Mental distress and stigma: exploring the significance of interactions in the context of support provision

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ABSTRACT

Reducing stigma and discrimination encountered by people who experience mental distress is a policy objective of the British government's current mental health strategy. This strategy considers third sector organisations providing support to people who experience mental distress to have a responsibility for, and a role in, stigma and discrimination reduction. The study takes a case study approach involving two third sector organisations in the North East of England; participant observation over the course of 6 months, 30 semi-structured interviews with staff and members, and 6 focus groups also involving staff and members. It is this combination of methods and the location of the study which makes this contemporary empirical study on stigma and discrimination relating to mental distress and support, and its contribution to knowledge, original. The research explores, describes, and analyses members' experiences of stigma and discrimination, and staff and members' experience of providing, performing, and receiving support. The study not only explores experiences of stigma and discrimination but also focuses on interactions in the support environment. Particularly by considering how relationships fostered in the support context of the organisations contribute to support which members describe as relatively free from stigmatising interactions. Employing a predominantly interactionist analysis of the empirical material, the findings indicate that the notion of 'proximity' of actors in the support environment is integral to deepening our understanding of stigma and relationships deemed by members as 'supportive'. Exploring the wider socio-political context in which support is performed highlights how aspects of the stigma discourse continue to be individualised via the paradoxical attribution of 'self-stigma' by some staff members- despite the 'hidden labour' of many members. However, and as identified by this study, the ways in which staff 'work' to reduce the distance that members are 'set apart' or 'distanced' seems to be a significant contributing factor to truncating the scope for stigmatising interactions in the context of the case study organisations.

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Declaration

I declare that this is my own work and has not been submitted for the award of a higher degree anywhere else.

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CHAPTER 1:

Introduction

1.1 Background to the study and overall objective of the research

Stigma and discrimination are significant issues affecting the everyday lives of people who experience mental distress. The Stigma Shout Survey (Time to Change, 2008) claimed that people who experience mental distress are most likely to be stigmatised and discriminated against by family, friends, employers, and staff of mental health services, as a result of negative attitudes and stereotypes. England's current mental health strategy, *No Health Without Mental Health* (Dept. of Health, 2011a;2011b;2011c;2011d;2012a;2012b), considers stigma and discrimination to be "driven by ignorance and fear" which can negatively affect the life chances of those who experience it (Dept. of Health, 2011a:28). According to the strategy, stigma and discrimination are also attributable to people being socially isolated and can prevent them from working (Dept. of Health, 2011b:83). As part of current mental health policy in England, two of the largest mental health charities,[1] with financial and political support from the present government, currently lead the Time to Change campaign (2015). The campaign began in 2007 and aims to improve public attitudes and reduce institutionalised discrimination inherent in many organisations, with a particular focus on reducing stigma and discrimination encountered in support services (2011a:29). To do this Time to Change campaign to increase public understanding of mental health (2011a:28; 2011b:83). The existing strategy makes clear that support services, including those provided by the third sector, have "shared responsibility" for tackling mental health stigma and discrimination (Dept. of Health, 2014:35).

There are a number of significant sociological frameworks for understanding stigma and discrimination relating to people who experience mental distress. Concepts range from those developed by interactionist theorists (e.g. Goffman, 1963; Scheff, 1999), to modified labelling theory (Link et al., 1989), and the much-cited conceptual model of stigma propagated by Link and Phelan (2001). The latter made explicit that the concept of 'power' is integral to conceptual understandings of stigma. In doing so, Link and Phelan (2001) suggest that it is a "power situation" which allows processes of labelling, stereotyping, being set apart as different, and ensuing rejection, exclusion and/or discrimination, to unfold. The significant contribution of interactionist theorists to the study of stigma, particularly from Erving Goffman who focused on how people 'manage' themselves in day

[1] Mind and Rethink Mental Illness

to day interactions, cannot be ignored. However, critiques of Goffman's work from Disability Studies scholars also critically highlight the importance of 'power' and structural factors as key contributors to stigma and discrimination (Finkelstein, 1981; Oliver, 1990; Barnes and Mercer, 2003). This is a concern reflected in the call for a paradigm shift to focus on discrimination rather than stigma (e.g. Sayce, 1998; 2003). In a special issue of *Social Science & Medicine* entitled "Structural Stigma and Population Health" (2014) the concept of 'power', along with reference to contextual and structural considerations, was further highlighted as significant for deepening our understanding of stigma. Specifically, Link and Phelan (2014) recognised that the impact of direct discrimination, interactional discrimination, structural discrimination, and discrimination operating through the stigmatised person, can (re)create unequal social structures which perpetuate stigma and discrimination.

As contemporary literature relating to stigma indicates, concepts and experiences of stigma and discrimination cannot be explored in a political or structural vacuum. Whilst exploring interactions is important for understanding stigma production, so are the socio-political contexts in which they arise. The policy framework concerned with stigma reduction in England (Dept. of Health, 2011a), amongst a plethora of objectives, calls for the commitment of organisations providing support to people who experience mental distress to reduce stigma (Dept. of Health, 2014:35). However, some literature suggests professionals working in the field of mental health are often cited as being just as stigmatising, if not more stigmatising, as members of the public (Sayce, 2000; Schulze, 2007; Corker et al., 2013). Whilst the reduction of stigma and discrimination is a political project endorsed by the government funded campaign Time to Change, there have been no in depth contemporary qualitative studies from a sociological perspective about how stigma reduction may or may not occur within third sector organisations providing support to people who experience mental distress. As a result, this Ph.D. study developed to consider this underexplored area and I employed qualitative methods to explore experiences of mental distress, support, and stigma. Thus, the overall objective of the thesis is to examine the support context and the relationships within those contexts, imbued with degrees of 'power', as they relate to experiences of stigma and discrimination.

1.2 Specific aims of the study and outline of investigation

The specific aims of the study are to explore and answer the following research questions:

1) How are stigma and discrimination identified, defined, and experienced by people who experience or have experienced mental distress and also receive support from third sector organisations?

2) What is the impact of stigma on experiences of support provided by third sector organisations?

3) How do support and the relationships within the support environment impact on stigma and how might this support help reduce/mitigate the impact of stigma and discrimination?

4) What recommendations, if any, can be made for policy makers and practitioners to mitigate the negative effects of stigma and prevent discrimination?

The research questions are exploratory which suggested a mixed qualitative methods approach and multiple case study design was most appropriate (Stake 1995; Robson 2002; Yin 2003). It was integral to involve both the staff and members in the research because stigma and discrimination, as social phenomena in the support context, necessarily involve interactions which include both staff and members. Two anonymised case study organisations providing support to people who experience mental distress in the North East of England, which I call in this thesis Creative Mindz and Bright Futures, took part in the study and provided me with a practical way of 'framing' the research. An organisational case study approach enabled me to draw boundaries within which research methods were conducted and the data collected. I spent three days a week at each organisation for three months as a participant observer. During this time, I also conducted 30 semi-structured interviews with staff and members, and carried out three focus groups at each organisation. The rationale behind involving two case study organisations was to provide different examples rather than to form wider generalisations. This approach also enabled me to explore issues of wider significance in relation to stigma and discrimination.

1.3 Terminology

The participants in the research were either staff at the case study organisations, or members of the organisations who were in receipt of support from the staff, and attended because they had experienced or experience 'madness and distress' or 'mental distress'. I

use the nouns 'member' or 'staff' to refer to the participants generally, but when it comes to describing participants' experiences as being those of 'madness and distress' and/or 'mental distress' I selected the terms carefully. The terms I used during the period of fieldwork and write up of the thesis changed throughout my three years of study. When I began the study I used the term 'those of us with mental health conditions' to try and avoid a separation between 'us and them'. This terminology also served to create distance between the person and the 'mental health condition'. However, during the course of the Ph.D and the rise of Mad Studies in the UK I selected the terms 'madness and distress' or 'experiences of mental distress'. Employing this language recognises how service users and survivors of psychiatry "have pushed for a shift away from the language of 'illness'" and/or conditions (Mills, 2015) and instead focus on frameworks of distress (Cresswell and Spandler, 2009:138). This, as Mills (2015:202) highlights, "emphasises people's relationship to society and locates the experience of distress within the social."

Burstow (2013) acknowledges the significance of words and that the active selection of words "keeps us on track" (2013:85). As Beresford (2010:24) points out, "language in the context of 'mental health' is a field of conflict" to which there is no consensus of opinion. For example, Speed (2006) identifies three 'types' of 'service user' of mental health support services in sociological literature; patient, consumer, and survivor. These identified terms indicate different ways of talking about 'mental illness' and point to different ways of thinking about agency on the part of the service user. For example, Speed (2006) suggests, as a patient it could be argued a person identifies with the passive acceptance of a diagnosis, whereas a consumer may also accept a medical model but argue for reform from the middle ground within psychiatry. Conversely, survivor discourse is much more political and indicates resistance to medical hegemony and reluctance to re-enter 'patienthood' or be supported by psychiatric services. Although selecting terms is complicated I resisted using the term 'mental illness' as, following Smith (1990:131), 'mental illness' seems to me to be a recycled reality; a social construction which is formed at the intersection of people's experiences and the practices and structures of psychiatry. However, and although controversial, the term 'madness' provides an alternative to the terms 'mental illness' or 'disorder' as a response to emotional, spiritual, and neuro-diversity, and rejecting clinical labels that:

> pathologize and degrade; challenging the reductionist assumptions and effects of the medical model; locating psychiatry and its human subjects within a wider historical, institutional, and cultural contexts; and advancing the position that mental health research, writing and advocacy are primarily about opposing

> oppression and promoting human justice… to take up "madness" is an expressively political act.
>
> (Menzies et al., 2013)

Language is important and I thought carefully about the terms I used to avoid stigmatising language, and to ensure I was not complicit in reducing individuals to diagnoses or as a user of a service; particularly given the links to psychiatric diagnoses, psychiatric services, and stigma. Furthermore, using the term 'distress' refers to something people experience, not what *they are*. As a result I selected to use the term, or variations of the term, 'people who experience mental distress' or 'madness and distress' throughout the thesis.

It should also be noted that I place many contested terms and diagnoses in scare quotes to emphasise their contested nature. In the case of discussing the work of others, I often refer to the terms those particular authors use, and in the case of discussing what the participants said, I use the language and words they use to refer to their experiences, emotions, and thoughts.

1.4 Structure and direction of the thesis

I have very briefly introduced the policy and sociological contexts of stigma and discrimination pertaining to experiences of madness and distress in 1.1. In Chapter 2 I provide a brief overview of the history of mental health 'care', critically describe and evaluate current policy concerned with stigma reduction, along with an appraisal of contemporary anti-stigma campaigns supported by that policy to form the policy context for the study. Moving on I consider sociological concepts of stigma and discrimination in depth and critically appraise theoretical models of stigma, from Erving Goffman to contemporary Mad Studies, including an important critique of stigma from Disability Studies scholars. As a result I consider the importance of understanding stigma as discrimination and/or sanism, ensuing as a result of the exercise of 'power'. Finally in Chapter 2 I consider the literature pertaining to stigma and mental health support painting a mixed picture of what may be construed as stigmatising support in some contexts, but not in others.

The political and theoretical context delineated in Chapter 2 provided me with the conceptual tools to design the empirical study which is described in depth in Chapter 3. In Chapter 3 I tell the story of the research journey which begins by describing the rationale for the study, and how I arrived at the research questions. I describe the case study approach and the organisations involved in the project; Bright Futures and Creative Mindz,

along with the recruitment process. The qualitative methods I employed (participant observation, semi-structured interviews, and focus groups) are discussed and justified. This is accompanied by a discussion about how those particular methods interact and were triangulated. Finally in Chapter 3 I reflect on my own position in the research, the process of analysis, ethical considerations impacting the study, and how the findings will be disseminated.

Chapters 4, 5, and 6, contain the findings from the study. Chapter 4 explores members' experiences of stigma in other contexts and I describe what members consider to constitute supportive relationships, and the interactions characterising relationships deemed 'supportive' and generally non-stigmatising. In particular I consider the relationships between members, and between members and staff. I explore how staff members use themselves and their experiences of mental distress as a 'support device' and I suggest that such interactions could signify a reduction in the distance that members are set apart as 'different' and thus, contribute to reducing stigma. Simultaneously I consider how the notion of staff selectively disclosing what they say about their experiences of mental distress could result in 'distancing' members. I suggest that this is perhaps inextricably linked to the performance of a 'professional role' within the context of the organisation as explored in Chapter 6.

In Chapter 5 I explore how elements of the empirical material suggest that staff members may attribute 'self-stigma' to members displaying certain behaviours and consider how this attribution is potentially, and in itself, stigmatising and may contribute to a cycle of stigma. In doing I also recognise that those attributions are imbued with socio-political, personal, professional and organisational issues, along with the limits of what support, in the contexts of these organisations, is able to provide.

In Chapter 6 I bring the organisational context to the forefront of the discussion by exploring what sorts of interactions and 'ways of being' create a context which is largely non-stigmatising in the eyes of members and staff. In doing so I consider the role of humour, an element of 'informality' between members and staff, and the knowledge staff build up about certain members over time, and how staff members use that knowledge to support members. The notion of 'distance' is once again considered in relation to how staff members draw lines around their relationships with members in the context of the organisation, and members' response to that. Chapter 6 ends with a discussion about how the ways in which staff and members 'work' in the organisations might be conceptualised, with particular attention paid to the stigma discourse.

Finally, in Chapter 7, I conclude the thesis by considering the implications of the findings for members in receipt of support, staff providing support, and the practicalities of

creating supportive, non-stigmatising environments. I also summarise the implications of the findings for sociological understandings of stigma and the implications for social policy, before briefly considering avenues for further work, prompted by this study.

CHAPTER 2:

Stigma and discrimination: A policy and sociological context

2.1 Introduction

This chapter contextualises the study by providing a brief history of some of the relevant legal and policy developments in England before critically delineating relevant social policy relating to mental health stigma and discrimination reduction. I also outline and examine sociological concepts of stigma and discrimination which informed the study, with a particular focus on literature pertaining to stigma and support. It is the political and sociological contexts referred to in this chapter which led to the design of the empirical study described in Chapter 3.

