion that that all public opinion is interactional (Myers, 2004). Myers’ consideration of people’s opinions comes from the standpoint of linguistics rather than cognitive psychology and because of this his approach and emphasis is very different to Haslam’s. While the individualised, psychological approach to interpreting how people make sense of mental illness which Haslam proposes is helpful in some ways, it does not really describe what goes on as people negotiate the issue of mental illness in the social reality of their lives.

Similarly, questionnaire based attitude research fails to take account of the social and interactional processes which contribute to people’s sense making and position taking, processes which continue in the context of being given a questionnaire to complete. This study has demonstrated that position taking in relation to mental illness is plural, context specific and collaborative, meaning that it is a process, in flux and therefore cannot be properly described either by over-simplified attitude measures or by the too-rigid folk psychiatry approach.

#### **5.2.4 Stigma and discrimination.**

The present research did not set out to establish the degree to which the young people who participated stigmatise mental illness or discriminate against the mentally ill. However, the issue of how to deal with mental illness stigma in an educational setting underpinned the research process, and in seeking to better understand young people’s sense-making around

mental illness, some findings about how ‘stigma’ operates amongst young people were reached. These include the following:

- ‘Derogatory’ language isn’t always derogatory.
- People experience a tension between doing the ‘right’ thing and doing what others do.
- Behaviour that seems familiar provokes supportiveness; behaviour that seems unfamiliar provokes suspicion and restrictiveness.

Each of these findings will be considered in relation to literature on mental health stigma, and implications further considered alongside Link & Phelan’s model of mental health stigma. The preceding section on young people’s opinions and positions about mental illness shows that their views fluctuate, are context dependent, influenced by others, and dominated by ambivalence. Combined, these findings indicate that the notion of stigma as a measurable attitudinal trait may in fact not make sense. This section will go on to discuss this, considering the nature of stigma in relation to mental illness and the validity of the concept.

### **‘Derogatory’ language isn’t always derogatory**

The language used by young people throughout the discussion series indicated that they often did not really know how best to talk about mental illness. The awkwardness with which they selected terms to describe mental illness is demonstrated in Excerpt 18. Section 2.2.2 also described a qualitative study which usefully demonstrated the words and phrases used by British 14 year olds when describing a person who experiences mental health problems (Rose et al. 2007). Rose et al. title their study ‘250 words used to stigmatise people with mental illness,’ and conclude that young people have a large repertoire of stigmatising language which they use liberally. When I talked to the young people who participated in the present study about how they use language, it became clear that they use terms in flexible ways, often without any insulting intent (for example in their use of the word ‘tapped’). They also demonstrated that they are also aware of the offensive power of the language they do use (see Excerpt 16 and Excerpt 17) implying that they wouldn’t use offensive language in the presence of people who had experienced mental illness.

There are several ways in which the data from the present study afford opportunities to make comparisons with Rose et al.’s findings. The results of the mind-mapping exercise can very easily be directly compared, but it is also possible to trace the words and phrases used by the young people throughout the discussion series. Rose et al. reported that over 50% of the

terms provided by the 400 respondents were popular derogatory terms. I organised the analysis of the mind-mapping exercise differently, but the category of ‘descriptors’ which is broadly equivalent to ‘popular derogatory terms’ accounted for 37% of the responses given, indicating a similar pattern of responding. The other categories used by Rose et al. were: negative emotional states; confusion between physical disabilities, learning difficulties and mental health problems; violence and sadness and isolation. Most of these categories were covered by the responses the young people in the present study gave in the mind-mapping exercise. However, there is a striking difference between Rose et al.’s findings and those of the mind-mapping exercise in the present study, namely that in the latter, responses relating to violence were entirely lacking. Linking of violent behaviour to mental illness came up later in the discussion process, but it is interesting that during the mind-mapping exercise, held right at the beginning of the process, the young people did not make this link. It is only possible to speculate as to reasons for this, but it is conceivable that the young people in the present study did not instinctively make a link between mental illness and violence, and only began to think about it when given stimuli which were suggestive of the possibility (namely the presence of knives in the *Simon* photo-vignette). This might be evidence that the linking of violence to mental illness is not as prevalent as some studies report (i.e. Watson et al. 2005). Returning to the consideration of attitude measurement studies, those which present respondents with statements relating to violence effectively stimulate people to make the link, even though they have the opportunity to reject it. That the young people in this study did not make that link unprovoked is a potentially important finding, which may warrant further exploration.

The present findings offer an additional dimension to the interpretation of Rose et al.’s results, demonstrating that the ways young people use language in relation to mental illness are more complex than simply that they unthinkingly employ a wide range of (unequivocally) stigmatising language. It also seems that finding the ‘right’ way of talking about it is difficult, and that adolescents have a very wide variety of derogatory slang terms in their vocabulary, many of which have nothing to do with mental illness and some of which do. It is easy to assume that we know the meanings attributed to slang words by young people and the intentions behind the ways they deploy those terms. However, it is important when researching the language used by young people to find out from *them* what meanings they attribute to particular terms and how they use them in practice. What looks like stigmatising language to researchers may actually be employed in ways which are intended to be benign and do not actually indicate stigmatised positions.

### **People experience a tension between doing the right thing and doing what others do**

Another important finding of the present work in relation to previous research about the stigma of mental illness is concerned with the relationship between what people say they might do, and what they actually do in reality. In seeking to assess the stigma people attach to mental illness, most previous studies use attitude measurement techniques such as social distance measures to ask respondents to describe their behaviour (i.e. Watson et al. 2005; Roberts et al. 1981). Social desirability bias in self-reported behavioural intention is a well documented drawback of such techniques (Link, Yang, Phelan, *et al*, 2004), and refers to the way in which people report that they will do what they think they *should* do rather than what they would actually do when faced with a given scenario. In the present research, an interesting dimension to this phenomenon was revealed. The tension which characterised Rahim and Farzan description of their likely reactions to a person with a mental health problem demonstrates that how they feel they should behave and how they think they would actually behave are likely to clash. (See Excerpt 6) They describe a conflict between feeling sorry for a person but going along with unkind behaviour demonstrated by others. What emerges here is something important about the complexity which underlies the way people think about how they would behave in a hypothetical scenario. Rahim's and Farzan's articulation of the tension came about in the context of group discussion. Had they been asked to describe their behavioural intentions in the context of responding to a questionnaire, it is fairly likely that they would have given the socially desirable response, which would have been an 'inaccurate' result. Most importantly though, whatever response they had given, the questionnaire format would have precluded the possibility of their expressing the actual ambivalence and complexity which they described in the context of group discussion.

This highlights another important weakness in attitude measurement methods – not just that respondents tend to give socially desirable responses, but also that where ambivalence and complexity are present, they cannot be captured by the response mechanisms on offer. This has significance for understanding the social behaviour which results from stigma, and in turn is important to take into account when designing anti-stigma education.

### **Behaviour that seems familiar provokes supportiveness; behaviour that seems unfamiliar provokes suspicion and restrictiveness.**

The finding about young people's knowledge that they tend to regard behaviour which they could account for in terms of their own experience as *not* mental illness plays out in a related way in terms of stigma and discrimination. Where young people found behaviour to be understandable, they tended to feel that the person in question should be supported, have

someone to talk to, and generally be encouraged to find solutions to their problems. In contrast, when people exhibiting unintelligible or strange behaviour were being considered, the responses tended to be characterised by suspicion and restrictiveness. In attitude studies, the latter responses would be interpreted as negative attitudes, and as evidence of stigmatisation, failing to make the distinction between types of responding. What is most important about this finding is the way it relates to the nature of discrimination.

As we saw in section 2.1.4, discrimination is treating someone unfairly on the basis of characteristics which ought to be irrelevant. We are familiar with the idea that paying someone less for doing the same job because of their gender, race or sexuality is unfair, and amounts to sexism, racism or homophobia – all forms of discrimination. It could be assumed that comparably unfair treatment of a person with a mental illness is the same. However, the findings of this study demonstrate that mental illness is a special case, and differs from gender, race, or sexuality in the way in which discrimination functions in relation to it. It is different in that, for individuals who experience it, mental illness is not a constant, unchanging feature. If you are a woman, you are a woman every day – your ‘womanness’ is fixed and definite; likewise with skin colour or sexuality<sup>5</sup>. If you have a diagnosis of a mental illness, there is firstly the issue of the hugely various types of mental illness you may have. Furthermore, no matter what the diagnosis, it is likely that you have had periods of your life when you have been less able to function than others, along with periods of your life when you are entirely able to function. In other words, the way in which the mentally ill part of a person impacts on their life fluctuates, is inconsistent, variable. What this means is that there are times when it is appropriate and right to treat a person with a mental illness differently to someone who do not have a mental health problem – for example when they are currently in throes of madness ‘proper’. However, a person with a diagnosed mental illness who is free of symptoms and yet is unfairly treated differentially is therefore being subjected to discrimination in the sense that they are being judged on the grounds of characteristics which ought to be irrelevant. This result of this is that the idea of ‘stigma’ in relation to mental illness simply does not make sense as a fixed dimension of people’s attitudes. The interaction between the fluctuating, changeable nature of mental illness along with people’s context-specific, plural position taking in relation to it is characterised by too much subtlety and nuance to be rendered simply in terms of stigma.