2.2 Stigma and discrimination reduction: a policy context

2.2.1 Brief historical overview

Before focusing on the detail of contemporary mental health policy relating to stigma and discrimination reduction, this section summarises and acknowledges more widely, some of the relevant legal and political developments in England. By contextualising contemporary mental health policy in this way I begin to consider how historical developments have perhaps contributed to the stigma and discrimination encountered by those of us who experience mental distress.

Pilgrim and Rogers (2010:189-196) document the inception of the asylum and state responsibility for 'lunatics' in England following the enactment of the Lunatics Act 1845 which compelled the county authorities to establish asylums and regulate the incarceration of individuals who were deemed 'insane' . Pilgrim and Rogers (2010:189) refer to Jones (1960) who suggests that the Lunatics Act 1845 was a result of humanitarian aims and a number of reports which drew public attention to the poor state of workhouses and private madhouses. However, historians such as Scull (1979) reject Jones' (1960) account of events and consider the incarceration of mentally distressed people in county asylums as being linked to the confinement of social deviancy, similar to the increased confinement of criminals in prison. Scull (1979) suggests that mass confinement, such as that constituted by the asylum system of the 19th century onwards, was a product of urbanization, industrialization, and capitalist forces which shaped the first half of the nineteenth century. Although there are conflicting accounts explaining the development of the large county asylums (Pilgrim and Rogers, 2010:191), the beginning of the nineteenth century saw a gradual process of segregation taking place. Poor people who could work were sent to

workhouses, and they were separated from those who couldn't work, including those considered 'insane' who were incarcerated in asylums. Furthermore, and as documented by Foucault (1967), 'the mad' presented a challenge to the notions of rationality and reason which dominated the post-enlightenment period. The mad were thus incarcerated to remove them from the rational public sphere, because they were seen to be without reason.

Whilst state responsibility for the insane had been established, there were also a number of important developments in the law and psychiatry which served to form foundations for a relationship which continues to exist between the two professions. For example, Busfield (1996) in *Men, Women and Madness: Understanding Gender and Mental Disorder*, explains how the Madhouses Act 1744 established the requirement of medical certification of madness in order to incarcerate people in private madhouses, and the Small Act of 1819 which gave magistrates the authority to detain patients who were deemed insane. The later Mental Treatment Act 1930 introduced the status of 'voluntary patient' and further endorsed medicine's claims to have a curative programme for the mentally ill because it referred to both incarceration *and* treatment. In 1948 the NHS (National Health Service) was established which was based on three core principles; that it meet the needs of everyone; that it be free at the point of delivery; and that it be based on clinical need, not ability to pay (NHS, 2015). At this point it is important to highlight how psychiatry is often critiqued for being awkwardly located in the discipline of medicine. For example, Szasz (1974) suggests psychiatry merely obscures the ethical and political problems we face as human beings. Whilst Fulford highlights the subjective nature of psychiatric diagnosis in comparison to physical illness:

> Mental illnesses are more overtly value-laden than physical illnesses…because the value judgements expressed by "illness" in respect of mental conditions tend to be …contentious, while the corresponding value judgements expressed by the term "illness" in respect of bodily conditions tend to be widely agreed and settled upon" (2004: 75)

That said, psychiatric services and treatment were, and continue to be, provided by the NHS. Psychiatry's contribution to stigma and discrimination is covered further in 2.3.4.

In 1961 Enoch Powell, Conservative Minister for Health, announced the "elimination of by far the greater part of the country's mental hospitals." It took 25 years for these plans to materialise and the closures to start. What followed was the birth of a slow and challenging transition from the provision of psychiatric services in institutionalised

inpatient asylum settings to deinstitutionalised mental health services in the form of community support and care. Facilitated by legislation, policy, and practice, some of which is summarised below, this transformation has been critically articulated and documented in more detail elsewhere (see Jones, 1972; Scull, 1977; Busfield, 1986; Goodwin, 1997).

At a similar time to Powell's announcement, Goffman (1961), writing in an American context, published the seminal text *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* which described asylums as being "total institutions" in which the "mortification of the self" occurred via "degradation ceremonies" and "confessionals". According to Goffman, a total institution is a place where all aspects of life are conducted in the same place and in the presence of others, where there is strict differentiation between "inmates" and "staff", where the lives of the inmates are open to continuous scrutiny, and where inmates have little privacy. Goffman describes the "mortification of the self" as a process of initially stripping a person of their identity via "degradation ceremonies"; for example, replacing their clothes with hospital clothes and taking away personal belongings. Goffman describes inmates taking part in "confessionals" with staff and in therapy groups where they were incited to disown or devalue their past lives and their madness. Goffman's *Asylums* detailed text was the result of ethnographic fieldwork in St. Elizabeth's Hospital, Washington, D.C, and shed light on the treatment of mental patients and the erosion of their individual identities.

In a British context, reports were also coming to light which suggested the hospital environment wasn't helpful for patients and highlighted some of the wide scale neglect and abuse occurring in British asylums. For example, Wing (1962) drew attention to the social withdrawal and passivity of hospitalised patients which he found correlated with the length of stay. Scott (1973) suggested that the environment of the mental hospital itself induced 'symptoms' of mental illness. Braginsky et al. (1973) found that acute patients wanted to leave hospital but chronic patients took no interest in their clinical condition. Martin (1985) reviewed the care patients received in British mental institutions between 1965 and 1983 and documented some of the inhumane and brutal treatment suffered by patients at the hands of staff, along with the negligence patients experienced. Thus, in response to many of the criticisms of the large asylums, as Carpenter and Raj (2012:458-9) point out, the shift to care in the community must be considered and understood as part of a "broader social democratic turn" where efforts were made to "'liberalize' attitudes towards and treatment of people diagnosed with mental health problems." It was the Mental Health Act 1959 specified that people must be treated, where possible, away from institutional care and in the community.

Whilst the plans to close asylums were coming to fruition there was also a move towards ant-discrimination in England with the implementation of legislation in the 1960s to 1970s enacted to tackle race and gender discrimination, such as the Race Relations Act 1965 and 1976, the Equal Pay Act 1970, and the Sex Discrimination Act 1975 (for a detailed account see Thompson (2006:3-16)). With an increasing public awareness of discrimination and oppression, there were also two key grassroots movements taking shape which impacted upon people who experience mental distress; the Disabled People's Movement and the ex-psychiatric service user movement (for further discussion see 2.3.4). The Disabled People's Movement highlighted the oppression and abuse experienced by disabled people, and the ex-psychiatric survivor movement made public the abuse occurring inside institutional settings and perpetrated against those who had been entrapped by the psychiatric system. The pressure exerted on the government via campaigning, particularly as a result of the work of the Disabled People's Movement, contributed to the enactment of the Disability Discrimination Acts 1995 and 2005, which were later repealed by the Equality Act 2010 (discussed again in 2.4). From 1995, anti-discrimination legislation included 'mental impairment' as a 'disability'. The core concepts in the Disability Discrimination Acts placed duties on public bodies, making it unlawful for a public body, employers or service providers to treat a person less favorably for a reason related to a "person's disability", and failure to make a "reasonable adjustment." "Reasonable adjustments" requires employers, service providers etc. to take steps to remove barriers from disabled people's participation in society. Thus, the aforementioned legislation made it unlawful to discriminate against people who are disabled as a result of their experiences of mental distress. Furthermore, the enactment of the Human Rights Act 1998 (HRA), codifying the protections in the European Convention on Human Rights (ECHR) into UK law, also represented a focus, not only in terms of legal protection from discrimination but also highlighting the notion of 'rights'. Particularly relevant to psychiatric treatment and confinement is Article 3 of ECHR granting freedom from torture and inhumane degrading treatment, and Article 5 of ECHR which gives citizens the right to liberty and security:

> Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law… (e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants. (Council of Europe, 2013:7-8)

Article 5 allows for the detainment "of persons of unsound mind" provided a domestic legal procedure is in place to allow for their detainment. As a result, contemporary domestic mental health legislation can, and does, lawfully curtail this particular human right. Following the enactment of the Mental Health Acts of 1983 and 2007, not only could a person be involuntarily detained, often referred to as 'on section', but the current 2007 act extends psychiatric powers into the community in order to enforce treatment. Thus, a patient can be subject to a community treatment order. This means that if a service user does not comply with their psychiatric treatment, which is often taking psychiatric medication, they can be detained in hospital against their will. This introduces a further degree of coercion which, some writers suggest, is related to the 'pharmacological revolution' (Pilgrim and Rogers, 2010:196-198) i.e. the psychiatric drugs developed by the pharmaceutical industry make it easier to control patients in the community (Scull, 1977) and the profit motive of pharmaceutical companies (Healy, 2012).

In terms of service delivery, when New Labour came to power in 1997, community care was the norm, and the once "stigmatised" places of the asylum had undergone a process of rationalisation (Cornish, 1997). Therapeutic and treatment settings became embedded in the community on a much smaller scale and in a "normal" community environment (Philo, 1987). As Parr (2008:19-20) writes, community care comprised a "diverse panoply of care homes, drop-ins, hostels, day centres, clinics, social projects and independent living arrangements." Post-1997 many of these community care services were 'contracted out' from direct public sector delivery, and a large majority of current community mental health support services are provided by third sector organisations with charitable or public funding (Clarke et al 2010; and also see section 3.3.4 of this thesis where the nature of this shift and the shape of these organisations are discussed in more depth).

In 2010 a Conservative and Liberal Democrat coalition government came to power and announced a programme of austerity to reduce public spending, lessening the government budget deficit and the welfare state; the NHS budget was 'ringfenced' and protected from funding cuts. That said, "mental illness causes almost a quarter of our burden of disease (22.8 per cent) yet receives only 11 per cent of NHS funding" and mental health services are regularly referred to as a "Cinderella service" (NHS England, 2013). As a response to this long standing criticism regarding the proportion of NHS spending on mental health services, the Health and Social Care Act 2012 created a new legal responsibility for the NHS to deliver 'parity of esteem' between mental and physical health by 2020. Additionally, there has been an investment of £400 million over four years in psychological talking therapies referred to as IAPT (Improving Access To Psychological

Therapies programme) (Dept. of Health, 2011a:3; Dept. of Health, 2011c) as a way to help people with mental health problems improve personal relationships, including relationships which will facilitate employment, as they will "understand themselves better" (Dept. of Health, 2011b:48). However, and as noted above, it is the third sector which is often contracted to provide mental health services and a recent report from the King's Fund (2015) suggests that:

> The reduction in the prices paid to mental health providers in 2014/15 (which exceeded reductions for hospitals providing physical health care) led many to conclude that institutional bias against mental health remains as strong as ever.

Due to the reduction of funding for third sector organisations, either as a result of the reduction in social care funding (also see 3.3.4 of this thesis for a discussion of the impact of the personalisation agenda in adult social care on third sector organisations) or a reduction in the prices paid to mental health providers, many of these organisations have more recently endured budget or service cuts and/or closures in the name of 'austerity'. For example, in 2011 it was predicted that the UK voluntary and community sector would lose around £911 million a year in public funding by 2015-16 (National Council for Voluntary Organisations, 2011). During 2011 £77 million of cuts were reported to the Voluntary Sector Cuts website (UK Civil Society Almanac, 2012).

It is not only third sector organisations experiencing cuts or a reduction in income as a result of the austerity programme. Welfare benefits for people who experience madness and distress such as ESA (Employment Support Allowance) and PIP (personal independence payments) have also been cut, and these benefits are becoming increasingly harder to qualify for (Grover and Soldatic, 2013). In 2011 43% of ESA claimants specified mental/behavioural disorders as their primary condition (UK Parliament, 2012:14). However, in 2013 six out of ten ESA claimants with a mental health condition or learning difficulty experienced a sanctioning of their benefits i.e. had their benefits stopped (Benefits and Work, 2014).

There is also growing body of literature which suggests disabled benefit claimants themselves often experience stigma and discrimination (Turn2us, 2012), particularly as a result of negative and stigmatising media coverage (Garthwaite, 2011; Briant et al., 2013). Mladenov (2014) explains how austerity policy measures discriminate against disabled people:

> In the aftermath of the financial crisis of 2008, disabled people in the UK have been hit disproportionately hard by austerity. Austerity measures have had a strong impact on economic redistribution, in terms of widening income inequalities between disabled and non-disabled people. Furthermore, austerity has had an impact on disabled people's cultural recognition and political representation as well.

The recent reforms and policy environment surrounding contemporary social welfare provision and services for disabled people referred to above are increasingly based on conditionality, efforts to towards productivity, and specific efforts to 'recover'. As some writers suggest, this is an attempt to shrink the 'disability category' and in doing so, it is the state which dictates eligibility for welfare provision and effectively defines what disability means (Roulstone, 2014). Similarly, there is an attempt by the state via contemporary mental health policy to redefine 'recovery' by rendering economic activity an imperative of recovery (see 2.2.2.) A critique of this policy from Mad Studies scholars and disability studies writers is considered in more depth in 2.2.3.

This subsection has provided a brief overview of some of the historical and socio-political developments that have led us to our current legal and policy framework relating to, and impacting on, people who experience mental distress. I have summarily outlined some of the ways people who experience distress have been segregated, abused, oppressed, and coerced, which may contribute to stigma and discrimination, along with how grassroots movements and legal frameworks have sought to tackle discrimination in recent decades. Many of the issues introduced in this section will be revisited and built upon as I explore the sociology of stigma in 2.3, discrimination in 2.4, and mental health support and stigma in 2.5.

Deinstitutionalisation may have ameliorated elements of stigma and discrimination relating to mental distress, not least because vast numbers of people are no longer warehoused in large asylums or physically 'shut away' on account of their experiences of madness and distress. However, many people who experience mental distress do encounter stigma and discrimination in their everyday lives (Time to Change, 2008). The next subsection describes and explores current mental health policy focusing on contemporary stigma and discrimination reduction. In doing so, it is important to note that *how* the issues or problems of stigma and discrimination are politically framed, set against the backdrop of the wider context delineated in this subsection, affects the type of 'solutions' put forward for stigma and discrimination reduction; a key consideration running through this chapter.

2.2.2 Contemporary mental health policy: a focus on stigma and discrimination reduction

In 2011 the Department of Health, under the 2010 to 2015 Conservative and Liberal Democrat coalition government, published *No Health Without Mental Health: a cross-government mental health outcomes strategy for people of all ages* (2011a). Although a Conservative Government was elected in May 2015, the Strategy[2] continues to provide the current framework for delivering mental health services in England, and a national policy context for the provision of projects supporting people experiencing mental distress. An overarching theme of "shared responsibility" is embedded within the Strategy and pervades the six shared objectives (2011a:6):

I. More people will have good mental health;
II. More people with mental health problems will recover;
III. More people with mental health problems will have good physical health;
IV. More people will have a positive experience of care and support;
V. Fewer people will suffer avoidable harm; and
VI. Fewer people will experience stigma and discrimination.

The commitment of employers, schools, local authorities and the third sector is emphasised as key to achieving the objectives (Dept. of Health, 2011a:3). Hence the objectives are presented as "shared", and third sector organisations seemingly derive responsibility from, and for the delivery of, NHWMH. The objectives are linked and not mutually exclusive, but given the focus of my study I will concentrate on the policy objective relating to 'reducing stigma and discrimination'.

NHWMH indicates stigma and discrimination are driven by ignorance and fear which can negatively affect the life chances of those who experience it, particularly by preventing them from seeking help and support (Dept. of Health, 2011a:28). Stigma is cited as affecting attitudes and behaviours of clinicians and support services staff, who often have low expectations of people with "mental health problems" which can impact upon their "recovery" (2011a:28). Stigma and discrimination are also attributable to keeping people socially isolated and preventing them from working (2011b:83). The Strategy details how a reduction in the number of people experiencing stigma and discrimination will be achieved by educating mental health professionals and the public.

[2] No Health Without Mental Health: Delivering better mental health outcomes for people of all ages (Dept. of Health, 20011b) elaborates on how the Strategy's objectives are to be achieved. In conjunction with a number of other companion publications (Dept. of Health, 2011c; 2011d; 2012a), I will refer to the documents comprising the Strategy collectively as 'the Strategy' or 'NHWMH' throughout the thesis.

Recognising that legislation, namely the Equality Act 2010 (introduced by the previous Labour government and discussed again in 2.4), is insufficient to tackle discrimination, the Dept. of Health makes an undertaking to part-fund and work closely with the Time to Change campaign (www.time-to-change.org.uk) led by the charities Mind and Rethink Mental illness:

> improving public attitudes and reducing the institutionalised discrimination inherent in many organisations, including support services (2011a:29).

NHWMH trusts that "public understanding of mental health will improve and, as a result, negative attitudes and behaviours to people with mental health problems will decrease" (2011a:28; 2011b:83). Improvement is monitored by the government via a "dashboard" (Dept. of Health, 2013a; 2013b), alongside Time to Change, which takes into consideration results from the annual British Social Attitudes Survey (2011b:85) and other existing publicly available sources of information to give a picture of mental health outcomes as a whole, as measured against the objectives set out in the strategy. In the context of the Strategy, reducing stigma and discrimination is to be achieved by public education via campaigning and raising awareness, along with provision of training for professionals. Professionals in all sectors and citizens alike, by virtue of the Strategy, appear to be considered by the government to have a responsibility to educate and to be educated, and to develop less stigmatising and discriminatory attitudes.

Stigma and discrimination reduction is measured by a set of indicators divided into two sections; the first relates to knowledge, attitudes and behaviour of the general public, and the second relates to service users' experience of stigma and discrimination. The National Attitudes to Mental Illness Survey (with additional analysis conducted by the Institute of Psychiatry) demonstrated no significant improvement in overall mental health knowledge and no significant improvement in public attitudes towards people with mental illness between 2008 and 2012 (Dept. of Health, 2013a:66). Public responses regarding "intended behaviour" in relation to people with mental illness showed very slight improvement between 2009 and 2012 (2013a:67). In terms of service users' experience of stigma and discrimination, the Viewpoint Survey (conducted in partnership with the Institute of Psychiatry) reveals that service users who report no discrimination increased from 9% in 2008 to 13% in 2009 but the trend since reversed, and the figure was 9% for 2012 (2013a:68). Little or no qualitative research was conducted to consider why this may be the case or what the statistics mean for people in receipt of support.

Published in January 2014, also under the coalition government, *Closing the Gap: priorities for essential change in mental health* (Dept. of Health, 2014) builds on NHWMH. *Closing the Gap* acknowledges some relationship between social inequality and mental health problems, along with experiences of stigma and discrimination:

> people with mental health problems who often live in poverty, have poorer social networks, and more difficulties accessing housing, employment, education and other opportunities. These issues are, of course, heightened by the stigma and discrimination still experienced by people living with mental health problems. (2014:27)

The bold assertion that stigma and discrimination around mental health will be "stamped out" (2014:33), principles also underpinning the Time to Change campaign, is accompanied by research demonstrating a 5.5% reduction in average levels of discrimination between 2008 and the publication of *Closing the Gap*. According to the report, people with mental health problems experience less discrimination from friends (14% less than 2008), family (9% less) and in their social life (11% less) (2014:33-34). It is unclear how this data was collected, who were asked, sample size, etc. Finally, the report closes by reiterating this notion of "shared responsibility" which comes together under the mantra "mental health is everybody's business" and the "call to action" requires "the input of partners, charities and representative organisations- as well as employers, families and carers" (2014:35).

2.2.3 Critiquing contemporary policy

In 2.2.1 I briefly considered the wider and more historical context(s) of the social situation of people who experience mental distress. In 2.2.2 I described and reflected upon existing policy informing and relating to stigma and discrimination reduction, with a focus on the context of the provision of contemporary mental health services. However, it is also important to read this policy context more critically and in the light of the developments covered in 2.2.1. The Strategy and related publications recognise the negative impact stigma and discrimination can have on the lives of people experiencing mental distress (2011b:84) and the Dept. of Health wants to reduce the stigma and discrimination regularly experienced by those of us who experience mental distress. Calling on practitioners to reflect on their own behaviour and to develop and receive appropriate training (2011b:84), along with anti-stigma interventions e.g. increased group and personal contact between different social groups to reduce conflict and increase understanding (Case Consulting, 2005), seems a step in the right direction. Nevertheless, there are a number of

considerations introduced below and elaborated upon in the remainder of this thesis which demonstrate the complexity of addressing stigma and discrimination with such an approach.

As introduced in 2.2.1, there is no mention of how stigma and discrimination may be considered to be 'created' by inter-related hegemonic medical, psychological, psychiatric, and political discourses. Time to Change subscribe to an 'illness' model, and both the Time to Change campaign and the Strategy appear to endorse an individualised approach to 'mental health problems'. This is evidenced by the language used in the Strategy pertaining to responsibility for recovery and the reliance on talking therapies as a veritable answer to the mental health needs of the nation, along with a smattering of what can only be described as a public education programme encouraging individuals to 'come out' and talk about their experiences in order to confront stigma and discrimination. Furthermore, whilst there is recognition some clinicians and professionals may display negative behaviours associated with stigma, there is no interrogation of the concept of mental health problems/illness itself, upon which stigma and discrimination may be considered to be predicated.

The Strategy considers stigma and discrimination to impede "recovery" and suggests we should take a certain amount of personal responsibility for our lives and our "recovery," and that "being in control of your own life helps you recover" (2011a:25). The concept of 'recovery' relating to mental distress has attracted criticism as being void of the social justice principles which were once central to the service user movement which saw recovery as a personal journey (McWade, 2015). 'Recovery' is criticised for being co-opted by biomedical psychiatry which complies with neoliberal policies and values which can do more harm than good (Poole, 2011; Morrow, 2013). In this respect, the notion of personal responsibility is both problematic and inherently political; a point which the Strategy only partly acknowledges. For example, NHWMH recognises that social conditions and inequalities impact upon our 'mental health', acknowledging that "only recently has attention been paid to the importance of employment and housing in the recovery process" (2011a:8) and that our most "deprived" communities have both the poorest mental and physical wellbeing (2011a:9). Firstly, it should be pointed out there is a substantial body of research which has been making the link between poverty and its impact on 'mental health' for decades (Faris and Dunham, 1939; Faris, 1944; Dunham, 1957; Bartley et al., 1998; McLoone, 1996; Reading and Reynolds 2001). Secondly, whilst the link between social conditions (particularly poverty and poor housing) and mental health is acknowledged by the Strategy, other government departments (as introduced in 2.2.1) are meanwhile systematically targeting, curtailing, and cutting disability related

benefits with detrimental effects to disabled people's (which includes people experiencing mental distress) living conditions (Kaye et al., 2012). Whilst the government purports that this is in the name of social inclusion, critics of this process argue that this is another way of marginalising disabled people and eroding their citizenship (Tyler, 2013; Hughes, 2015). It seems that whilst the Strategy acknowledges social conditions, piling on notions of responsibility and encouraging individuals to alter their outlook when they have very little economic agency may be more realistically framed as an insult rather than a solution.

Critique directed at the Strategy for focusing too much on the individual may also be levelled directly at the anti-stigma campaign, Time to Change. As mentioned above, the campaign operates within an illness paradigm, and relies on personal stories of recovery which avoid criticism of mental health services and benefit cuts. The campaign focuses on 'overcoming' mental health problems and any ensuing stigma, with a particular focus on overcoming stigma so people feel comfortable accessing psychiatric or psychological help and support. White and Pike (2013:246) point out, in the context of the Canadian anti-stigma campaign "Opening Minds", how it is problematic to seek to dispel myths relating to the nature and danger of "mental illness" by educating the public on what mental illness *really is* i.e. a disease or illness. White and Pike (2013:247-9) continue:

> The insistence that the necessary starting point is getting the mentally ill to talk about mental illness immediately screens out those who are unable or unwilling to talk, as well as denies the historical processes of social, political and economic exclusion that systematically silenced mad people in the first place…rather than identifying social stigma as the primary barrier to the empowerment of the mentally ill, we argue instead that a more significant barrier to achieving meaningful social justice may in fact be the state failure to recognise its own participation in past injustices and the lack of the courage it would take to initiate a radical change.

A review of the Time to Change campaign's first year published in *The British Journal of Psychiatry* indicates further systemic and complex problems with tackling stigma via the public education route. Smith (2013) recognises the picture is mixed, falling short of the change in attitudes which was hoped for, and still required (2013:49-50):

> We have made gains, not least in turning a 'non-issue' into an issue, but such change has been slow, patchy and vulnerable. This leaves anti-stigma campaigns with a critical strategic dilemma: do we increase the dose (more time, more

> advertising, more contact) or change the treatment? If the latter, what might such a change look like?

Corker et al. (2013) revealed there had been no significant reduction in reported discrimination from mental health professionals. Thornicroft et al. (2013) conducted a content analysis of local and national newspapers and found an increase in anti-stigmatising articles but no decrease in stigmatising articles. Henderson et al. (2013:70) assessed the attitude of employers towards people with mental health problems and reported an increased awareness of common mental health problems:

> Employers continued to believe that job candidates should disclose a mental health problem, but became less likely to view colleagues' attitudes as a barrier to employing someone with such a problem. Formal policies on mental health and the use of workplace accommodations became increasingly common.

Friedrich et al. (2013) evaluated the success of the training intervention for medical professionals and trainee professionals and concluded that intervention produced short term advantage but there was little evidence to suggest the effects would persist. There was a suggestion that ongoing training intervention measures should be incorporated into the medical curriculum to reduce stigma.

Hinshaw (2013) described the results of the campaign to date as "modest" (2013:104) and Nettle (2013) criticised the low response rate of the service user survey and noted there was no attempt to analyse the qualitative data obtained from data gathering exercises. I concur in that the quantitative approaches in each of the reports briefly summarised above are inadequate for capturing the experiences of people experiencing stigma. Instead they provide a grainy snapshot of small or modest improvements which appear to be statistically ambiguous; Time to Change is only able to ameliorate stigma marginally, if at all.

Whilst a critical understanding of stigma in the context of a mental health policy framework is integral to situate the study in the relevant political milieu, it only affords us a partial perspective skewed by a government of the day which funds the Time to Change campaign as a panacea for tackling stigma. Thus, sociological concepts of stigma and theoretical models for understanding madness and distress introduced below, and which build on some of the historical developments considered in 2.2.1, may aid us in suggesting alternative and 'deeper' ways to consider stigma. They may also serve to interrogate the rather dubious effectiveness of methods employed to achieve the policy objective of

reducing the amount of people experiencing stigma and discrimination. Furthermore, the concepts outlined below provided the theoretical tools which informed the design of the empirical study and the basis for the ensuing analysis.

2.3 Sociological concepts of stigma: from Erving Goffman to Mad Studies

2.3.1 Stigma and interactionism

When it comes to sociological concepts of stigma, Erving Goffman provides an unavoidable starting point. Goffman defines stigma as an "attribute that is deeply discrediting", reducing the bearer "from a whole and usual person to a tainted, discounted one" (1963:13). "Mental disorder" is categorised by Goffman as a "blemish of individual character" (1963:13) and thus constitutes stigma because of "undesired differentness" (1963:15). Goffman distinguishes between "discredited" individuals where "differentness" is evident from the outset, and "discreditable" individuals where "differentness" is neither known about by those present nor immediately perceivable (1963:14). According to Goffman (1963), stigmatised individuals employ one of two techniques in social interaction with "normals"; "passing" (hiding the sigma) and "covering" (reducing the significance of the stigma). The primary focus of *Stigma: Notes on the Management of Spoiled Identity* (1963) relates to "managing" the information which the "stigmatized" convey about themselves in contact with "normals" in attempts to project or protect the self, how "normals" respond and, how "normals" encourage the adoption of adjustment.