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<sup>5</sup> I acknowledge that this point is oversimplified, and that gender, sexuality and race are more complex constructs than they are presented here.

## **Mental health stigma considered**

At this point, it is helpful to return to the current accepted model of stigma in relation to mental illness. This is Link & Phelan's (2001) model which was described in section 2.1.3. Link & Phelan define mental health stigma as "the co-occurrence of its components: labelling, stereotyping, separation, status loss and discrimination." (Link and Phelan, 2001, p. 363). Their model regards stigmatisation as a process in which a person is labelled with a difference that has social relevance. This labelled difference is then linked to unfavourable characteristics. The social label makes it possible to separate "us" from "them" meaning that the labelled person can then be regarded as being fundamentally different from everyone else. Once an individual has been labelled, stereotyped and separated in this manner, a foundation has been established which allows them to be devalued and excluded. The present data suggests the possibility that when it comes to making sense of mental illness, engaging in the first three stages of this process isn't necessarily what young people do. The first component of the stigmatisation process is labelling. As we have seen, the young people in this study, as well as those who participated in Secker et al.'s (1999) research and respondents to a number of other studies (see Wahl 2002) are extremely cautious about labelling behaviour as mental illness, and wherever possible prefer to draw on explanations which diminish rather than emphasise social difference. When it comes to unintelligible, strange behaviour, young people resort to characterising it as madness, or mental illness, and in this case it is certainly sometimes true that they go on to draw on stereotypes which are linked to inauspicious characteristics and qualities. However, the urge to engage in the process of separation of "us" from "them" is not as automatic and inevitable as Link & Phelan's model might suggest. Context is again extremely important, and the amount and nature of biographical information young people have about a person certainly influences whether or not such separation occurs. For example, in the case of the *Simon* vignette, the young people seemed keen to hang on to their sense of Simon being like them rather than the opposite. When they received the second vignette, depicting him later in life, this heightened the effect, seeming to increase their interest in him as well as their empathy for him.

As we have seen, the ways in which those considering others with mental ill health respond to them fluctuate and vary, are inconsistent and dependent on important factors such as how that person is currently affected by their mental illness. Combined with the fluctuation and variability of mental illness itself, this makes it difficult to establish clearly whether people are stigmatising and discriminatory or not. It also presents difficulties in terms of how to engage with people's understandings in order to enable them to appreciate, accept and process the



possibility that a person who has been mentally ill in the past and may be mentally ill in the future, can be currently unaffected by it.

In this context, it is extremely important to acknowledge that young people's responses to people who may be considered to be experiencing mental health problems vary depending on the familiarity or strangeness of the behaviour. I have argued that the idea of the stigma of 'mental illness' is too dense a category to be properly meaningful. A person with an eating disorder is so different from a person in the midst of a psychotic episode that it makes no sense to treat the two as though they are the same when broaching the issue of discrimination. In young people's sense making and position-taking, intelligibility and explicability are absolutely key. The distinctions they make between people who are experiencing problems of living and those who are "proper mental" seem to determine whether or not they draw on stereotypes to make assumptions about that person. Because "proper mental" behaviour is less familiar and inherently more frightening than the explicable behaviour of someone who is unhappy it is not surprising that people draw on resources from outside their own experience to make sense of it. The resources that are widely available to young people include the images from films they described themselves (for example, a girl ripping her jaw off in the film *Mirrors*) as well as cultural resources such as the notion of spirit possession. In attempting to 'reduce stigma,' I suggest that it is detrimental to ignore the fact that these resources contribute to people's sense-making toolkits. The message "that girl ripped her jaw off because she has a disease, but it's ok because we can treat the disease with medication, and therefore the girl is no different from you, so you should treat her just the same as everyone else" is patently unconvincing. Although this results in a messy and complicated state of affairs, it is necessary to both acknowledge and embrace the full complexities if real progress is to be made.

### **5.3 Implications for research/ epistemology**

The findings of this study demonstrate that the ways in which young people make sense of and respond to mental illness are more complex than previous studies have shown. These findings lead to a number of important implications for other research. This section will consider these implications, in particular addressing the epistemological assumptions of previous research investigating knowledge of and attitudes about mental illness, and the stigma of mental illness.

The mental health literacy approach to researching knowledge about mental illness assumes a particular perspective on what constitutes knowledge, placing the western biomedical model of mental illness in pole position, and regarding other explanatory models as wrong. It also

leaves no space for trans-cultural interpretations of mental illness (Watters, 2010), which are cast aside as illegitimate. Given the continuing contention and unresolved controversy surrounding mental illness, this represents a hegemonic presentation of assumptions as facts. It sidelines and excludes non medical model interpretations, viewing them as evidence of illiteracy. There is a growing body of evidence that people take less negative stances towards people who are experiencing “problems of living” than they do towards the abstract notion of biologically based mental illness (Harper, 2005; Read, 2007; Read, Haslam, Sayce, *et al*, 2006). It may be that conceptualising life difficulties as mental illness increases fear, confusion and suspicion. Findings of this kind may be overlooked because they do not tally with the dominant discourse, but it is important for researchers concerned about stigma to engage with the fact that what constitutes ‘knowledge’ about mental illness cannot be taken for granted and to recognise that to do so may represent a dangerously narrow and potentially totalitarian approach.

Research investigating the stigma of mental illness nearly always uses questionnaire based methods designed to measure attitude (Byrne, 2001; Pinfold, 2007). Although there has been some research investigating service users’ experiences of stigma and discrimination (Rethink, 2008), the existence of mental illness stigma has largely been established through using attitude surveys to capture how members of the public respond to questions about ‘mental illness.’ There are a number of problems with using such attitude measurement instruments. Although detailed work on the dimensions of mental health stigma (Link & Phelan, 2001) has been applied to the development of ‘stigma scales,’ (King, Dinos, Shaw, *et al*, 2007; Link, Yang, Phelan, *et al*, 2004) these frequently require respondents to respond to the label ‘mental illness’ with no description provided as to what is meant by it. As Bourdieu points out, “the first imperative in evaluating a poll is to ask what question the different categories of people thought they were answering” (1993: 151). Let’s consider what people responding to attitude questionnaires about ‘mental illness’ might think they are being asked about.

The category of ‘mental illness’ is semantically problematic, and studies investigating young people’s knowledge of mental illness have shown that the ways in which the notion of mental illness is understood are extremely wide ranging and disparate (Spitzer & Cameron 1995; Bailey 1999). Even if one were to assume all the knowledge of a scholarly psychiatrist, the overarching category of ‘mental illness’ is still problematic, particularly when it comes to attitude measurement. For example, in response to the attitudinal statement “people with mental illness are dangerous,” it is surely impossible to answer “I strongly disagree” without further information. If the respondent assumed that the mental illness in question is a form of

severe personality disorder with psychosis, and the individual experiencing it has a history of committing violent acts, it would be senseless to deny that the person was, at least *potentially* dangerous. However, if the respondent was thinking of someone with an eating disorder, with no previous history of violent behaviour, then it would be equally senseless to assume they were any more dangerous than a person without a diagnosis of mental illness. The complication does not stop there, though. It is troublesome enough that ‘mental illness’ is such a broad umbrella term incorporating a huge range of diagnoses, but even if we were to consider a single diagnosis, psychiatric labels don’t describe fixed states or affect different individuals uniformly. At any given time a person with, say, bipolar disorder, may be entirely well, indistinguishable in every way from a person who has never had a mental illness. Or, they may be extremely unwell, taken over by mania and quite disconnected from reality, or indeed, mildly depressed and only slightly impaired by the illness. The way in which they relate to others will be shaped by their current state. Asking someone to indicate how discriminatory they might be towards a person with bipolar disorder therefore requires the respondent to draw on and assimilate a complicated set of information with many variables. When considered in this way, the only really meaningful answer to the attitude question would have to be ‘it depends how the person is currently affected by having bipolar disorder.’

Attitude measurement studies invariably expect respondents to assimilate what they know about mental illness to such a degree that it is impossible to know what each respondent has in mind when they are answering, effectively rendering the category of ‘mental illness’ meaningless. That respondents to questionnaires interpret questions or their intended meanings when selecting a response very differently has been drawn attention to in the context of health status questionnaires (Mallinson, 2002). Mallinson’s findings - that respondents find the wording of some items difficult to understand and that response options are often inadequate to describe their views - are as applicable to attitude research as they are to self-reporting of health status.

As has been argued in Chapter 2, the phrase ‘mental illness’ is so vague and essentially contested to such a degree that its meaning to one individual versus another cannot be known. Vignettes used as stimuli in attitude measurement instruments tend to describe individuals using diagnostic criteria from the DSM-IV, focussing on symptoms at a moment of acute illness. In a field which is ridden with complication and tangled nuance, one thing which is certain is that mental illnesses ebb and flow. A person with schizophrenia is likely to sometimes be relatively unaffected by their illness and be impaired by it at others, so finding out how people respond to a person at a moment of acute illness gives no indication of how

they might feel about such a person in a period of recovered stability. Measurement instruments are not able to capture this complexity. Furthermore, bipolar response scales in attitude measurement studies insist on *either* positive or negative responses to scale items. The findings of this study demonstrate that young people actually make sense of mental illness in much more complex ways than absolute positivity and absolute negativity. Ambivalence, ambiguity and uncertainty are very real and very important features of young people's sense making. Although this is inconvenient for questionnaire based research it nevertheless raises important questions as to the solidity of epistemological assumptions made by research carried out in this way.