Davis (1961) outlines a similar process of "deviance disavowal", where difficulties in the interaction between people with a visible impairment and non-disabled people become normalised over time via similar adjustments predominantly made by the disabled person. In particular, Davis (1961:121-2) refers to the "sticky" interactions in everyday social encounters between disabled and non-disabled people. Such encounters have been said to "reinforce, and to be reinforced by, any lingering disablism the people involved may have" (Scully, 2010:27).

Jones et al. (1984) present a conceptual framework of stigma which correlates with Goffman's notions of "discredited" and "discreditable" people; they use the term "mark" as a descriptor which encompasses the range of conditions considered deviant (including 'mental illness') which leads to society initiating the stigmatising process. They identify six dimensions of stigma: how obvious the stigma is/how easy it is to conceal, whether the stigmatising condition is reversible over time, whether the "mark" disrupts interpersonal interactions, to what degree the "mark" initiates "instinctive" reactions of disgust, how the

condition came into being/where is the perceived responsibility for the condition, and lastly, the feelings of danger or threat that the "mark" induces in others.

Labelling theory, a branch of interactionist theory, incorporates the idea of the stereotype as a result of societal reaction (Scheff, 1966; 1999) where the label of 'mentally ill' can be ascribed to a person as a master status 'producing' 'mental disorder' from which stigmatisation follows. However, Scheff's labelling theory has been heavily critiqued. For example, Gove (1982) rejects Scheff's proposition that labelling produces mental illness, asserting instead that society's perceptions of the "mentally ill" come about as a direct result of people's behaviour. Moreover, Gove argues that "for the vast majority of mental patients stigma appears to be transitory and does not appear to pose a severe problem" (1982:280). Chauncey (1974) suggests there is a shortage of evidence to support Scheff's argument because he "merely attempts to defend the existence of the social reality while ignoring the question of its relative significance with respect to disease" (1974:251). Gove (1970) concurs by asserting that Scheff neglects any biological dimension of mental distress. Whilst this might be the case, Scheff's 'labelling theory' draws important attention to how social interactions are impacted by psychiatric labelling, and how psychiatric labelling and social stereotyping can occur as a result of 'disordered' behaviour; psychiatric labels matter when it comes to stigma.

Finding some middle ground between Scheff and Gove, 'Modified labelling theory' (Link et al., 1989) suggests that even if labelling does not directly produce 'mental disorder' as Scheff suggested, it may lead to negative outcomes. Employing quantitative analysis of structured interviews with samples of "mental patients" and "untreated" community residents, Link et al. (1989) found that "'most people' will reject mental patients" (1989:400). Finding a mid-way between the arguments of Scheff and Gove, and following Mead's (1934) concept of the 'generalised other' (the internalised shared social attitudes of the society around us), Link et al. (1989) explain how most lay people have a conception of what it means to be a 'mental patient' or 'mentally ill'. They suggest that when a person becomes labelled as 'mentally ill', usually via medical treatment or as a result of certain behaviour, societal conceptions of what it means to be 'mentally ill' suddenly become relevant to the person who has been labelled. A person's response to this can be secrecy i.e. to conceal they are receiving treatment; withdrawal i.e. they withdraw from, or limit, social interaction; and/or they feel they want to educate people about their condition.

Link et al. (1989) suggest that psychiatric labelling can have negative consequences for a person's self-esteem, earning potential, social networks, etc. Furthermore, individuals can be vulnerable to new disorders or repeat episodes of the existing disorder, which may further impact negatively on self-esteem, social networks, employment prospects etc.

'Modified labelling theory' recognises that people do have a set of negative attitudes and beliefs about how people will treat people experiencing mental distress which, when they are labelled mentally ill themselves, endorse the coping mechanisms of secrecy, withdrawal or educating others. Ultimately, stigma can't be easily explained away (Link et al., 1989:419) and it can leave patients and former patients vulnerable to experiences of further 'disordered episodes' (1989:421); implying that stigma also impedes 'recovery'. As Rogers and Pilgrim (2010:36) conclude:

> Thus, this modified labelling theory is not about the unidirectional impact of the prejudicial actions of one party on another but an interaction that creates social rejection based upon shared acculturated assumption.

'Modified labelling theory' recognises that people develop conceptions of 'mental illness' through their socialisation process and if they are labelled 'mentally ill' those conceptions become personally relevant and can lead to them adjusting their behaviour in particular ways (Link et al., 1989). This is similar to what Steel and Aronson (1955) describe as the "stereotype threat" i.e. people know what stereotypes may be applied to them and that may become a threat if they don't behave in accordance with the typified behaviour of that particular stereotype and thus alter their behaviour; in this case it seems no one needs to have perpetrated an act of discrimination against the person in question.

Literature covered in this subsection so far raises a key point in relation to stigma and social interactions: stigma is related to being labelled *and* the social reaction or response to the label. However, it has been said that interactionist literature often focuses too much "on the defensive manoeuvrings of disabled people" (Barnes and Mercer, 2003) by concentrating on the individual in a world that "at once creates and oppresses it" (Freidson, 1983:359). Much of the criticism directed at the portrayals and analyses of stigma covered in this section so far, particularly Goffman's concept, emanates from disability scholars. For example, Higgins (1981) argues that disabled people are not always preoccupied with "fitting in" and "avoiding embarrassment" as Goffman suggests. Oliver (1990) argues 'stigma' is not a useful concept for tackling prejudice and social exclusion because it serves to concentrate the stigma within the individual. Elaborating on this he states Goffman does very little to explain why stigmatisation occurs and fails to incorporate collective responses as opposed to the personal responses he discusses (Oliver, 1990:60). Similarly, Finkelstein (1981) accuses Goffman of individualising the issue of stigma. By ignoring a broader view relating to cultural representation where disabled people become

‘other’, Goffman is also indicted for only being interested in spoiled interaction to cast light on the interaction of “normals” (Watson, 2003:37).

Whilst Goffman has received much criticism, interactionist literature *is* credited for repositioning “the problem of impairment from the body to the social, in that it is the social that creates the stigma” (Watson, 2003:38). Particularly, as Keith (1996) suggests, interactions between disabled and non-disabled people continue to be characterised by confusion. Hunt (1966:12) claims that disabled people regularly defer to non-disabled people, agreeing uncritically to whatever is the “done thing”. Furthermore, Scully (2010) describes the “hidden labour” regularly employed by disabled people in interactions to manage the discomfort of others. Despite some legitimate criticism with regards to what could be construed as Goffman’s political naivety and neglect of wider structural and material perspectives on the interactions he writes about (Bourdieu, 1989; Oliver, 1990; Reynolds, 1993; Abberley, 1993; Wendell, 1996; Longmore, 1998), Goffman’s ideas are by no means redundant. As Smith (2000:85) points out, Goffman highlights how different contexts result in different things being constituted as stigma, this focus is particularly important for this study. If interactions are less stigmatising in a support context what is the impact on experiences outside of the support context and vice versa? What ‘hidden labour’ is done by people who experience mental distress within and beyond the support context?

Interactionism is important for understanding stigma. It is interaction which sustains the social order (Scambler, 2011:220) and an interactionist perspective on disability:

> opens up a much-needed concern with how individual actors interpret social situations and their embodied positions within them, recognising the different abilities that bodies allow while not reducing disability to a property of the person. (Coleman-Fountain and McLaughlin, 2013:134-5).

However, what is ‘different’, and thus could initiate a stigmatising process, depends on the social, political and physical environment, highlighting the importance of context which is considered further below. As Scambler (2011:220) suggests, “it’s time to move on, rather than *beyond:* it is not that Goffman was wrong but that there were questions he did not ask.”

2.3.2 Link and Phelan (2001) and the relevance of 'stereotypes' to stigma

Developing Link et al.'s (1989) 'modified labelling theory', Link and Phelan (2001) reassessed the concept of stigma. Highlighting many of the arguments from a disability studies perspective referred to above (2.3.1), they recognise that often those who research stigma are not part of the stigmatised group and so researchers give priority to their theories as opposed to the words of the people they study (Schneidre, 1988). Link and Phelan's (2001) reconceptualisation of stigma breaks stigmatisation into four theoretical components including: labelling; stereotyping; being set apart as different; and forms of disapproval such as rejection, exclusion and discrimination. According to Link and Phelan, stigma ensues when the four components co-occur "in a power situation that allows these processes to unfold" (2001:382). They are more diligent than the interactionists in recognising the importance of wider social contexts and the 'power' necessary to connect "labelled difference" (differences which matter socially, such as 'mad behaviour' which attracts a psychiatric label) to an "undesirable characteristic" to produce a stereotype. The term 'label' is selected because, according to Link and Phelan, it is something that is affixed and "leaves the validity of the designation as an open question" (2001:368). The stereotype, as a result of labelling an "undesirable characteristic" such as 'mental ill health', contributes to the stigmatisation of people experiencing mental distress. Often, in the context of 'mental illness', a person can 'become' the thing they are labelled (Estroff, 1989). For example, someone with a diagnosis of schizophrenia *is* a schizophrenic and one of 'them', whereas someone with a diagnosis of cancer is still one of 'us' but just happens to be ill; we *have* cancer but we *are* mentally ill. As a result, those of us experiencing mental distress can often be 'set apart as different'. The fourth and final component is unique to previous concepts of stigma because it explicitly includes the status loss and discrimination which can occur as a result of the unfolding of the previous three components. Discrimination is conceptualised to include both individual discrimination such as the refusal of a job, and structural discrimination where institutional practice works to the disadvantage of people experiencing mental distress, such as less allocated funding for mental health services. Status loss can also be a form of discrimination in instances where people experiencing mental distress appear less attractive to socialise with, resulting in them not being involved in social activities etc. Stigmatised groups, according to Link and Phelan (2001:371-5) are disadvantaged, yet it can be difficult for people to specify any single event which produced the unequal outcome, revealing the complex and intersectional nature of both stigma and discrimination.

It must also be noted that each of the four conceptual elements comprising Link and Phelan's stigma framework is dependent upon 'power'. Power can be social, economic

or political, but whatever the power is, it is recognised that it is "essential to the social production of stigma" (2001:375). The idea of stigma itself can portray the stigmatised group as helpless and passive victims (Fine and Asch, 1988) without power, and may therefore be responsible for producing more undesirable attributes. Furthermore, stigma is a matter of degree (Link and Phelan, 2001:377); different people in different contexts (and particularly different psychiatric diagnoses) experience it differently. This suggests some form of stigma hierarchy which interacts with not only the diagnosis or 'symptoms' or behaviours associated with particular disorders, but also environmental factors; hence the importance, once again, of context.

Link and Phelan (2001:379) refer to stigma as a "persistent predicament" in the lives of those of us with experiences of mental distress which can subsequently affect life chances, including family life, psychological wellbeing, employment, education etc. Three types of mechanisms were identified as ways in which stigma operates. They include individual discrimination, structural discrimination, and "discrimination that operates through the stigmatized person's beliefs and behaviors" (2001:379). Link and Phelan (2001:380) highlight the complexity of stigma and refer to a multitude of associated outcomes which not everybody will experience i.e. not everyone should be seen as trapped "in a uniform disadvantaged position". The 'solution' to mitigating stigma appears to be changing deeply held attitudes or beliefs and changing the circumstances to limit the power of the groups who are doing the stigmatising (2001:381). Link and Phelan (2001) suggest interventions will fail if only one mechanism is targeted at any one time, suggesting we require interventions which produce changes in attitude AND power relations. For example, the use of 'contact theory' which suggests interpersonal contact is one of the most effective ways to reduce prejudice between majority and minority group members (Allport, 1954). The findings of Lucas and Phelan (2012) resonate with the principles of 'contact theory' and suggest that direct contact with a "mentally ill person" is the most effective approach to reducing "mental illness stigma" (Reinke et al., 2004). As a result of the efficacy of direct contact, Lucas and Phelan (2012:18) found no evidence that mental illness or physical disability operated as a 'master status'. This can be contrasted with the work of Becker (1963), where 'master status' overrides other attributes viewing the person only as the stigmatised label.

Drawing on conceptual understandings of stigma from wider sociological health studies, Schneider and Conrad (1981) found people with epilepsy 'adjusted' to the stigma surrounding their condition and as a result individuals fell into one of three categories: pragmatic type (downplaying epilepsy only disclosing when necessary); secret types (concealed epilepsy because they saw it as stigmatising), and quasi-liberated type (going

beyond pragmatic type to publicly proclaim their epilepsy and educate others). The latter rebuts the personal tragedy model or deviance paradigm, and there was also a remaining unadjusted group for whom the illness became a 'master status' subsuming others (Scambler, 2011:224). A study by Scambler and Hopkins (1986) led to a "hidden distress model of epilepsy" which made a distinction between "enacted" and "felt stigma". As Scambler (2011:225) explains, enacted stigma was actual treatment and overt discrimination, where felt stigma was that sense of shame and fear of encountering enacted stigma. Scambler (2011) suggested that when people are diagnosed with epilepsy, because of the sanction of authority of diagnosis and a medical label, and following Bourdieu (1977), individuals develop an epilepsy 'habitus'- a disposition to see and experience the world in a certain way resulting in a strong sense of "felt stigma" and a predisposition to secrecy and concealment.

Many of the concepts covered so far relate to, or rely on, the contribution of stereotypes to the stigmatising process. By ignoring individual variability within a social group, Rogers and Pilgrim (2010:29) explain that to shift from stereotyping to stigmatization, there must be an enlargement of prejudice against that social type which includes an error of reasoning combined with two other processes. There is an emotional process (anxiety, hostility, pity) and a moral process dependent on deviance, moral outrage/revulsion, or paternalism. According to Rogers and Pilgrim (2010:29):

> The negative stereotypes of people with mental health problems contain three recurring elements about: intelligibility; social competence and credibility; and violence.