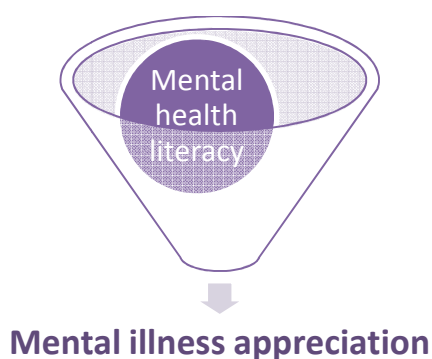
Other writers have explained why 'stigma' is a potentially harmful conceptual framework to use to describe the unfair treatment of people with mental illness, demonstrating how it can lead to a version of victim blaming. However, there are additional ways in which the construction of 'stigma,' and the ways in which it has been researched, are problematic. 'Stigma scales' which attempt to ascertain the degree to which individuals hold stigmatised attitudes, and 'stigma reduction' initiatives share the problem of assuming that stigmatising attitudes are a fixed dimension in people's beliefs. The present data indicate that this is not necessarily the case, and that rather than being either 'stigmatisers' or 'non-stigmatisers,' people take different positions at different times, according to a range of contextual and social factors. It seems that the way 'stigma' plays out in the real world is rather different from what might be supposed based on the use of stigma scaling techniques. Relationships with others shift and change, and the day to day positions people take in relation to others with mental illness are influenced by social context. For adolescents, the need to maintain one's own in-group status is a priority (Coleman & Hendry 1999). As Rahim and Farzan explained, they are likely to take positions which protect their in-group status even if it means they participate in socially excluding behaviour towards others which they feel bad about. Research which focuses upon stigma and assumes stigmatising attitudes to be fixed, provides an impoverished picture of real world experience and what it can offer to anti-stigma enterprise is limited as a result. Research that explores how people take up positions of solidarity in relation to mental illness, as well as the social processes underpinning discrimination can provide a richer picture of day to day reality and a better starting point for initiatives designed to address the unfavourable positioning and social exclusion of people affected by mental illness.

## 5.4 Mental illness: Towards an alternative approach to knowledge, attitude and stigma

The discussion so far has demonstrated a number of ways in which existing approaches to investigating people's knowledge and attitudes to mental illness can lead to distortion, oversimplification and oversight. We have also seen how the dominance of the stigma concept, and resulting attention to the need to 'reduce' stigma carries limitations. In this section, I move on from this discussion by presenting some suggestions as to how these matters could be helpfully reframed. I will suggest alternative ways to conceptualise matters previously discussed in terms of 'mental health literacy,' 'changing attitudes to mental illness,' and 'reducing stigma.' I will then explain the reasons why this reframing is needed and how it will benefit education about mental illness.

### 5.4.1 Mental health literacy

In the case of mental health literacy I have argued that the concept reduces people's 'knowledge' to the extent to which they agree with the views of western medical psychiatry. Taking this approach means that ways of making sense which do not fit into the the orthodox view are viewed as illiterate and ignored as a result. It is useful to have a way of describing what people know and understand about mental illness, and in some ways the 'literacy' concept is seductive because it carries connotations of being able to identify, understand, interpret and compute information. However, the way it has been operationalised to describe people's understandings about mental illness is problematic, not only because of the political construction of what 'literacy' in this context means, but also because of the euphemistic use of 'mental health.' Jorm's description of what is meant by 'mental health literacy' reveals that it is all about what people 'know' about mental *disorder* and how to respond to it. I suggest that an alternative approach would be better described as **mental illness appreciation**.



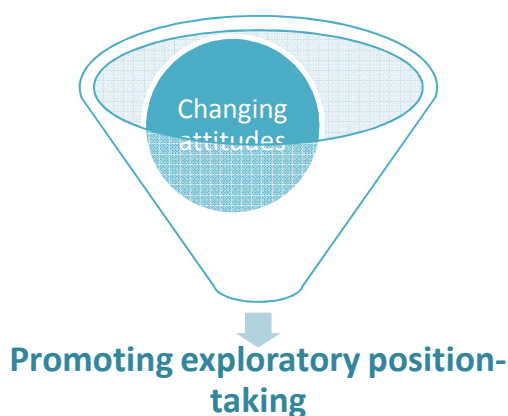
‘Mental illness appreciation’ places clear emphasis on the fact that we are talking about how people understand mental *illness*, avoiding confusing the issue by talking euphemistically. I suggest “appreciation” instead of “literacy” because it denotes both comprehension and acceptance. In finding a language to describe being well-acquainted with what mental illness is, I suggest that there is a distinct advantage in incorporating an element of acceptance in addition to knowledge. Because of the way ‘mental health literacy’ has been constructed to reflect the general public’s concurrence with medical model psychiatry, new language is needed to represent understanding which is more expansive and inclusive. I propose that ‘mental illness appreciation’ is a better conceptual starting point than ‘mental health literacy’ for educational interventions aiming to raise awareness of what mental illness means for people with a diagnosis, their friends and relations as well as the wider community. It takes into account the importance of starting from where people are in terms of their understandings as well being open and honest about the fact that this is a contested concept which can be approached from a range of standpoints.

#### **5.4.2 Changing Attitudes**

We have seen that the aim of much school-based mental health education has been to ‘change attitudes’ towards mental illness and the people who experience it. The concept of attitude usually assumes that people make evaluative responses to objects or phenomena (Eagly & Chaiken, 1993). It has been suggested that attitude is a function of the strength of a person’s expectations that an object or phenomenon has a particular set of attributes and of that person’s evaluation of those attributes (Perloff, 1993). Educational interventions about mental illness which identify attitude change as their principal purpose work on the basis of replacing people’s ‘incorrect’ beliefs and expectations about mental illness with ‘correct’ information which will in turn lead to a more positive evaluative response. There are many problems with this approach. For example, it assumes ‘mental illness’ to be a valid category, which people are able to make sense of. Furthermore, there is evidence to suggest that adopting ‘correct’ beliefs (such as seeing mental illness as a disease like any other) does not necessarily lead to changed expectations and more positive responses (Read, 2007; Watters, 2010). In addition, the questionnaire based methods used to investigate attitudes fail to capture the fluid and context-specific nature of responses which emerged in my data and other qualitative studies (Armstrong, Hill & Secker, 2000; Secker, Hill & Armstrong, 1999). Finally, it is based on an approach which assumes attitudes exist as the strength of a person’s affective response to an object or phenomenon, i.e. how positive or negative they feel towards it (Himmelfarb, 1993).

I suggest that, as the present data have demonstrated, the positions young people take in relation to others vary according to a range of factors, including the social context and the

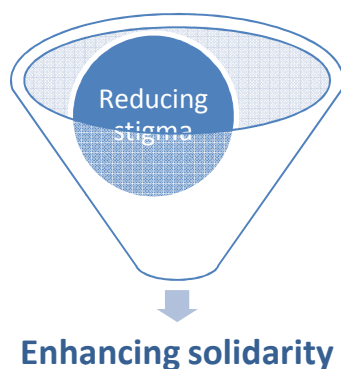
responses of those around them. I propose therefore that it would be more productive to think in terms of **promoting exploratory position-taking**.



The promotion of exploratory position-taking accepts that people respond to others variously according to a diverse range of factors. It also assumes that exploring the different ways in which it is possible to respond can be helpful in terms of raising awareness of their diverse implications, which in turn can lead to more positive position-taking, but crucially on the person's own terms rather than as a result of being told that a particular 'attitude' is the right one to have. Exploring positions that can be taken in different circumstances gives the opportunity to reach an understanding of the challenges and the issues for the person with it and the people around them.

### 5.4.3 Reducing stigma

When it comes to describing the ways in which people that have experience of mental illness are treated differently to others, 'stigma' dominates the discourse. I have illustrated various ways in which the notion of 'stigma' can be problematic. Strategies for improving the treatment of people with mental illness by society at large, including education initiatives are most commonly conceptualised as aiming to reduce stigma. Not only does this individualise what is essentially a social problem, but it also takes a negative stance towards the people who are doing the stigmatising. Because of these factors, I suggest that a preferable conceptual framework is **enhancing solidarity**.



‘Enhancing solidarity’ assumes that there is already some solidarity in place, and that intervention would aim to build on this rather than to remove something bad (stigma). It also places emphasis on the similarities between people, as opposed to the differences. Stigma refers to a taint or mark which is discreditable (Goffman, 1963). As we have seen from the findings of this study, many experiences which the psychiatric profession regards as ‘mental illness’ are regarded by young people as being perfectly understandable, and not discrediting at all. Where behaviour becomes particularly unintelligible, young people find it less straightforward to show solidarity with the person displaying that behaviour. However, it seems that the more they are able to understand about the range of possible explanations for ‘mad’ behaviour the more possible solidarity becomes. In addition, the appreciation of the fluctuating, varying nature of mental illness helps to increase solidarity during times when a person with a mental illness is well. The educational goal of enhancing solidarity is preferable because it sidesteps the victim-blaming problems associated with the stigma concept, as well as seeking to cultivate existing positive resources.

Furthermore, evidence from trans-cultural approaches to mental illness show that social and cultural factors play a powerful role in determining how mental illness is experienced and expressed (Watters, 2010). Of great significance is the fact that non-Western, non-medical approaches to psychotic illness such as schizophrenia have consistently been shown to lead to substantially better outcomes for individuals and communities (Castillo, 2003). One of the main reasons for this seems to be that people in societies which have alternative explanations for psychotic symptoms tend not to be socially excluding towards those who exhibit such symptoms (Pereira, Bhui & Dein, 1995). A supportive social environment not only fosters recovery, but also empowers people by giving them important roles to play (Lees, Manning & Rawlings, 1999). These social factors are inhibited and denied by a biologically based medical approach. For all of these reasons, the concept of ‘enhancing solidarity’ is much more useful than that of ‘reducing stigma.’

## **5.5 Implications for policy and practice**

The potential implications of this study for anti-stigma practice and education have already begun to emerge through the discussion in the preceding sections of this chapter. This section will aim to draw these out more explicitly and discuss them in greater detail. The findings of the study point to some important implications for anti-stigma practice, and the first part of this section will describe these. The second part of the section will consider policy in relation to education about mental illness.



### 5.5.1 Health policy

The discussion so far has illustrated the considerable complexity surrounding what constitutes ‘mental illness’ as well as what might amount to discrimination against people with mental illness. Previous initiatives which aim to reduce the stigma of mental illness have overlooked this complexity, tending to be predicated on biogenetic models of mental illness (Pilgrim & Rogers, 2005; Pinfold, Toulmin, Thornicroft, *et al*, 2003; Pitre, Stewart, Adams, *et al*, 2007). The assumption underpinning such interventions is that if people are ‘educated’ with messages such as ‘mental illness is an illness like any other’, and ‘mental illness is easily treated with medication’ then their knowledge will allow them to concur with the biomedical view and the result will be that they stop stigmatising it. This thesis has demonstrated many ways in which mental illness is not like any other illness - the social and political dimensions in the construction of mental illness being a case in point. Such oversimplified anti-stigma initiatives are destined to fail because they do not acknowledge or attend to the true complexity of mental illness, and they do little to engage with people’s genuine fears about the ways in which mental illness causes people to behave in ways which can be very worrying.

Anti-stigma or anti-discrimination work aiming to improve the ways in which we think about mental health problems needs to grapple with these problems of ambiguity and multiple meaning. The fact that people currently experiencing acute symptoms of mental illness *are* different from the general population, and maybe *should* be treated differently cannot be overlooked. The central issue which anti-discrimination education ought to focus on is that people can and do recover from mental illness. Where discrimination in the truest sense kicks in is when the effects of having been labelled as mentally ill continue to have negative consequences during periods of wellness or after a person has recovered. Mental illness is not a simple phenomenon. Stigma and discrimination are also not simple. Interventions designed to increase understanding of mental illness and to reduce stigma and discrimination simply will not work if they fail to take account of the full complexity of the subject matter, as well as the inevitably complex ways that people respond to it. When the results of the current study are considered against this backdrop, it becomes clear that the best focus for effort is to aim to equip young people with the resources to be able to navigate and make sense of an inherently complex area rather than to attempt to didactically implant ‘correct’ attitudes. This is not something which can be achieved with a quick-fix intervention, and certainly cannot be done by peddling simplified versions of essentially contested concepts of mental illness.

However, it is potentially quite threatening for the psychiatric profession to promote the exploration of these sorts of complexity. The need to uphold and maintain the legitimacy and

credibility of the profession may act as a barrier to taking the risk of encouraging the public to take on board the multiple possibilities about mental illness, including those which challenge the biomedical model. As Pilgrim & Rogers (2005) point out, anti-stigma education designed by psychiatrists has historically tried to do the opposite, aiming to close the gap between what is presented as professional knowledge and public misconceptions. The ubiquitously cited aim of anti-stigma enterprise to “improve help seeking” represents an effort to de-stigmatise mental health *services* rather than the individuals who experience mental health difficulties. Pilgrim & Rogers (2005) further argue that contra the arguments of psychiatry, diagnosis and contact with services is frequently unhelpful to the patient, particularly in respect of discrimination and social exclusion. If this is the case, psychiatric practice is in fact part of the problem of stigma rather than part of the solution. For all of these reasons it is important to consider the possibility that mental health education is better broached by those from outside the psychiatric professions.

### **5.5.2 Education policy**

There are two important issues for education policy in relation to education about mental illness. The first is whether mental illness education should become a statutory requirement in schools. The second issue is, assuming that such education should take place (whether statutory or not), how it ought to be conducted.

Given that mental health issues have become a feature of the landscape of the school environment, the need to promote greater understanding of mental illness in society becomes ever more pertinent. This study adds to the body of evidence that there is a place for education about mental illness (as distinct from mental health promotion) in adolescents’ lives (Pinfold, 2003; Rickwood, Cavanagh, Curtise, *et al*, 2004). There was a unanimous feeling amongst the young people I spoke to, both in pilot work and in the main study that they would like to know more about mental illness, that the topic is both interesting to them and relevant to their lives. How and by whom this education ought to be delivered is up for discussion.

The present study demonstrates that educational processes have the potential to positively influence young people’s understandings about mental illness. It also demonstrates that dealing with the issue of mental illness benefits from constructive approaches being taken, in which young people are taken seriously and given the opportunity to rehearse and explore a range of possible positions. The aim of constructivist education is personal autonomy – to enable people to be able to be governed by themselves and to think logically about any subject

or issue, drawing on their own resources to form both understandings and opinions (Gale & Steffe, 1995). This philosophy should be applied to the delivery of education about mental illness. I suggest that the broad educational aims of mental illness education should be twofold. Firstly, to enable young people to look at the issue from a number of different perspectives and secondly, to equip them with the resources to be able to construct open and positive positions towards others who may be experiencing or have experienced mental health problems. These aims diverge considerably from the goal of 'improving mental health literacy' with its related aspirations to 'change attitudes' and the negatively framed idea of 'reducing stigma.' I suggest they are better described as aiming to improve overall mental illness appreciation by promoting exploratory position-taking and enhancing solidarity. Delivering education which is able to meet these aims is will inevitably look very different to interventions derived from a didactically underpinned model. However, the findings of this study indicate that the potential outcomes of taking such an approach are very promising, and worth pursuing.

It is valuable to draw attention at this point to some of the difficulties facing teachers who might consider facilitating mental health education of the type I describe. Evidence indicates that mental health problems are common amongst teachers, being far more prevalent than population norms (Garner, 2005; Travers & Cooper, 1993). While this fact could be considered to have benefits, allowing those teachers who have had personal experience of mental health difficulties to draw on that experience to inform their teaching, the reality is that the idea of a teacher with a history of mental health problems is not one which is palatable to parents, pupils, or indeed to other teachers and education professionals. So, although mental illness is not uncommon amongst teachers, being open about having experienced it is extremely *un*common, with taboo and stigma meaning that most teachers conceal mental health problems from others, often citing physical illness as the reason for time off work because of mental illness (Stansfield, Head, Rasul, *et al*, 2003). Even in the context of considering the mental health status of their pupils rather than themselves, there is evidence that teachers are extremely uncomfortable in occupying discourse about mental illness, being uncertain about what language to use (Rothì, Leavey & Best, 2008). Given this problematic climate, the task of facilitating unguarded, exploratory and open mental health education is not at all straightforward for teachers to do. There are other reasons why teachers may not be best placed to deliver mental health education. In the case of the discussion series conducted for the present research, my feeling was that there were distinct advantages to my not being a teacher. My role as an outsider meant that the atmosphere in the group was significantly different from the atmosphere in a classroom. The young people knew that my involvement

with them was limited to that context, and therefore that anything they said would be contained, not ‘polluting’ the ways in which they are perceived in other contexts. In addition, the young people who participated in this study made it clear that they felt part of the success of the process rested on being able to conduct discussions in a small group. Whether it would be possible to translate the approach to make it work in a full-class setting is uncertain.

The findings of this study might point towards the further research working towards the development of policy which would implement a mental illness appreciation curriculum, driven by the aspiration to promote exploratory position-taking and enhance solidarity. However, further work is necessary to move the findings of this study into implementable practical application. Section 5.7 will discuss this in further detail, along with other research questions which arise as a result of the findings of the present study. The next section will consider some of the lessons learned from the conduct of the study, including its limitations.

## 5.6 Lessons learned from the conduct of the study

*Every limit is a beginning as well as an ending*

George Eliot (1872)

### **Limitations**

No research design is infallible and there are limitations to the research reported here which it is important to acknowledge. Issues of trustworthiness have already been discussed in Chapter 3, so will not be repeated here. There are, however, further points to make about the shortcomings of this work.