Returning to the work of the interactionists for a moment, Goffman (1963:14) acknowledges the relationship between "attribute and a stereotype" as a cause of stigma, but he elaborates no further. Scheff refers to labels of 'criminal' and 'schizophrenic' as carrying the weight of "moral condemnation" (1999:45). According to Scheff (1999:45) stigma is at the core "of the societal reaction to deviance" and stigma occurs because of a "surplus emotional response" to the deviance. Scheff explores in some detail the stereotype of insanity in the media, news and in language (1999:76-84) and in the support context (1999:80). What Goffman and Scheff do not do is explore in sufficient detail what may 'stir' or instigate such a response, and the dominant discourse and social structure which 'allows' stigma to manifest itself in this way.

One of the ways stigma seems to manifest itself is by the publication and implementation of policy. For example, in the 1990s there was a resurgence of the

conflation of 'madness' and 'badness' with the assertion that community care had failed, and that there was a strong case for confinement of the groups perceived as the most dangerous (Moon, 2000) as a matter of "public safety". In a letter addressed to Prof. Graham Thornicroft (the Chair of the External Reference Group of the National Service Framework for Mental Health, the task force charged with 'standard-setting' for mental health care) Frank Dobson, Labour Health Secretary, stated:

> Care in the community has failed. Discharging people from institutions has brought benefits to some. But it has left many vulnerable patients to try to cope on their own. Others have been left to become a danger to themselves and a nuisance to others. Too many confused and sick people have been left wandering the streets and sleeping rough. A small but significant minority have become a danger to the public as well as themselves…
> (Dobson, 1998)

This idea of 'danger' and 'risk' relating to people who experience distress was not new but the madness/badness conflation during this time inevitably influenced media reports and public attitudes (see below). Link et al. (1989) recognised public attitudes are not benign when it comes to "mental ill health" and literature indicates that the public tend to believe in stereotypes that individuals who are "mentally ill" are dirty, bizarre, unpredictable and dangerous (Rabkin, 1980; Link et al., 1992; Crisp et al., 2000). Whilst in some (comparatively rare) cases this may relate to an empirical reality, the linking of labels to undesirable characteristics may also be considered the result of the medicalisation of "deviant" behaviour (Rogler, 1997) and "indicates that 'visible others' in city neighbourhoods offer very real manifestations to a risk-averse public" (Moon, 2000:248). Loss of reason continues to attract societal judgment, psychiatric sanction, and the possibility or threat of detention against your will; and madness and distress is often understood as a result of the perceived loss of control or irrationality. These are all contributing factors to the stigmatising process and can reinforce stereotypes.

Stereotypes propagated by much of the media have been found to contribute to the stigmatisation of people experiencing mental distress (Wahl, 1995; Scheff, 1999). In part, the media raise the salience of danger in relation to mental distress (Moon, 2000:246). However, media reporting has been found to be biased (Clement and Foster, 2008). Philo et al. (1993) argue that stereotypes emanate from regular and disproportionate media portrayals of people experiencing mental distress as violent. Furthermore, a diagnosis of 'mental illness' is often conflated with evil or violence resulting

in the vilification of those of us experiencing distress. For example, the term 'psycho' draws on film-based stereotypes to create fear where the 'psycho' becomes the other (Sayce, 2003:626). It is therefore not surprising Aneshensel and Phelan (1999:4) claim that being identified as mentally ill is considered a "social transformation", where an individual's identity is altered, often irrevocably.

Many of the mass media's negative depictions of psychosis often exaggerate the violent propensity of people experiencing psychosis; this forms some basis for the 'othering' of those of us experiencing mental distress. Many of the headlines in newspapers referring to 'mental health problems' wouldn't be tolerated in the depiction of other minority social groups, and whilst this depiction isn't necessarily accurate, accuracy is important given that is where the public learn and understand about mental health issues (Wahl, 1995). The 'Time to Change' campaign works with the media, offering advice to journalists and script writers to attempt to combat discriminatory and sensationalist reporting, but as we have seen from the first year review (see 2.2.3), this hasn't been wholly successful. That said, Sieff (2003) notes the mass media may now lag behind the view of the general public who have a more subtle view of mental distress, and there are many more films which are more 'positive' in depicting distress and psychiatric issues. It must also be noted that a second negative and potentially stigmatising image that can often be conveyed is not one of danger, but of pathetic dependency, silliness, or social incompetence arising from different psychiatric diagnoses (Corrigan, 1998).

Stereotypes, both in the media and more generally in public attitudes, appear to be dependent upon the 'type' of diagnosis. There is considered to be a "psychiatric dichotomy" between 'stress' and 'depression' compared to 'schizophrenia' and 'bi-polar' (Rogers and Pilgrim, 2010:28). For example, stress and depression are often seen as extensions of normal existence and not necessarily as 'mental illness' (Pilgrim and Bentall, 1999). Gove (2004) also distinguishes between the public perception of a "nervous breakdown" and "mental illness" such as 'schizophrenia'. Although the public perceive "nervous breakdown" as incapacitating, it is also believed to be transitory and less stigmatising than it was in the past. Conversely, the public believe a diagnosis of schizophrenia continues to be very stigmatising; Gove (ibid) suggests this is due to a more problematic, permanent, and less transitory prognosis as a result of the label which medicalises 'bizarre' behaviour and the perception 'schizophrenics' are dangerous. Furthermore, a meta-analysis conducted by Schomerus et al. (2012) found the stigma of depression hasn't declined, and that stigma against people diagnosed with schizophrenia has got worse. Thus, stereotypes are an important component of the stigmatising process,

and the next section considers in more depth what happens when those stereotypes are applied to the self.

2.3.3 'Self-stigma'

Many scholars have explored how people who experience mental distress apply stereotypes to themselves and engage in a process of what is termed 'self-stigma'. Following Scheff's "labelling theory" based upon "residual rule breaking" – the infraction of unspoken social rather than codified norms (Scheff, 1999), Thoits (1985) develops a theoretical framework of self-labelling and applies it to voluntary treatment seeking. Thoits asserts that Scheff's theory only applies to people who have been publicly/officially labelled and suggests it is therefore limited in application (1985:221-2). According to Thoits, 'self-labelling' occurs when disorder is conceptualised as emotional deviance as the result of "unsuccessful emotion management attempts" (1985:222) and that:

> Individuals can self-label because they are able to observe and classify their behaviors, thoughts, and feelings from the perspective of the wider community. (1985:243)

Thoits argues that rule violations associated with mental illness do not constitute residual deviance as Scheff suggests; there are no residual rules because the rules can be culturally identified (1985:224). Following Hochschild's (1979) work on the "sociology of emotions", Thoits considers culturally identified rules in an emotional context by considering "emotion rules" i.e. we learn from society that there are appropriate times and places for certain types and degrees of emotional expression. Emotional behaviours are governed by the social context, when individuals think they deviate from the appropriate response they often label themselves and seek treatment voluntarily:

> Persistent or recurrent emotional deviance in the course of identity enactment or identity change will cause individuals to attribute psychological disturbance to themselves, which in turn will motivate help seeking.
> (Thoits, 1985:244)

Thoits suggests "social support" (1985:238-240) can provide a number of valuable roles in ameliorating this form of self-labelling including understanding and acceptance i.e. validation of deviant reactions; validation of deviant feelings to improve self-esteem; and emotional management assistance or coping assistance. Without this social support (which, Thoits notes, does not have to be "professional") prolonged or recurrent discrepant feelings cannot be transformed, yet the theory simultaneously recognises social support

can increase incidences of self-labelling e.g. being around other people with "emotional problems" can confirm your own self-labelling (1985:239).

In Thoits' (1985) "self-labelling" and "emotion rules" we observe an internalisation of, in Mead's terms, the "generalised other" as it applies to emotions, and also the internalisation of many of the stereotypes already discussed. Literature (Corrigan and Watson 2002a; Corrigan and Watson, 2002b; Rusch et al., 2005) indicates a distinction, but also a relationship, between public stigma (reactions of the general public towards a group based on stigma about that group, often based upon stereotypes) and 'self-stigma' (turning the attitudes of, or stereotypes held by, stigmatising groups against themselves). Corrigan et al. (2009) explain, albeit very simply, that self-stigma arises when people are aware of a stereotype, agree with it, and apply it to themselves; the result being an attitude of 'why try to engage in opportunities or develop personal goals?' However, Corrigan et al. (2009) suggest that this attitude may be ameliorated by services, particularly peer support, which can 'empower' people and develop their personal identity (Corrigan et al. (2006); Watson et al. (2007:1317). Previous research has explored the negative effect of self-stigma on self-esteem of people experiencing distress which often leads to individuals feeling reluctant to pursue work or other opportunities; not because of illness, but because of self-discrimination (Rusch et al. 2005:531). Thus, tackling self-stigma and feelings of shame about experiencing mental health problems has become a cornerstone of support services and public campaigns to reduce stigma as described in 2.2 above.

Holmes and River (1999) describe a number of ways in which individuals cope with social and self-stigma, including secrecy, selective disclosure, and cost/benefit analysis. Interestingly, Moses (2009) found that adolescents who self-label in the way Thoits describes, report high rating of self-stigma and depression yet, more generally in the population, less adolescents self-label because they don't view their problems in a pathological way and/or are confused about the nature of their problems. This suggests that there is some link between self-labelling and psychiatric knowledge and knowledge of the biomedical model of 'mental illness'. Corrigan (2004) identified that individuals will often avoid mental health services or refuse to participate in them fully to avoid a psychiatric label and as a way of avoiding self-stigma. Other studies echo similar findings, in that the stigma of 'mental illness' means individuals do not seek mental health services (Pietrus, 2013; Clement et al., 2014). Conversely, individuals may actually seek mental health services and medicalization to legitimate unintelligible behaviour. Once again the context of psychiatry looms large in terms of how stigma is understood and can be, perhaps, applied to the self as the writers in this subsection suggest. The following

subsection considers this psychiatric context further, along with a number of important critiques.

2.3.4 The importance of 'context' for understanding stigma and stigma reduction: psychiatry, stigma, and Mad Studies

It is clear from the concepts of stigma and its contributory components discussed so far, that it is important for theoretical understandings of stigma to take into account structural constraints and intersectional social factors. The notion of 'context' seems integral to stigma production, both at an interactional and/or individual level, along with consideration of more institutional or systemic inequalities. Following on from this, it is also important to note that how we understand stigma effects what methods are proposed to reduce it. Rusch et al. (2005) consider stigma reduction strategies to fall into three categories; education, contact, and protest. Most interventions to reduce stigma are about 'empowering' the individual who experiences distress i.e. equipping them with the tools and skills to challenge and overcome stigma and discrimination in the form of information giving (Rhodes et al. 2005) or public education, and familiarising society with the "stigmatised group" (Angermeyer et al., 2004). NHWMH and Time to Change subscribe to a stigma reduction programme via education and contact. As introduced above, they also subscribe to a biomedical/psychiatric illness model of mental distress which is individualised. However, whilst mental health professionals are willing and sometimes strong advocates of anti-stigma activities, they can simultaneously be the stigmatisers (Schulze, 2007). As Pilgrim and Rogers (2005) highlight, psychiatrists have shown an interest in tackling stigma, but only within their profession; in a campaign endorsed by psychiatrists, a discussion regarding the social processes of stigma was avoided- the campaign concentrated on how stigma was allegedly applied to one diagnosis and not another. What about the contribution psychiatric labels and the medical model (as a way of understanding mental distress) make to stigma? This is something the strategy and Time to Change fail to consider and consequently will be considered here, particularly by drawing on the scholarly contribution of 'anti-psychiatry', the psychiatric survivor movement, and Mad Studies.

Cooper (1967) first used the term "anti-psychiatry" to refer to a critical way of thinking in psychiatry. Whilst there is no exact definition of the phrase or a specific time we can identify which denotes when the movement began (see Crossley (1998) for a comprehensive discussion), the anti-psychiatry movement is considered by many to have emerged in the 1960s with publications by Laing (1960; 1961; 1967a; 1967b), Goffman (1961), Scheff (1966), Foucault (1967) and Szasz (1974). A theme these scholars developed,

albeit with a myriad of diverse and often conflicting approaches, was that madness is nothing more than a social construction created by psychiatry as a form of social control. They asserted their suspicion of psychiatric labels which they believed to conceal social and political realities.

Following Szasz (1961), Pilgrim and Tomasini (2012:633) summarise the weaknesses of psychiatric labelling including, poor conceptual validity (two patients with the same diagnosis can have very little, if anything, in common); poor predictive validity (prognosis/outcomes are often unclear); poor aetiological specificity (we don't know the cause); poor understanding of pathogenesis (we don't understand the mechanisms which result in particular symptoms); and poor treatment specificity (common treatments are used for a range of psychiatric diagnoses). Pilgrim and Tomasini point towards the gradations of "being unreasonable in everyday modern life" (2012:637) which are often overlooked when it comes to policy; it is this idea of "reasonableness" and the following four nuances (2012:638-641), which may also be read as contributory factors to stigma which policy and anti-stigma campaigns either confuse/conflate or don't appear to acknowledge:

1) nuisance and danger: a person can be a nuisance/irritating/benign or alternatively, someone could be actively dangerous- often they are treated very similarly but their rule transgressions are very different;
2) the manner in which someone is a risk to themselves: the state and psychiatry can intervene to prevent self-harm and suicide but there are different rules for binge drinking, obesity, and unprotected sex. There is psychiatric control for some behaviours and not others;
3) the manner in which one is a risk to others: e.g. boxers and soldiers are trained to be violent and, for example, violence is perpetrated by many drunk people every weekend but we don't give them a curfew. However we do detain mental patients or subject them to a community treatment order.
4) self-centredness and the impaired recognition of others: we're all expected to make sense of our actions following rule transgressions. Someone being self-centred and unreasonable as the 'result of' a personality disorder is very different to a politician who is also self-centred and ambitious. It's the work behind the scenes we do or don't do and what we project which can result in the label (or in Goffman's (1959) terms where public performance and backstage performance conflict). Furthermore, whether to 'come out'

depends on the label, as in the case of celebrities, self-disclosure of depression is easier than schizophrenia.