Some of the limitations of this work are those which are shared with much qualitative research. The fact that the main study focussed on only seven participants means that the findings are particular to those individuals. It could reasonably be argued that working with such a small group of people means that it is impossible to generalise from these findings. I would suggest that, while generalisability in terms of statistical trends is certainly unfeasible in this case, these findings are nevertheless likely to indicate ways in which adolescents other than those who took part make sense of mental illness. It is certainly likely that a different group of young people would bring their own particular biographies, resources and modes of interaction to a similar discussion process, and that the resulting discussions would in some ways look quite different from those reported here. However, given that the findings of this work seem to resonate in some ways with those of other studies investigating how young

people make sense of mental illness, it is also likely that there would be similarities in terms of how discourse is occupied and appropriated.

A criticism often levelled at qualitative studies is that the quality of the data and the analysis is heavily dependent on the skills of the researcher, and therefore prey to human inconsistencies (Miles & Huberman, 1994). This study is as open to such criticism as any other piece of qualitative work. The work reported here is inarguably the product of one person's decision making and judgements, from the definition of the problem and generation of data to the analysis, interpretation and discussion of that data. It is my hope that this thesis has presented this process with sufficient transparency to assure the reader of the consistency in my approach to all stages of the research process. Furthermore I trust that my openness in describing the processes which led to conclusions drawn will establish confidence that they were not simply based on gut instincts or personal inclinations. I acknowledge that my own experiences and values have informed and coloured every stage of this research, and that the ways in which I influenced the data that were generated, analysed and interpreted are embedded throughout. However, the idiosyncrasy of the research, while being an important feature to acknowledge, carries many benefits as well as being a limiting factor.

A further limitation is to do with the impact of the artificial construction of the discussion group. The discussion series which was facilitated in order to generate data for this study engaged a group of young people in conversation about mental illness. It is important to recognise that they were being *stimulated* to think and talk about a topic which they may well not otherwise have considered. Indeed, there is strong evidence that talking about mental illness was unfamiliar to the young people who took part. It is therefore probable that ways in which the young people in this group constructed and occupied discourse on the subject was not typical of how they would go about making sense of mental illness had they not taken part in this group. Because of this, it is impossible to separate the impact of being in the group from young people's 'spontaneous' discourse on mental illness. The ways in which they made sense, constructed understandings and communicated this was of significant interest to this study. However, the present findings may not be able to indicate how young people might make sense of mental illness on a day to day basis.

As discussed in 4.5.3, some of the conclusions drawn about how engagement in the discussion process impacted on participants relied on interpretations of comments made by members of the group. It is possible that in making these comments, the young people felt a certain amount of compulsion to say positive things to me about the experiences they had had in the

group. Given that I elicited some of these comments by asking direct questions it may also be that the young people felt they had to give an answer because the question had been asked. It is likely that the young people's responses to the evaluative questions I asked them at the end of the process would have been different if they had been asked by someone other than me.

Another limitation is concerned with the application of the study's findings to future practice. The findings indicate that engagement in the discussion process had a number of positive impacts on the participants, which is an encouraging outcome, and might be cause to propose the wider implementation of similar approaches to education about mental illness. It would be naive, however, to underestimate the significance of my own role in the success of the process. Inevitably, if a different facilitator replicated the process described here, the resulting discussions would be very different because they would approach the task with a different style, underpinned by different values. My disclosure of personal experience of mental illness was a crucial part of the success of the process and not something which could be replicated in off-the-shelf teaching resources. This represents a limitation in terms of how the findings of this research might be used to inform the development of approaches to teaching about mental illness in schools. That is not to say that this study does not provide useful insights which can be made sense of by practitioners and policymakers in mental illness education, but rather that the methods described here are not directly translatable to a pedagogical approach which can be delivered by anybody. Of course, I am not suggesting that successful mental health education of this type could *only* be delivered by someone like me but rather that translating the pedagogical findings of this study into practically applicable teaching strategies would require considerable care and attention.

In addition to limitations which relate to the conduct and outcomes of the research, there are, of course, limitations in the thesis itself. Chapter 2, although substantial, did not consider a number of relevant bodies of literature. For example, literature which describes and critiques anti-psychiatric social movements driven by those with experience of mental illness (Crossley, 2004; Gabriel, 2004) would have been a helpful addition. Greater attention could also have been given to non-Western and spiritual explanations and interpretations of mental illness (Dein, Alexander & Napier, 2008; Leavey, 2010), particularly relevant because of the fact the young people participating in the study raised these issues. Similarly, an analysis of the literature examining how mental illness is represented in the media (Harper, 2008; Nairn, 2007; Sieff, 2003) would have been helpful, given the young people's use of television and films as a source of information. It would also have been useful to consider literature describing educational initiatives which have attempted to address prejudice towards other

stigmatised groups, for example those with learning disabilities (Quicke, Beasley & Morrison, 1990) or HIV (Denman, 1995). However, it was simply not possible to give due regard to all of these areas.

### **What would I do differently if I did the study again?**

*Of all forms of wisdom, hindsight is by general consent the least merciful, the most unforgiving.*  
(Fletcher 1999)

There are, of course, a number of things I would do differently if I had the opportunity to conduct this study again. I could identify many mistakes I made, and moments in the research process where I wish I had done things differently. It would make for tiresome reading to go through all of these, but some are significant and therefore worthwhile to mention. They include relatively small details as well as larger considerations. I will describe some examples of each.

I had already completed fieldwork by the time I properly engaged in analysis of the mind-mapping exercise. Carrying out the analysis made me very much regret not having asked the participants to repeat the exercise during the final session of the discussion series. This would have been a valuable opportunity to see how the young peoples' responses to the exercise would differ after having engaged in the discussion process and would have made a rich addition to the data.

The fact that the voice recorder was switched off by one of the members of the group during Session 5 was a huge disappointment, and it meant I did not have a transcript of the conversation in which I made my disclosure to the group. Being somewhat laissez-faire in my demeanour during the discussions was generally a good thing, but if I were to repeat the work I would certainly be more diligent in my protection of the recording equipment.

If more time had been available, I would have analysed more of the data I generated. For example, I generated a substantial amount of data during pilot work which was not analysed in any detail. I also asked the young people from main fieldwork group to complete Wahl's 'Youth knowledge and attitudes about mental illness' questionnaire (Wahl, 2009) and facilitated a group discussion with them about their views on the meaning of the questionnaire and their responses to it. This data has also not been analysed due to lack of time.

There are, of course, infinite other approaches which could be taken to exploring adolescents' sense-making around mental illness, and the development of education on the subject. If I was

to have the opportunity to conduct a re-run of this study, I think it would be improved if the following changes in research design were implemented:

- Engaging a wider range of young people with differing backgrounds;
- Having a different person to carry out follow up interviews;
- Holding the discussion series over a longer period of time in order to see whether more ways of making sense of mental illness emerged later.

These are only some of the possible changes one might make to the study, and there are doubtless many other methodological improvements which could be made. In conducting this study, I was limited by resources and what it is possible to achieve as a lone PhD student, so making these changes would only be possible if circumstances allowed.

## **5.7 The need for further research arising from this study.**

This study engaged a small group of young people in a process which was part data generation and part health education. It was an exploratory piece of work which revealed important new information about how young people make sense of mental illness and how educational processes can interact with their sense making to equip them with resources to take positive positions in relation to it. These findings, as well as providing some answers to the questions this research sought to address also raise new questions and point to areas which need further investigation. The questions meriting further investigation which seem to be the most pertinent fall into three categories: questions about pedagogy; questions about discourse; and questions about epistemology. In the following short section, I will suggest potential research questions for future investigation along with brief discussion about how each question has emerged.

### **5.7.1 Pedagogy**

*How can educational facilitators help young people talk to each other fruitfully about difficult subjects?*

A remarkable feature of this discussion process was the young people's lack of fixed attitudes and combined with this, their openness to thinking in completely different terms about mental illness. The ways in which the young people influenced each other in the process of group discussion were very productive. Further investigation into how such constructive discussions can be encouraged would be valuable in the development of educative approaches to the topic of mental illness, but also other difficult and complex subjects.



### *What is the impact of participation over time?*

The young people reported that taking part in the discussion series had impacted on the ways they thought and felt about mental illness and that it was something they would remember. It would be useful to conduct a more longitudinal piece of research in which a similar educational intervention was deployed, with participants being followed up over a longer period.

### *Exploring alternative ways to incorporate 'direct contact' into educational initiatives*

One of the unique features of the work conducted was that I was able to adopt the role of facilitator throughout the bulk of the discussion series, and to disclose my own personal experience of mental illness towards the end of process. This feature is not something which could be replicated in a set of off-the-shelf teaching resources. Further research might usefully investigate the extent to which teaching resources such as videos could be used in lieu of such a relationship. This might, for example take the form of a series of biographical, particular, contextualised stories to be shown to a group of pupils and used as a springboard for discussion. Alternatively, it might be possible for a facilitator without first hand experience to refer to the stories of a person known to them personally. Facilitators might be engaged in training in which they were able to meet people with lived experience of mental illness, and practice role playing or acting out that person's story as part of an educational intervention.

## **5.7.2 Discourse**

### *What is the nature of adolescent peer discourse on difficult and serious subjects?*

A striking finding of this research was that the male members of the group were extremely surprised at their peers' capacity to talk seriously and empathically about mental illness. Despite the fact that Rahim, Farzan and Malik were good friends, it seemed that they rarely (if ever) talked about 'serious' things together. Through engaging in facilitated discussions, they witnessed each other occupying discourse in a way they found surprising, and which ultimately led to them having an increased repertoire of resources for communicating. I have no data indicating how members of the group talked to each other (and other peers) outside the group discussions. It would be beneficial to the development of educational strategies for dealing with the issue of mental illness, as well as other difficult subjects to understand more about the mechanics of peer discourse. Finding the right methods to investigate this would be important – it may be that a participatory research design would be necessary, in which young people themselves conducted the research.

### *How do young people use language to make sense of mental illness?*

This research has indicated that young people are uncertain in selecting terms to talk about mental illness. It also revealed that the ways in which they employ terms which may seem to be derogatory is complex, and that they sometimes use terms of abuse quite warmly, even affectionately between friends. The semantics of mental illness discourse are problematic for the general population as well for professionals working in the field of mental health. The power of language should not be underestimated, and further investigation of the ways language is employed in talking about mental illness would be extremely helpful in deepening understandings of how mental illness is regarded, as well as contributing to the development of effective mental health education.

### **5.7.3 Epistemology**

#### *How could a critical realist approach to understanding mental illness assist in developing more value-free research?*

Late on in this study, I began to consider the possibilities of adopting a critical realist stance to researching how mental illness is understood in society. Critical realism offers a way of considering the interface between the natural and social worlds which is more expansive than either social constructionism or empiricist positivism. Bhaskar & Danermark (2006) explain the “double inclusiveness” which critical realism allows, which is particularly helpful in understanding disability, including mental illness. The difficulties in conceptualising and describing what mental illness is pose particular ontological and epistemological challenges, which have become apparent through conducting this research. These challenges lend themselves to being considered through a critical realist lens, which, at the ontological level, attempts to take account of *all* potentially causally relevant levels of reality. Taking such an approach could lead to the possibility of understanding mental illness more comprehensively and being able to more fully make sense of why it leads to fear, stigma and socially excluding behaviour. This maximal understanding could in turn be helpful in making progress towards solutions to those problems.

#### *Are ‘stigma scales’ and attitude to mental illness questionnaires valid?*

The assessment of people’s attitudes to mental illness using attitude questionnaires and stigma scales is widespread (DoH, 2009), and it is assumed that the analysis of such data can be taken at face value. This study has shown that the positions young people take in relation to mental

illness are variable and context specific, and that the same individuals sometimes express positive views while at other times expressing negative opinions. An examination of what respondents to questionnaires are actually thinking as they complete them would be beneficial in determining validity. It may be necessary to develop alternative means of ‘measuring’ people’s ‘attitudes’ to mental illness.

## 5.8 Summary of discussion and implications

This chapter considered the findings of the study in their wider context and discussed some of the implications of the findings in practical terms. The main findings of the study were revisited in relation to the previously discussed literature on young people’s knowledge of mental illness, their attitudes to it, and the handling of mental illness stigma. The results of this exploration revealed considerable discrepancies between the findings of previous studies and those of the present research. The reasons for these discrepancies were explored through examining the impact of the epistemological foundations of previous research. An alternative approach to the consideration of knowledge about, attitude to and the stigma of mental illness was then put forward. This approach recommends that it would be beneficial to work from a conceptual foundation which uses *mental illness appreciation* as an alternative to ‘mental health literacy’; *promoting exploratory position-taking* instead of ‘changing attitudes’ and *enhancing solidarity* in place of ‘reducing stigma.’ Implications of the study for anti-stigma practice and education policy were then discussed, followed by some suggestions for further research questions which arise from the findings of the study. Finally, some of the limitations of the research were considered.

## 5.9 Conclusion to the study

This study set out to investigate how ordinary young people negotiate the issue of mental illness, with an underlying interest in how education might contribute to reducing the unfavourable positioning and social exclusion of people with experience of mental illness. Through the process of examining previous research into people’s knowledge about and attitudes to mental illness, it became clear that the multifarious ways in which people make sense of these things was being missed. When research is conducted within the terms of the dominant discourse, alternative discourses are excluded and interpreted as evidence of ignorance. Some of the elements of previous researchers’ findings were evident in the ways young people talked about mental illness. However, the ambivalence and fluidity which characterised the discourse I observed had not been reported elsewhere. The heavily stigmatised attitudes which surveys suggest are prevalent amongst young people (DoH, 2009) simply did not play out as fixed beliefs among the participants in the present study. While they

had some genuine concerns about how mental illness could be disruptive, they were also open to considering the possibility that people who have been mentally unwell in the past can recover. They also showed the capacity to display solidarity towards others who had experience of mental illness, along with a willingness to make sense of people's experiences through likening them to things they were familiar with.

Combined, these findings offer a compelling argument that what is needed in order to improve social responses to mental illness is a reframing of the issues; a conceptual shift. Stepping outside the terms of the dominant discourse reveals that far from being the product of poor comprehension of biomedical psychiatry, 'stigma' may in fact be just one of a set of responses that can be taken to people with mental illness. The repertoire of positions taken by the young people also included those which are empathic, open and supportive. Which position is taken at any given time is dependent on a variety of factors including the social, cultural, contextual and personal. Educational efforts to engage with people's beliefs, opinions and feelings about mental illness would do well to acknowledge this complexity, taking seriously the variety of competing concerns which make up the ways in which mental illness is approached in day to day life. Given that mental illness sometimes causes people to behave in ways which are frightening, disturbing and unusual, it is vital that education accepts this reality rather than attempting to sidestep it by insisting that it is all alright because medication will make it better.

The conceptual shift that this study points towards is a first stage. In order for such a shift to take hold, a straightforward language to describe it would be needed to be developed. One of the reasons that the concept of 'mental health literacy' has taken off is that it trips off the tongue. Although I propose that 'mental illness appreciation' is a better concept, the phrase itself is awkward. Similarly, 'promoting exploratory position-taking' works conceptually, but is less punchy than the notion of 'changing attitudes,' just as 'enhancing solidarity' lacks the terseness of 'reducing stigma.' For real change to happen, concepts have to translate into language which can capture the public imagination. This is one of the challenges in taking this work forward.

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## Appendices

Appendix 1 – Making sense of my own mental illness

Appendix 2 – Information for participants

Appendix 3 – Mind mapping exercise

Appendix 4 – Profile building exercise

Appendix 5 - Extract from narrative account of Session 2

Appendix 6 – Example of coded transcript

Appendix 7 – Completed coding frame

## Appendix 1: Making sense of my own mental illness

The “making sense” of mental illness I refer to in the title of this thesis was as much a journey for me as it was for the young people who were engaged in the research. It is outside the main remit of this thesis to describe this personal journey, but this autobiographical account is included as an appendix. It is important to be clear that the following account details my own particular perspective on the events described. Those around me very likely experienced things differently and in this sense what follows is not a definitive account.

My diagnosis of bipolar disorder and the experiences it describes have been troublesome to me on many levels. By the time I began this PhD in 2007, I had become ‘accustomed,’ as much as one can, to having bipolar disorder. During the time I was conducting this research I grappled with and questioned the validity of my diagnosis. The three manic episodes I’d had between 2000 and 2003 were all explicable by way of factors beyond the random fluctuation of the chemicals in my brain. I found it very difficult to believe that there was a fundamental biochemical flaw in my makeup which had caused these experiences to happen.

But those episodes of madness were very real, and even if I was uncomfortable with the label, or a purely biological explanation, the mania itself was undeniable. Following each episode, reflecting on how I had behaved after the mania had subsided was an agony, and the accompanying embarrassment was acute. Not because I was ashamed of having manic depression per se, but because the things I had done were out of character, outlandish. I didn’t understand what possessed me to do them myself, so trying to explain it to others and make amends was not easy.

When I was discharged from hospital in 2003, and returned to work, I was determined to do whatever I could to avoid mania taking hold of me again. I went along with the psychiatrist’s advice, taking mood stabilising, anti-psychotic and anti-depressant medication when recommended. I also took seriously the need to look after myself; to exercise, eat well, enjoy myself, sleep properly. It seemed to work. I had no ‘symptoms’ of bipolar disorder, and although the consequences of living with the diagnostic label remained prominent, my day to day life was just fine.

Like many people, I am someone who would prefer not to take medication of any kind unless it is absolutely necessary and in some ways it seemed strange to be taking the mood stabiliser carbamazepine every day when there was nothing wrong with me. I talked to my psychiatrist, and he told me that most psychiatrists share the view that for patients with bipolar disorder, coming off mood stabilising medication should only be tried after five years of stability whilst taking medication. My five year ‘stability’ anniversary was in October 2008, which coincided with my 30<sup>th</sup> birthday and I felt being medication-free as I hit 30 would be a great milestone to reach. So, in January 2008 I agreed with my psychiatrist that I would start reducing the amount of carbamazepine I took, with the goal of being off the drug completely by October.