(list adapted from Pilgrim and Tomasini, 2012:641)

Whilst biological and psychiatric framing of mental distress can be considered contributors to stigma for the reasons referred to above, Easter (2012) believes that biological or genetic framing of eating disorders reduces stigma as it removes the element of personal responsibility, blame, and guilt. However, whilst presuming biological explanations may reduce stigma relating to eating disorders (Herpetz-Dahlmann et al., 2011) the reverse was found in relation to psychiatric diagnoses such as schizophrenia, for which genetic explanations have been found to exacerbate stigma (Read et al., 2006; Angermeyer et al., 2011). This is perhaps tied to other elements of stigma, for example, eating disorder stigma centres on personal responsibility not dangerousness or unpredictability. Easter (2012:1409) talks about 'volitional stigma' where conditions such as eating disorders are viewed as choices and thus judged by normal behavioural standards, hinting at a dualism of biological attribution (where problems are seen as being in the body) versus volitional. Genetic or biological framing can reduce volitional stigma- blame, fault, responsibility etc., but may also exacerbate stigma, in that it could imply "scarier genetic psychiatric problems" (2012:1412) and supplant other narratives and overshadow other explanations such as childhood abuse and social inequalities. Easter (2012) also revealed some concerns that genetic explanations would engender a fatalistic self-fulfilling prophecy where genetics became an "excuse". Others suggest that most powerful ascriptions regarding madness do not come from psychiatrists; psychiatrists simply "rubber stamp" decisions already made on common sense grounds (Coulter, 1973). Furthermore it is suggested that even without psychiatrists, we would still have the social judgments without diagnoses (Westermeyer and Kroll, 1978). What is clear is that it is difficult to extract ourselves from a culture dominated by psychiatric understandings of mental health given the subjugating psychiatric discourse.

The biological paradigm might appear to absolve people of some volitional stigma or 'responsibility', but as we have seen from NHWMH there is still a moral imperative which expects people to take ownership or responsibility for their recovery. However, if stigma is a pervasive and persistent predicament, so is the biological and psychiatric model of 'mental illness' which constructs a 'catch 22' for those entrapped by the system. To explain further, following a biomedical model you are firstly deemed to have no agency because the aetiology of your 'illness' is genetic or biological. However, you are expected to take responsibility for your own recovery, yet denied agency via legal and psychiatric

sanction when your behaviour isn't quite right, or your behaviour is deemed 'unreasonable' in a particular context. Furthermore, systems outside of psychiatry also operate under the diagnostic code, for example, the administrators of welfare support such as Employment Support Allowance are predisposed to require a diagnosis or label. More often than not there must be a medical label to access support services and this biological reductionism is 'safe' because it's within the current structure which psychiatry dominates. The same could be said for tackling stigma; how do we tackle stigma if campaigns, policy, and welfare support refuse to fully acknowledge that some responsibility for stigma lies in psychiatric labelling? What does that mean for people who are receiving support when those organisations, such as the ones I worked with in this project, also operate within a similar paradigm?

Historically, due to suspicion of the 'great intellectuals' as its source of motivation, the anti-psychiatry movement had little effect on the 'survivor movement' which also problematised psychiatric labels. Crossley (1998) said that if anti-psychiatry is a "revolt from above", the psychiatric survivor movement is a "revolt from below" from psychiatric patients themselves. The movement organises itself around resistance to oppression including resistance to psychiatric drugs, ECT (electro convulsive therapy), compulsory treatment, and stigma. The survivor movement values alternative experiences such as hearing voices, and provides a refocus for society's response to so-called mental illness.

There is no contemporary unified movement encompassing those of us who experience mental distress and physically disabled people, although many people associated with the emerging movement of Mad Studies (see below) are forming alliances with, and recognising the debt Mad Studies owes to, disability studies (Menzies et al., 2013:12). For example, the critique of Goffman offered by disability studies scholars referred to in section 2.3.1 is a perspective in line with the wider conceptualisation of a social model of disability, i.e. distinguishing between the impairment a person may have and the social disability experienced by individuals as a result of the discriminatory, oppressive or abusive actions, behaviours and attitudes directed at people with an impairment in society (UPIAS, 1975; Oliver, 1983). The disabled people's movement rejected individual, medical and tragedy models of disability, which often included using terms such as 'stigma' for understanding disability, in order to highlight structural oppression. Beresford (2000; 2002) suggests developing a social model of madness and distress to reflect the paradigm shift to the social model in disability studies in the 1980s. However, unlike the earlier disability movement, the 'psychiatric survivor movement', whilst considering structural oppression, considers the stigma of 'mental health problems' as something important to address. This is because the psychiatric label and the

medical/psychiatric model of mental illness are indicted by the survivor movement for being the prime instigator of the stigmatising process; stigma and structural oppression are linked. The notion of stigma can capture "this social repudiation of those identified as suffering from mental distress, something that goes beyond what is usually denoted by terms such as discrimination or injustice" (Tew, 2015:71).

Beresford et al. (2010:14) found that users of mental health services, particularly in Western cultures, perceive public understanding of madness and distress as a deficit deviant model i.e. there is "something wrong" with the individual, usually medical, which is solved by taking medicine. This model is similar to deficit models of disability which view disability as functional loss, impairment (body deficit) and handicap (social loss) (Bury, 1991). However, people's personal understandings of mental health issues don't solely, if at all, involve biological causes but it is affected by, and a response to, broader social and environmental factors (Beresford et al., 2010:16). It has been suggested that a 'bio-psychosocial model' of mental health and illness might provide a more measured way of understanding mental distress, i.e. that biological, psychological and social factors play a role in mental health and illness, which would perhaps lead to more balanced understandings of stigma. However, critics of the model see it as another way of prising people out of what Parsons (1951) describes as their 'sick role,' and, unlike the social model of disability, the bio-psychosocial model targets disabled people and continues to frame them as victims of their own biological, psychological, and social conditions (Jolly, 2012).

Beresford et al. (2010) found that the medical model of 'madness and distress' continues to dominate public and professional understandings, something which service users see as damaging, unhelpful, and from which labelling and stigma ensues. Pilgrim and Tomasini (2012) argue that the social context of 'reasonableness' (e.g. dangerousness, incapacity to make decisions) is key to understanding the ambivalence from both groups and as a result, there is an unwillingness to forge a common identity. Psychiatric survivors don't always want to identify as disabled and disabled people don't always want to include people with psychiatric diagnoses or experiences of mental distress (Beresford et al., 1996; Mulvany, 2000; Beresford, 2015:248). Additionally, those of us experiencing mental distress don't always like the association with disability believing that it would add to the stigma and imply that their "devalued status" is permanent (Beresford et al., 2010:19-20).

More recently there has been a move towards Mad Studies with the publication of *Mad Matters: A Critical Reader in Canadian Mad Studies* (Menzies et al, 2013) which counts disabled people and the disabled people's movement amongst its allies. Mad Studies is a movement connected to activism and change which avoids psychiatric reductionism by rejecting clinical labels and "developing democratic and feasible alternatives to support our

understandings of and responses to madness and distress at both individual and societal levels" (Beresford, 2013:ix). Thus, it is interesting to contemplate the relationship between Mad Studies and Disability Studies; there are certainly similarities in terms of looking to the practices and structures of society as an explanatory framework for inequality and exclusion (also see 2.4. below) as the social model of disability so readily focuses. Particularly as the notion of what we understand as the social model has been expanded by Thomas (2007:43) to include private social oppression:

> Disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.

The psycho-emotional dimension of disablism is particularly pertinent to those of us who experience madness and distress because often, our experience of it is something that can become a 'symptom' of 'mental illness' itself. This is something which is countered by Mad Studies scholars, along with the idea that 'mental illness is an illness like any other' peddled as a way in which to reduce stigma. As Beckman and Davies (2013:54) point out:

> 'Mental illness is an illness like any other.' This brave little slogan has been fighting the stigma of mental illness for eons. Sadly, it hasn't worked and is unlikely ever to because it's not true and everybody knows it. Aside from the fact that mental illness is the only illness for which you can be involuntarily incarcerated, it is obvious to all that something that goes very wrong with your mind falls into a naturally different category from something that goes very wrong with your pancreas.

Beckman and Davies (2013:58) continue to say that unlike gay activists, feminists, and a smaller Mad Pride movement "the great majority of people with mental health labels don't want to celebrate the experience that so defines them." Burstow (2013:79), following Smith (1987; 2005), describes psychiatry as a "regime of ruling" and states the bottom line "as long as the medical model remains hegemonic, as long as the average person believes in "mental illness," we cannot appreciably stem the tide of psychiatry…" From a Mad Studies perspective psychiatry is the instigator of the stigmatising process, and the anti-stigma campaigns, such as those run by Time to Change on the premise of illness or disease are fundamentally flawed, as White and Pike (2013:250) explain:

> The premise of illness or disease acquires its *truth* in part through the remedy of professional diagnosis and treatment. At the same time, the implied truth in the

> premise of illness or disease renders the imperative conclusions (diagnosis, treatment, state intervention) *true.* Such imperatives legitimize the exclusion and subjugation of those so declared as ill, as well as those who might resist dominant models or identities of mental illness… Again the assumption typically is that if the social barriers of stigma are removed, the *natural* inclination for those we consider to be suffering from mental health issues will be to seek professional treatment.

The arguments from an anti-psychiatry, survivor movement, and Mad Studies perspective illuminate the philosophy that whilst stigma reduction may be a policy objective, the means of achieving that objective fall short if institutions such as psychiatry, support services, and mental health policies which inform support and psychiatric services are not interrogated as a stigmatising power. Although interactionist perspectives on stigma are vital for understanding stigma production, context is integral, as is an analysis of the structural context of interactions and a theoretical appraisal of how social structures, often theorised from outside the field of symbolic interactionism, have causal effects on the interactions themselves (Scambler 2006). The next section considers the structural facets of many of the concepts covered in this section which link to notions of 'setting apart', discrimination, and sanism, providing an avenue to explore the notion of 'stigma power' in more depth.

2.4 Discrimination, sanism, and 'stigma power'

As introduced in 2.2.1, in UK law, protection from discrimination is enshrined within the Equality Act 2010. Discrimination means unfair treatment because of who you are with reference to the nine protected characteristics; 'disability' is a protected characteristic and thus it is unlawful under the Act for employers, businesses and organisations providing goods and services, health and care providers, someone you rent or buy a property from, schools and education providers, transport services, and public bodies, to discriminate against you or treat you unfairly as a result of your physical or 'mental impairment.' In terms of how discrimination links to stigma conceptually, Link and Phelan (2001) incorporate wider social structures and discrimination into their understanding of stigma, yet they do not separate stigma from discrimination as a concept. Discrimination is included as a component of, rather than the result of, stigma. According to Link and Phelan (2001) discrimination includes both individual discrimination such as being verbally harassed or physically attacked in public (Read and Baker, 1996), and structural discrimination where institutional practices work to the disadvantage of stigmatised groups, resulting in inequality in areas such as employment, housing, and health (Sayce,

2000; Mental Health Foundation 2000; DRC, 2002; Sainsbury Centre for Mental Health, 2010; LSE, 2012).

Sayce (1998; 2000; 2003) and Thornicroft (2006) seek to promote a paradigm shift which reallocates the focus from concepts of mental health stigma to a framework of discrimination. In doing so, Sayce (2003; 1998) does not deny the importance of delineating stigma to incorporate discrimination or ignore the relevance of stigma to the debate on discrimination. Instead Sayce (1998) argues that studying the concept of stigma alone is limiting and refers to discrimination as a more useful and separate framework on which to base social and structural change. From this perspective stigmatisation is considered as a process by which discrimination is always the result. Concentrating efforts on a model which focuses on discrimination also creates "resonances with other fields where it has already been established that discrimination occurs, and is unethical" (Sayce, 1998:340). Additionally, Sayce (2003:628) questions whether 'stigma' is the best term to use for conceptualising both acts of discrimination and the personal experience of being labelled, stereotyped, or being set apart as different. As Webb (2015:160) argues, discrimination is often "hidden behind" stigma and "it needs to be called by its correct name, which is discrimination." This is a pertinent point for writers such as Chamberlin (1997) who argues that by applying stigma to experiences of madness and distress in any way, even if it does encompass discrimination, is itself stigmatising. This is because it implies that there is still something 'wrong' with an individual, whereas discrimination puts the onus on those who are practising it (Chamberlin, 1997). In subverting stigma in this way, the "mark of shame" would (and perhaps should) reside with the perpetrators of discrimination rather than the individual with a psychiatric diagnosis and/or experiencing mental distress (Sayce, 1998:332).

The framework focusing on discrimination is politically valuable for tackling inequality as it focuses on material and structural change in the form of legislation, education, and social inclusion (Sayce, 2003). From this perspective, parallels may be drawn with the social model in disability studies (Oliver, 1990; Barnes and Mercer, 1997:1-2; Barnes, 2012:19). However, blatant discrimination such as exclusion from employment for which a person has legal redress under the Equality Act 2010 can be more easily identified than subtle forms expressed in negative attitudes or stereotyping (Pettigrew and Meertons, 1995). This highlights the importance of focusing on the day to day lives of people and their experiences in a particular support context- if the focus was on discrimination as "unfair treatment" alone (Sayce, 2000:17) the study may omit subtle nuances where individuals are 'set apart as different'- a key component of stigma.