It went well. I didn’t feel any different and life carried on as normal for almost a year. In the summer of 2009, things became a bit hectic for me. I had lots of stressful events and competing pressures in my life, and I didn’t feel I could say no to any of them. I don’t really remember a precise tipping point, but sometime during August, mania crept up on me and I started doing things I wouldn’t normally do. In ‘clinical’ terms, the episode was mild. I did not need to go to hospital, I was ‘compliant’ with medication and although I made some bad decisions, the medics didn’t feel I was in danger. Nevertheless, I was manic for over two months and during that time, I said and did things I would not normally say and do.

Once the mania subsided, I found myself in a strange place. I was a final year PhD student with a thesis to write. I had spent money with exuberance as salient as the frugality I had



exercised for the years I had been well, so I was in a financial mess. I had damaged relationships with those who were closest to me, and embarrassed myself in my professional life. Most painfully, I was no longer a person with a diagnostic label that described things in my past. Instead the reality of madness was right there, and making sense of it was something I had to do all over again. Soon after I had 'stabilised' and begun to get back into the groove of my normal life, depression hit. The months that followed were incredibly difficult. I lost confidence in every area of my life.

My job was to write this thesis. For weeks, I couldn't write a sentence. I tried to read, but nothing made sense. I pored over the transcripts of the interviews I'd conducted, convinced it was all a load of rubbish. I met my supervisor and had nothing to say, other than that I couldn't do anything. I avoided going into university in case I bumped into fellow students, and didn't answer the phone when my friends called because I didn't know how to have conversations any more. I forced myself to do things that, for the years I'd been well, I believed had been cornerstones of my wellness. I went running, I sang with my choir, I ate porridge, I tried to meditate, I played the piano and baked bread. All of it was a tremendous effort, and none of it gave me any pleasure at all. The grip of this depression was horrible, as real and devastating as the mania had been. I was prescribed anti-depressants, and took them willingly, desperate for something, anything that might make a difference. Whether it was the pills or the passing of time I don't know, but by March 2010 I was starting to emerge. Getting out of bed became easier. I managed to write a bit. I noticed myself laughing at something a friend said.

In August this year I wrote to a friend that the events of last year felt like a foreign country to me now; that I was myself again, back in my own skin. I'm still taking mood stabilisers and anti-depressants and I still don't know which thing does what or why. I don't worry about it too much. The process of writing this thesis has helped me to make sense of my own mental illness in such a way that allows me to accept there are realities *and* constructions. I don't really believe that I have a severe, chronic illness, comparable to say, multiple sclerosis. But, something happens to me sometimes, usually when I'm under a lot of pressure, which causes me to think, feel and behave differently to how I normally do. Thankfully, this thing that happens seems to happen quite infrequently, and in between times, life is very much worth living. Working out that this is how it is required me to assimilate an awful lot of conflicting messages – from the friends who rejected me, to the doctors who said I would never be able to work full time, to the young people who expressed so much surprise when I told them I have a mental illness. This 'making sense' is not linear; there is no end point. Rather, it is ongoing, to be negotiated as circumstances shift and evolve. The need to make sense of it all is no doubt of more pertinence to me than it would be to someone without a diagnosis. But, the more this kind of sense making process is out there, part of the world, the easier it will be for everyone to negotiate mental illness however it touches their lives. I hope that the ideas in this thesis go some way towards enabling this 'making sense' to happen.

Manchester, December 2010

## Appendix 2: Information for Participants

My name is Emma Lindley. I am a research student in the school of education at the University of Manchester. I am carrying out a piece of research on young people's attitudes to mental health and illness. The aim of the work is to find out how teenagers think about people with mental health problems. This information will be used to develop ways of teaching young people about mental health issues.

I would like to ask you to take part in the research. This will involve taking part in group interviews once a week for six weeks. There will be five other people from your class in the discussion group. During the interviews I will lead a range of activities which will encourage you to talk about mental health issues. The interviews will take place at school during normal school hours.

The discussions will be recorded using a digital voice recorder. These recordings will be written up, so that I can refer back to what was said during each session. The analysis of this data will be used to write my Ph.D thesis. It may also be used in journal articles or conference presentations. Anything that could identify you will be removed from the data, so your contribution will be completely anonymous. Everything you say during the discussions will be confidential.

Participation in this study is entirely voluntary. If you decide at any stage that you do not wish to continue with the interviews, you have the right to stop and will not be required to give a reason.

The research is being overseen in your school by Miss Edwards who will be available to talk to you about any concerns you might have.

If you would like to ask me any questions please feel free to contact me by email.

Please complete and return the attached consent form.



## Appendix 4: Profile Building Exercise Example

Participant constructed profile followed by the 'real' story

Is a TV presenter

Has extreme fear of abandonment and finds it difficult to get close to people because of this fear. Frequently has overwhelming feelings of self-hatred which sometimes leads to suicidal thoughts.

Lives with partner

Has a lot of friends

Is fit and healthy

Is on incapacity benefit

Has extreme fear of abandonment and finds it difficult to get close to people because of this fear. Frequently has overwhelming feelings of self-hatred which sometimes leads to suicidal thoughts.

Lives alone

Stays in the house a lot

Doesn't know many people

## Appendix 4: Extract from narrative account of Session 2

Molly demonstrated both how ambiguous she finds the language of mental health, and also how important it is to know what is meant by the terms being used. She said, “by mental health, what does that mean exactly?” Simone showed how this confusion was also an issue for her, by asking “do you mean like a breakdown, or do you mean a proper mental disability.” It's not clear what she means by a 'proper mental disability' – it could be that she's actually thinking of learning disability or neurological impairment, or that she means severe mental illness. The fact that she asks the question like this shows clearly that there is an awful lot of room for confusion. I did not handle this confusion by providing a definition or description of mental illness, but instead turned it around by reminding them of some of the things we'd talked about in the previous week's discussion, and asked them to also recall the things they'd said. The fact that members of the group were asking for more clarification about what is meant by 'mental illness' suggests that the previous week's discussion had not led to them having a clear understanding about it. The fact is that the concept of mental illness *is* rather confusing and ambiguous, and the range of experience that is described by the term is very wide. So, I don't think the problem here is that I had not provided an adequate definition or was withholding information which might have made it easier to be clear about what was meant, but rather that it is just inherently difficult to pin down and the young people are reflecting the complexity that exists for everyone. This was the second session in the series, and part of the purpose of the first session had been to locate the discussion within the intended realm. I do not think that the confusion being demonstrated here by Molly and Simone amounts to evidence of this having failed, but rather is a corroboration of the underlying complexity and ambiguity provoked by the topic under discussion. I think that understandings of the term 'mental illness' developed as the discussion sessions continued.

Members of the group mentioned some of the examples of mental illness which had come up in the previous week's discussion. Molly said, “Schizophrenia.” This led to a surge of conversation, with several of the boys all talking at once, with some excitement. After slowing them down and asking them to speak one at once, it emerged that Farzan was talking about a film he'd seen recently which he thought featured schizophrenia or something similar. *Mirrors*, the film he was talking about is a horror film, made in 2008. It seems that the film has a somewhat crude storyline, which exploits stereotypes associated with schizophrenia. The female character that has a diagnosis of schizophrenia is violent, unpredictable, and at one point in the film tears her own face apart, very gruesomely. I had not seen or heard of the film when the discussion took place, so I wasn't very well equipped to get Farzan to talk about what he thought of the way the film portrayed schizophrenia. When I asked him simply what he thought of the film, he said, “I thought it was pretty scary.” He elaborates, “There's a part in it where a girl rips her jaw off.” It appears that he is comfortable to accept stereotypical portrayal of schizophrenia and appears to feel that the main point of the film was to scare him and that it was successful in doing this. Had I known a bit more about the content of the film in advance, I would have asked different questions about the character in question, and maybe have asked Farzan to reflect on how 'real' people with schizophrenia might feel about portrayals such as this one. The discussion about the film led Molly to mention another film: “I've seen *Donnie Darko*. That's about schizophrenia.” Molly explains that she found the film very confusing and although it was 'about' schizophrenia, it left her feeling more confused about what schizophrenia really was. She says, “it didn't make me understand it.” When Rahim then asks, “what is schizophrenia? I don't even know what it is myself,” Molly replies immediately, and demonstrates some understanding and knowledge: “It's where you, like, hear voices, or have an imaginary friend or something.”

## Appendix 6: Example of coded transcript

EL - Exactly, and there's lots and lots of different things so, you know, there's a lot of different experiences which all get classed as mental illness.

- You know with anorexia - can you have that mild and serious? *P5 F19*

EL - Yeah (boys laughing in background). Hang on. What's funny?

- This guy's cracking me up (pointing at Haider) *F4*

EL - What are you doing?

- I'm reading these notice boards, miss. They're really interesting.

- Kick him out miss.