Sayce is an advocate of shifting the focus from stigma to concentrate on those who are perpetrators of discrimination. However, distrust and fear of madness seems ingrained in public policy and attitudes, and as we have seen in the previous section, often this distrust and fear is related to rationality. Society places a high value on being 'rational' and if a person is not rational, we can mistrust, reject, and exclude an individual (Rogers and Pilgrim, 2010:40). Comparing this with racism or sexism, race and sex aren't 'rational reasons' to exclude a person (although historically there have been supposed 'rational justifications' for prejudice, discrimination, and exclusion on the basis of gender and race, and such discrimination hasn't necessarily been eradicated). However, as a result of the current legal framework surrounding the psychiatric system, people can still be 'legitimately' excluded from society via legal and psychiatric sanction, along with being viewed as being in need of cure or care. As a response to this 'legitimate exclusion', 'sanism' is seen as "a form of systemic discrimination similar to sexism or racism, which targets psychiatric survivors" (Perlin, 1991:92). Sanism is a concept often referred to by Mad Studies scholars and described as being:

> a devastating form of oppression, often leading to negative stereotyping, discrimination, or arguments that Mad individuals are not fit for professional practice or, indeed, for life…sanism also allows for a binary that separates people into a power-up group and a power-down group. The power-up group is assumed to be normal, healthy, and capable. The power-down group is assumed to be sick, disabled, unreliable, and, possibly violent. This factional splitting ensures a lower standard of service for the power-down group and allows the power-up group to judge, reframe, and belittle the power-down group in pathological terms…
> (Poole and Ward, 2013:96-7)

So far in this chapter, it seems that concepts of stigma focus more on micro analyses favoured by phenomenologists and interactionists. Concepts such as discrimination and sanism could be said to focus on macro analyses more associated with structural functional or conflict theory (Scambler, 2002). However, as Scambler suggests:

> A post-individualist and post-Goffman sociology of stigma relations must accept that they are part of a nexus of social structures: and, relatedly, that stigmatization (enacted stigma) is rarely the sole ingredient of the disadvantage... (2011:230)

Link and Phelan's (2001) conceptualisation of stigma attempts to reconcile structural theories of discrimination with interactionist frameworks of stigma. In doing so, they

highlight the importance of a "power context" or "power differential." It is this power context or imbalance which 'allows' stigma to occur. Link and Phelan (2001) don't go much further than this with 'power' yet power is something which is explicit or implicit in all of the concepts considered so far. Thus, it seems it is essential to explore power in more depth, along with its relevance to stigma and the 'stigma/discrimination' debate.

Reflecting on whether stigma and discrimination are "one animal or two", Phelan et al. (2008) identify three ends people attain via stigma. Firstly, exploitation and domination, i.e. keeping people down; secondly, the enforcement of social norms, i.e. keeping people in; and thirdly, the avoidance of disease i.e. keeping people away. According to Phelan et al. (2008) whatever the result, there are always motives lying behind the exercise of stigma, even if the stigmatisers themselves are perhaps not always aware of those motives. Following their work in 2001, Link and Phelan (2014) use a Bourdieusian framework to develop the concept of "stigma power". They argue that "hidden, misrecognized processes serve the interests of stigmatizers and are part of a social system that gets them what they want" (2014:24). This ethos has many parallels with 'self-stigma' considered in 2.3.3 as:

> many of the things people with mental illnesses do to cope with stigma ultimately achieve the goals of stigmatizers by inducing strong efforts to stay "in", "down" or "away." When this happens, persistent, patterned and in this instance hierarchical social relationships between people with mental illness and people without them are created and sustained. (Link and Phelan, 2014:24)

This approach broadly recognises the impact of direct person to person discrimination, structural discrimination, interactional discrimination, and discrimination operating through the stigmatised person. According to Link and Phelan (2014:25), "a person interacting with someone who carries a stigmatized status may behave differently, with hesitance, uncertainty, superiority or even excessive kindness." This highlights why interactions are an essential focus for this study and the importance of considering interactions which do not constitute obvious acts of discrimination. However, Link and Phelan's (2014) concept does not problematise the idea of a stigmatised status or from where that status emanates; it simply takes for granted its existence. Such a conceptualisation assumes little agency on the part of the 'stigmatised person' and leads us to further unanswered questions which are important for this Ph.D. study. In what ways do people resist or negotiate being kept down, in, or away? What role does environments and relationships set up to support individuals play in the 'stigma power' game?

The concept of "stigma power" is introduced by Link and Phelan (2014) as part of a special issue of *Social Science and Medicine* exploring "structural stigma." In the introduction, Hatzenbuehler and Link (2014:2) define structural stigma "as societal level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and well being of the stigmatized." As suggested throughout 2.3, Corrigan et al. (2005:557) also elucidate how stigma may operate via "the policies of private and governmental institutions that restrict the opportunities of stigmatized groups." The special issue builds on the work of Evans-Lacko et al. (2012) which suggests mass anti-stigma campaigns can lead to a "virtuous circle" by disrupting negative feedback engendered by public stigma and can thereby reduce self-stigma. Evans-Lacko et al. (2012) also suggest knowledge, attitudes and behaviour can be improved by facilitating disclosure, social contact and access to care and help. However, it should be noted the work predominantly uses an individualised biomedical model of mental illness, the problems of which were noted in 2.3.4.

Recognising that structures are not unidirectional and static, there is potential scope for linking the macro to the micro (Phelan et al., 2014). In particular, three questions are posed (Hatzenbuehler and Link, 2014:3):

1) Are structural and individual forms of stigma distinct or separate, i.e. is the structural stigma the aggregate effects of one to one discrimination?

2) Is there a synergistic relationship between individual and structural stigma i.e. does structural stigma intensify the impact of individual stigma on health?

3) How do stigmatised individuals respond to, and cope with, structural forms of stigma?

Angermeyer et al. (2014) suggest individual forms of discrimination are distinct processes from structural stigma or discrimination. Pachankis et al. (2014), exploring 'gay related rejection' interacting with structural stigma to predict substance misuse, found that high structural stigma in particular states of the USA was accompanied by elevated rates of alcohol consumption. Pachankis et al. (2014) conclude that this correlation demonstrates structural stigma producing health behaviours. Hansen et al. (2014) examined structural and policy changes in the American welfare system; via ethnographic study they suggest that recent changes have led to the medicalization of poverty i.e. the requirement of a diagnosis of permanent disability or a health condition which warrants an individual

physically disabled in order for them to receive social security payments. In doing so they highlight that the relationship between individual and structural stigma, as Hatzenbuehler and Link (2014:3) observe, is "dynamic, contextual and continually evolving."

Researching unequal access to mental health services, Yang et al. (2014) worked with a group of Fuzhounese immigrants diagnosed with a 'major mental illness' living in New York but who were not entitled to mental health services. They found that they internalised discrimination which reduced their capacity to advocate for change and that those who were able to participate in highly valued cultural activities, particularly paid employment, could resist stigma. Following a similar theme, Richman and Lattanner (2014) suggest that 'low power' encourages a heightened awareness of social threat, with negative effects including carefully controlled decision making and people constraining their own behaviour. In summary of Richman and Lattaner's (2014) work, groups with 'low power' are often found to be inhibited and such inhibition can result in adverse health conditions. What these studies do demonstrate, albeit not very well, is that we need a greater attention to power and status "to generate new understandings of the pathways through which structural stigma affects health" (Hatzenbuehler and Link, 2014:4).

Reflecting on contemporary attempts to reduce 'mental illness stigma', Corrigan and Fong (2014) found that stigmatising behaviour of stigmatisers is better challenged by contact rather than education. They also found that psycho-education and 'cognitive reframes', such as the use of cognitive behavioural therapy, for stigmatised people may not be as effective at reducing self-stigma as the promotion of interventions to encourage disclosure. However, whilst this may be moderately effective, "focusing on how people might eradicate their personal struggle with self-stigma may unintentionally perpetuate the notion that stigma is *their* problem, that it is another sequelae of the illness for which they must be treated" (ibid:112). Targeting stigma reduction at a grassroots level as opposed to population based approaches seems more effective. Finally, increasing knowledge and pity can yield unintended consequences which can result in the undermining of life opportunities of people with a psychiatric diagnosis. Whilst they recognised pity may mean the public are more willing to help, promote legislative changes and movement for greater resources, it was also considered to derive negative effects with a concentration on what a person cannot do, i.e. a 'benevolent stigma' which renders those of us who experience mental distress incompetent (ibid:115). Suggesting that anti-stigma advocates ought to be cautious about appealing to pity, instead they must "cultivate empathy that leads to parity, not to condescension and exaggeration of difference" (ibid:115).

Link and Phelan's (2014) conceptualisation of "stigma power" does provide focus in terms of broadening what we understand as discrimination and for considering nuances

which are less obvious and more interactional. Link and Phelan (2014:30) link this idea of 'stigma power' to macro factors driving stigma processes; 'stigma power' is a factor which (re)creates social structures. It is suggested by Link and Phelan (2014) that to reduce stigma effectively, any structural address must be combined with a transformation in the balance of power between the stigmatised group and the stigmatised. Thus, the literature in this subsection raises key areas of consideration for this study. Support environments potentially provide a space for power balances to be transformed; can the effect of support be construed as a keeping in, down or away, or does it ameliorate this? What acts of resistance against structural stigma occur in these spaces? And can 'stigma power' be subverted?

This recent work on 'stigma power' demonstrates the nuanced nature, not just of stigma, but of power too. As Finkler (2013:236) suggests:

> Psychiatric survivors experience multiple intrusions daily, whether at home, work, or in public spaces. Leaving the asylum does not translate into freedom from oppression. One-dimensional interpretations of sanism focused solely on critiques of state power do not incorporate understanding of such intrusions.

Finkler's comments echo Foucauldian notions of power:

> One impoverishes the issue of power if one poses it solely in terms of legislation and constitution, in terms solely of the state and state apparatus. Power is quite different from and more complicated, dense and pervasive than a set of laws or a state apparatus…power isn't localized in the State apparatus and that nothing in society will change if the mechanisms of power that function outside, below and alongside the State apparatuses, on a much more minute and everyday level, are not also changed.
> (Foucault, 1980:158-60)

There are numerous conceptual understandings and approaches to 'power' (Lukes, 2005) and there is not the space to appraise them here. Although there is a persuasive argument to suggest institutions such as psychiatry and government funded anti-stigma campaigns can contribute to stigma itself, it is clear that power is not a 'zero-sum game'. We know from the literature and research covered in this chapter that stigma and discrimination do not simply emanate from the state or institutions, prescribed policy, or 'top down power'. Foucault's concept of governmentality (Foucault, 1991) explains how power works through

the individual as a normalising force which sees the person acting upon themselves to self-regulate, paralleling many of the arguments relating to self-stigma. According to Turner (1997), Foucault's analysis of power saw:

> Power as a relationship which was localised, dispersed, diffused and typically disguised through the social system, operating at a micro, local and covert level through sets of specific practices. Power is embodied in the day-to-day practices of the medical profession within the clinic, through the activities of social workers, through the mundane decision-making of legal officers and through the religious practices of the church as they operate through such rituals as the confessional.
> (1997:XI-XII).

Power can also be productive and offer ways of being, as Foucault describes:

> If power were never anything put repressive, if it never did anything but say no, do you really think one would be brought to obey it? What makes power hold good, what makes it accepted, is simply the fact that it doesn't only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms of knowledge, produces discourses. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression.
> (Foucault, 1980:119).

The theoretical workings of power within concepts of stigma and discrimination are important to consider and bear in mind but also somewhat tangential and form the wider backdrop to the study. What the discussion demonstrates is that stigma and discrimination can be examined from macro, meso, and micro perspectives (Scambler 2011:235-236). With this in mind, and having considered theoretical frameworks of stigma and discrimination, I will now turn to the literature which specifically considers the relationship between stigma and support.

2.5 Stigma and support

In section 2.2 I reflected on contemporary mental health policy, in particular the objective of reducing the amount of stigmatising and discriminatory encounters people experiencing mental distress are subjected to. This objective was developed in recognition of the notion

that it's not only the 'general public' who stigmatise people who experience mental distress; people providing 'mental health support' are also the perpetrators of stigma and discrimination. In 2.3.4 and 2.4 I explored how psychiatry, an important form of 'support' (or 'treatment') for many people experiencing distress, subscribes to an individualised medical model of mental health which can be stigmatising in itself. As Friedson (1965; 1970) argues, because of the 'powerful' nature of the medical profession, a label of 'mentally ill' can transform public perception of an individual; it is a medical label that is difficult to challenge or remove. Moreover, recent research indicates that over 68% of inpatients on psychiatric wards feel stigmatised by staff and describe instances of discrimination perpetrated by staff (NSUN, 2015). Psychiatrists have acknowledged themselves as perpetrators of stigma (Crisp, 2003) and it has been suggested that the attitude of psychiatrists often mirror negative attitudes of the general public (Chaplin, 2000; Corker, 2001). However, many of us who experience mental distress don't receive 'support' from psychiatry alone; social support is regularly 'contracted out' to be provided by third sector organisations. Schulze (2007) claims mental health professionals also attribute many of the negative and stigmatising stereotypes to service users, and Persis et al. (2008) found that professionals display stigmatising prejudice towards people labelled with 'mental illness'. It is therefore pertinent to explore which elements of the stigma discourse may permeate support environments.

Chamberlin (1978:95) makes an important observation about the provision of support services to people experiencing distress:

> The concept of a service implies the existence of two roles, the server and the served. No matter how much a group may attempt to break down such roles, some residue of them always remains when a group is delivering 'services'.

Furthermore Chamberlin argues (1978:95) that professional supervision can create a dependency pattern which may in turn cause recidivism. Lee (2013) argues that there is a distrust of caregivers and professionals because of the potential for coercion and repression, and that the process of 'recovery' is about ensuring a patient is compliant with 'treatment'- often characterised by patients saying things they know psychiatrists want to hear (Weitz, 1988). Sayce (2000:64-65) reports systemic discrimination within the British mental health system, particularly service users not being taken seriously, experiencing an invalidation of their views, or a reluctance to ask for help for fear of being involuntarily hospitalised. Other research suggests that people who know more about mental health issues are just as discriminatory as those who know less (Wolff et al., 1996).