EL - I'm not going to kick you out but do you think you could sit at the top of the table so you don't get distracted by those interesting notice boards? *(Pushing the Mickey) F16*

- Alright. Carry on.

- You're a girl, so it's alright. *F13*

EL - So, back to these facts. Research suggests that twenty percent of children have mental health problems in any given year. That's children from as young as 5.

- So, does that mean then like that we could get one now or could we get one in like year 11 or something?

- You can get it any time. You could get it tomorrow. *P4*

- Miss can people get mental health problems from like the stress of GCSEs? *P5*

EL - Yeah. *keeping it vague F5/F19*

Boys - Awww... man...

- we're all going go mental.

EL - so, the UK has the highest rate of self harm in Europe.

- Why in the UK, miss? *P5*

EL - Why do you think? *F3*

- Cos there's a lot of crime... or....?

- There's a lot of people about.

EL - There's a lot of people?

- I don't know why I said that. I mean, you know, there's just a lot of people.

- But, well, like it's a big thing.

- Yeah, but look at America. Look how big a problem it is there.

EL - I haven't got the stats for America. Do you think it's worse there?

F3

- Probably.

- I think it's because it's in the media a lot or something, you know, people get the idea and they think it's good way out of their problems.

- How do you know?

- Well, I don't. I don't self harm.

D3

EL - Last week, you were talking about EMOs and self harm, weren't you?

F20

- Yeah. Awwwww.

- Emos. Emos.

EL - And what were you saying?

- Attention seeking.

EL - That self harm is attention seeking. So, in a way you were saying it's like a fashion thing.

- It can be, or it can be... sometimes it's like, you know, sometimes it's because of actually a real reason, you know like depression but a lot of people our age do it for attention but they don't hurt themselves enough for it to be really serious they just sort of do it to make a statement. Some people have honest reasons.

O15

(something inaudible).

EL - What did you say?

- They're just weirdos.

EL - They're just weirdos? Can you imagine ever wanting to cut yourself?

- No

O3

- Ugh! No, especially not my arms.

- It's not hard cutting yourself. All you've gotta do is get a knife. Obviously, you gonna be like a bit scared cos you like when you say obviously oh I'm gonna hit my head so hard obviously you're gonna back out of it cos yeah you just are but it's pretty simple you just get a knife and you just go.... ooop.

EL - Why do you think people would do it? What would make you do it?

F9

- Maybe it's a way of getting relief. They go through the pain and then the pain. Maybe they put themselves through that pain and then once the pain's gone, everything in their head is fine.

- Or maybe they're so frustrated with themselves.

P1

- Pain gives them pleasure.

P4

5

P11

## Appendix 7: Completed Coding Frame

Knowledge and concepts							
K1	Features of mental illness	S1: P14 S1: P17 S1: P18 S1: P19 S1: P20	S2: P10 S2: P13 S2: P23		S4: P5 S4: P6 S4: P19 S4: P23		S6: P1
K2	First hand experience	S1: P14 S1: P17	S2: P10 S2: P13 S2: P23	S3: P2	S4: P6	S5: P3	S6: P10 S6: P15
K3	Use of medical terminology	S1: P3 S1: P11 S1: P13 S1: P18	S2: P3		S4: P6 S4: P22		
K4	Ideas about causality	S1: P4 S1: P10 S1: P11 S1: P14 S1: P17	S2: P1 S2: P7 S2: P8 S2: P9	S3: P4 S3: P10 S3: P11 S3: P12 S3: P15 S3: P17 S3: P19		S5: P14	S6: P9 S6: P13 S6: P15 S6: P15
K5	Uncertainty about normal responses to stress/ mild/ severe mental illness	S1: P3 S1: P4 S1: P10 S1: P11 S1: P14 S1: P18	S2: P1 S2: P3 S2: P4 S2: P10 S2: P13 S2: P24			S5: P14	S6: P1
K6	Vagueness about distinctions between m.i./ learning disability/ physical disability	S1: P2 S1: P3 S1: P5	S2: P1				
K7	Use of vague slang terms	S1: P3 S1: P4 S1: P5 S1: P7	S2: 17 S2: P24				
K8	Information from films/ television	S1: P11 S1: P18	S2: P2				
K9	Suggestions for coping strategies/ responses	S1: P14 S1: P15 S1: P20	S2: P16 S2: P20		S4: P5		
K10	Ownership of language	S1: P7 S1: P8 S1: P10 S1: P15 S1: 16	S2: P12				
K11	Tendency to explain in psychosocial terms	S1: P10 S1: P11 S1: P17	S2: P7 S2: P8			S5: P14 S5: P15	S6: P9
K12	Ideas about		S2: P10	S3: P17		S5: P14	S6: P15



	genetics/ biology					S5: P15	
K13	Unfamiliarity		S2: P13	S3: P19			
K14	Individual predisposition						S6: P9 S6: P10 S6: P15

Opinions/ Positions							
O1	Risks means people with m.i. should be controlled		S2: P7 S2: P16 S2: P17 S2: P22 S2: P24 S2: P25	S3: P1 S3: P2	S4: P16	S5: P11	
O2	Empathy	S1: P6			S4: P9		
O3	Lack of empathy	S1: P9	S2: P5				
O4	Pity	S1: P20	S2: P15 S2: P17				S6: P10
O5	Contradictory positions	S1: P20	S2: P16 S2: P17 S2: P29				S6: P15 S6: P19
O6	Fear	S1: P20	S2: P7 S2: P12 S2: P16 S2: P25				
O7	Sympathy	S1: P21	S2: P15 S2: P24				S6: P10
O8	Ambivalence			S3: P1		S5: P3	
O9	Respect			S3: P19	S4: P9	S5: P8 S5: P11 S5: P12	S6: P1 S6: P3
O10	Deficit view				S4: P3 S4: P16 S4: P18 S4: P19 S4: P20 S4: 22	S5: P5	
O11	You shouldn't be judgemental						S6: P14
O12	Interest		S2: P10- 12 S2: P14 S2: P28				S6: P15 S6: P17
O13	Acceptance		S2: P26				S6: P17
O14	Inevitability		S2: P17				S6: P20
O15	'Honest' reasons		S2: P5				
O16	Dangerousness		S2: P7 S2: P16 S2: P22 S2: P23 S2: P25				

Process							
P1	Collaborative meaning making	S1: P9 S1: P11	S2: P5 S2: P8 S2: P16 S2: P19 S2: P22 S2: P25	S3: P15	S4: P8 S4: P9	S5: P14	S6: P10
P2	Challenging each other's positions	S1: P7 S1: P17 S1: P21	S2: P9 S2: P18 S2: P21 S2: P24	S3: P13	S4: P10		S6: P6 S6: P11 S6: P16 S6: P19
P3	Questioning each other	S1: P19	S2: P2 S2: P3 S2: P11 S2: P20		S4: P6 S4: P8		S6: P15
P4	Digesting ideas		S2: P5 S2: P11 S2: P18 S2: P19	S3: P15	S4: P25	S5: P14	
P5	Asking EL for clarification about 'facts'	S1: P16	S2: P4 S2: P5 S2: P16	S3: P7		S5: P5	S6: P5
P6	Asking EL for clarification about whether there are right answers	S1: P13 S1: P16	S2: P14		S4: P1 S4: P9 S4: P11	S5: P12	
P7	Making associative leaps	S1: P16 S1: P18 S1: P21	S2: P6 S2: P7		S4: P5		
P8	Visualising the vignettes/ characters	S1: P11 S1: P17 S1: P18	S2: P15 S2: P17-19		S4: P2 S4: P4 S4: P7		
P9	Preserving group solidarity	S1: P21	S2: P7		S4: P3 S4: P6 S4: P7 S4: P8		S6: P10
P10	Politeness in expressing conflicting views		S2: P7 S2: P8 S2: P18		S4: P7		S6: P20
P11	Attempts to imagine others' experience	S1: P19	S2: P5 S2: P12 S2: P19			S5: P11	
P12	Direct personal comments		S2: P3 S2: P9	S3: P15	S4: P5	S5: P4 S5: P5	
P13	Surprise at each other's contributions		S2: P28	S3: P.18			S6: P16

Discoveries and insights						
D1	You can't see mental illness				S4: P14 S4: D1	S5: P8 S6: P13
D2	Anybody can have mental illness				S4: P26 S4: P28	S5: P4 S5: P8 S6: P14
D3	You can't know what it's like unless you've experienced it		S2: P5			S5: P6
D4	Huge spectrum between mild and severe		S2: P3			
D5	There can be positives associated with having mental illness					S5: P7 S6: P8
D6	Surprises and inversion of stereotypes					S6: P3 S6: P8 S6: P13
D7	You can get mental illness at any time		S2: P4			

Pedagogical process						
G1	Benefit of discussion	S1: P22			S4: P30	
G2	Benefit of mind mapping				S4: P29	
G3	Power of photos					S6: P7 S6: P8
G4	Newspapers exercise					S6: P9
G5	Suggestions about contact initiatives					S6: P13
G6	Benefit of profile building exercise					S6: P17
G7	Importance of the small group					S6: P19 S6: P21
G8	Criticism of PHSE					S6: P20 S6: P21