Thinking about these assertions in relation to concepts of stigma, Goffman would perhaps refer to the staff providing support in the case study organisations as "the wise" (1963:41). The "special situation" i.e. professional role of the staff "has made them intimately privy to the secret life of the stigmatised individual" (the traditionally 'stigmatised individual' being the service users) (Goffman, 1963:42). The implication is that when the "the wise" support the "stigmatized", interactions are not stigmatising. However, many of the aforementioned studies referred to in this section contradict Goffman's premise about 'the wise'. House et al. (1988) suggest individuals can perceive social support, such as the types provided by the case study organisations, as a form of social control emphasising the stigma of dependency created by the sick role (McCourt Perring, 1993). For example, classroom assistants for disabled children were found to amplify differentiation and marginalisation (Holt, 2004). Moreover, there seem to be different levels of support and acceptance by professionals, depending upon diagnosis or behaviour. For example, mental health workers have been found to be paternalistic towards 'psychotic patients' but can mistrust, reject and be suspicious of those diagnosed with a 'personality disorder' (Markham, 2003). These different levels of support and acceptance often relate back to the notion of risk and dangerousness. Whilst informality is cited as being very important in support relationships, there is tension between this informality and 'being professional' and assessing risk:

> 'care practice' is dominated by documentation rather than direct work with service users. The atmosphere of risk and managerialism that now pervades relationships between professionals and people who use services makes certain emotional attributes associated with caring very difficult to achieve.
> (Warner et al., 2012:321).

It is suggested that "the cumulative effect of a risk-averse culture results in an erosion of simple human kindness" (Neuberger, 2005:xii). Thinking about Link and Phelan's (2001;2014) conceptualisations of stigma, the element of power is integral, particularly with reference to how power is necessary for "setting apart" to become stigmatising. "Setting apart" is dependent upon one group, such as support staff, having the 'power' to set another group, such as service users and/or those of us who experience madness and distress, apart as different. Nevertheless, whether "setting apart" is stigmatising in the support context seems dependent upon a number of contributing factors. Examples suggested by the literature may include, staff attributing negative stereotypes to service

users, and treating service users as illnesses or as deviations from the norm from which staff may define themselves.

Whilst there seems to be some evidence that social support may contribute to the stigma cycle, Forrester-Jones and Barnes (2008) claim that social support can play a vital role in assisting individuals experiencing distress to manage a less stigmatising identity than that of "being sick". For example, community support may help forge a more positive identity such as "volunteer" or "artist" or "activist" or "adult learner" or "student" rather than "schizophrenic". Similarly, Scheyett (2005) believes the key to challenging stigma is to adopt an empowering and affirming model of disability, drawing on a "strengths" perspective. To ensure the provision of non-stigmatising support, Burns (2004) suggests that professionals, such as those working at the case study organisations, ought to exhibit personal traits or characteristics such as compassion, enthusiasm, empathy, tolerance and an ability to understand the viewpoints of people they support. The aforementioned points are raised as important issues to explore further during the research, particularly as they pertain to the stigma discourse in the support context and the wider experiences of people experiencing madness and distress.

O'Brien (1990) considered the harm that services themselves can do and also, about what is worth working for in a service or support context. Without prescribing what staff in a support context should *do,* he outlines what they should be working towards, including, community presence, community participation, having valued social roles, making choices, and increasing competence. Practically this includes people not being referred to as patients or clients, choosing whether/when they attend, venues free of stigmatising signs, groups in ordinary places, treated as autonomous individuals, equals etc. A question for this Ph.D. study is how much of this occurs practically in support contexts and what effect does it have on people in relation to stigma and discrimination?

Previous studies stress the importance of a safe space for refuge, social contact and meaningful occupation (Bryant et al., 2011), where people are accepted "without question" (2011:618). However, having this idea of safe space away from mainstream society doesn't sit well with the inclusion agendas promoting integration into mainstream society (Pinfold, 2000; Davidson et al., 2001). It is important that places such as the support environment, or places in which care work is carried out, foster a non-judgmental attitude, where conduct is governed by an unspoken code or 'unconditional regard' (Warner et al., 2012:318-320). However, there is also a danger that we idealise 'affective community spaces' and must recognise that within the informality there is the scope for inequality, i.e. there are favourites, some get more support than others, and situations can arise which may be prevented by a more formal code of ethics (Warner et al., 2012:321).

Holmes (2013) suggests 'Psychology in the Real World' groups bring together people with a shared interest rather than a shared problem, in non-mental health settings, they're not 'skills for ills' groups and there isn't the didactic transference of knowledge. Instead people develop their own way of critiquing the world which is ultimately about formulating different types of social action. Holmes suggests that working in this way can counter the effects of social devaluation and stigma (2013:258-265). In particular, Holmes recognises people become embedded in roles such as 'patient' which limits access to learning the skills necessary to take on more socially valued roles (2013:258) and works with the ethos that if you "treat people badly and they soon learn how to treat themselves badly" (2013:261). In 'Psychology in the Real World' groups, people who haven't had involvement with mental health services mix with those who have; prejudice and stereotypes are challenged this way (Holmes and Gahan, 2007) via informal contact. People go on to provide support to one another which leads to people being less fearful of each other and participants of the groups begin see mental health as being a sliding scale rather than a "them and us" scenario.

It's not only contact between different groups of people which may reduce stigma; the literature suggests peer support is essential. As Shaw (2013:294) points out, we support each other through our own social networks on a day to day basis, the only difference with mental health support is that it's more organised. Shaw (2013) suggests that it needs to be organised and different to support via our ordinary social networks because:

> people with mental health difficulties can feel misunderstood, stigmatised, vulnerable and have low self-worth; this means that it is harder to find people to give and receive peer support from when we really need it. (2013:294)

Shaw (2013) continues by suggesting that peer support groups can lower the sense of stigma and feelings of being marginalised, something which is difficult to do on our own. Ties to a socially defined collection of people was found to be important in the reduction of stigma (Jetton et al., 2001); it is also important that the members of a group consider themselves and the group positive and powerful (Rusch et al., 2009). There was an element of peer support in the organisations I worked with during this study. It isn't simply about the opportunities provided by, and interactions with, the support staff- it is also about members supporting each other in a much more informal basis. How do these interactions impact upon experiences of stigma and discrimination?

Sociological and philosophical critiques of psychiatric care such as those offered by Goffman and Foucault could be said to clearly demonstrate the stigmatising effect of

incarceration. There has been less sociological work carried out on stigma and discrimination in mental health care and support work in what Parr (2000) refers to as "semi-institutional" spaces of care and support such as the case study organisations I worked with. Empirical work has explored interactions in drop-in centres as places of care within a city (Conradson, 2003), café's (Warner et al., 2012) and contemporary inpatient settings which are considered to be places which no longer serve to sever links with the community (Curtis et al., 2009). This brings me to the primary focus of the study: to explore how interactions in third sector support contexts contribute to or mitigate experiences of stigma and discrimination, and how these interactions can shed light upon our conceptual understanding of stigma and discrimination.

2.6 Concluding comments

An overview of the historical developments in mental health 'care' and a critical delineation of the contemporary mental health policy pertaining to stigma and discrimination reduction provide the political landscape within which the study is situated. A critical review of interactionist concepts of stigma led me to consider more recent modified theoretical frameworks which have come to rely less on overt interactional principles in favour of contemplating the structural elements of stigma, discrimination, and sanism; with an emphasis on 'power'. Thus, interactions are of vital importance to the stigma discourse but it is imperative they are considered in context, in terms of both immediate environments and more structural milieu, which take into account power relations and relationships. The concepts I raised for consideration in this chapter provide the initial sociological framework for the study and the theoretical instruments I used to explore the context of third sector organisations providing support to people who experience mental distress.

CHAPTER 3:

Methodology, methods, and ethics

3.1 Introduction: methodology and the importance of 'interaction', 'power', and 'context' in the rationale for research design and method

Literature referred to in Chapter 2 suggests that interactions, structural factors, and notions of 'power' and context, are important conceptual elements for understanding stigma and discrimination relating to experiences of mental distress. Speaking to the theoretical concerns outlined in the previous chapter, methods were selected which would, as far as possible, attempt to capture interactions and take into account relationships imbued with power in support contexts. The rationale being that it is interactions which sustain the social order (Scambler, 2011:220) and as Goffman points out, "to describe the rules regulating a social interaction is to describe its structure" (Goffman, 1967:144). Thus, micro or interactionist conceptual approaches are integral to the stigma discourse and it was imperative that both interactionism and notions of power, particularly regarding relationships between staff and members, were taken into account when selecting appropriate research methods.

Recognising the experience of individuals constituting the 'marginalised' group is fundamental because of the privileged insights they are able to provide relating to this specific research area (Harding, 1993). However, including both groups of people (staff and members) in the project promoted involvement of those who may be considered more powerful (staff) and less powerful (members in receipt of support) in the context of the organisation itself. As a result, it was important to explore the views and experiences of both staff and members of third sector organisations supporting people who experience mental distress (Basset et al., 2006). Furthermore, involving both staff and members also constitutes a response to those who criticise existing work on stigma for focusing on the 'stigmatised' (Fine and Asch, 1988; Sayce, 1998).

The study set out to be exploratory in nature and a multiple methods approach provided an opportunity to speak to the conceptual and theoretical underpinnings of stigma and support. It became important to experience, for myself, interactions with staff and members in the context of the organisations via a case study approach and participant observation. My intention was to imbed myself in the practice of the organisations; practice taken to mean:

> as something that people do in "real" or everyday life. The doings of everyday life are seen as constituting a foundation for social order and institutions. What people do every day to get their work done, in this view, itself constitutes an explanation of social life, and it enjoys full explanatory status, substituting…for theories, explanations, norms or ideologies. (Miettinen et al., 2009:1313).

It was essential to ask both staff and members about their experiences in their own words both in interview, and less formally during my time attending the organisations. Exploring and promoting interactions and conversations between members and staff around the research area via focus groups also helped provide further insight.

It was imperative to hear from participants about their experiences in their own words and in a way which would embed individuals within the theoretical debate (Cresswell, 2005; Pembroke and Hadfield, 2010) in the socio-political context of an organisation providing support; acknowledging criticism from those who accuse Goffman and interactionist approaches to understanding social life of 'methodological localism' (Gouldner, 1971:390). Selecting a qualitative and exploratory method such as interviews, focus groups, and participant observation, provided scope and space to explore new insights into the experience, voices and understanding of those taking part in an organisation or project (Rose et al., 2010). As a result I wanted to employ methods of exploration which took into account institutions (in this case mental health support services) and their socio-political context, along with the individual actors (staff and members) and their interactions. Such an approach brings to the forefront the voice of a historically marginalised group and incorporating the rationale that:

> people with mental health problems should also be understood as creative actors, often capable of resistance, self- and collective empowerment and determination in the diverse spacings of madness, illness and mental health care…
> (Parr, 2008:12)

This chapter continues by delineating how I developed research questions in response to the theoretical underpinnings of stigma, discrimination, and the support environment. I then discuss the case study approach to the project, introduce the organisations involved, and the methods I employed (participant observation, interviews, and focus groups), along with how the selected methods interacted with each other to produce rich empirical material for analysis. Finally in this chapter I reflect on my own position as a researcher, how I undertook analysis and approached ethical concerns. I conclude by explaining how

the findings will be/are being disseminated, and reflecting on the research journey along with particular challenges I experienced.

3.2 Research Questions

Before formulating a set of research questions it was necessary to consider what had been asked before, and how those questions had been posed and explored. In 2006, Van Brakel conducted a review of 63 papers and distinguished between five foci and approaches to the measurement of 'mental illness stigma' which may be paraphrased as:

> 1) surveys of attitudes to people with certain health conditions, using samples of the general public;
>
> 2) assessments or audits of discriminatory and stigmatizing practice like in community, in healthcare work, media, education etc;
>
> 3) interviews with people affected by a condition about their experience of stigma and/or discrimination;
>
> 4) interviews with those affected by certain conditions about perceived or felt stigma; and
>
> 5) interviews with those affected by certain conditions about self or internalized feelings of stigma.

Although studies of stigma, particularly relating to mental distress, have been popular and experienced resurgence in the current political climate concerned with its reduction, the methods employed usually involve the collection and analysis of quantitative data and/or the reliance on basic interviews or questionnaires as illustrated by Van Brakel's (2006) literature review. Such approaches can be somewhat individualistic, and missing cultural and interactional elements identified as important in Chapter 2. Thus, the combination of methods I have selected, along with the case study approach, is what makes this empirical study on stigma and discrimination relating to mental distress and support original.

I set out with the overall aim of exploring, with the participants at each organisation involved in the study, how they have experienced stigma, interactions which may make the environment supportive as opposed to stigmatising, and how interactions may contribute to feelings of stigma, reduce or mitigate stigma, and/or reduce or mitigate the effects of stigma and discrimination. To do this I developed the following four research questions:

1) How are stigma and discrimination identified, defined and experienced by people who experience or have experienced mental distress and also receive support from third sector organisations?

2) What is the impact of stigma on experiences of support provided by third sector organisations?

3) How do support and the relationships within the support environment impact on stigma and how might this support help reduce/mitigate the impact of stigma and discrimination?

4) What recommendations, if any, can be made for policy makers and practitioners to mitigate the negative effects of stigma and prevent discrimination?

The remainder of this chapter looks at the methods I employed to answer these questions and my reflections on that journey. Discussion relating to *how* the selected methods speak to theoretical cornerstones of the stigma discourse is revisited in more depth in the following sections.

3.3 Case study approach, the organisations and their 'socio-political location'

3.3.1 The organisations

The ethos behind selecting two case study organisations was to provide examples rather than generalisations, using the same rationale at each organisation to explore issues of wider significance relating to mental distress, stigma, discrimination and support. Following Bryman (2008:53) the case study organisations were the focus of interest in their own right. Each organisation was selected to portray two single settings or contexts with the aim of contributing to existing knowledge (Simons, 2009:24) on stigma, discrimination, mental distress and the support environment. The case studies in this project are not necessarily presented as "representative or typical cases" because the objective in such cases is "to capture the circumstances and conditions of a common place situation" (Yin, 2003:41). Instead, a case study approach provided me with the opportunity to focus on key social processes relating to stigma, discrimination, mental distress and support, informed by the theoretical context (Chapter 2 and 3.1). Selecting two case study organisations was both a practical way of 'framing' the research and also a method by which interactions, power dynamics and the experiences of individuals could be considered

in context. As the link between wider political and structural understandings of stigma, and the interactionist approach to stigma was of key concern, I used a case study approach to form what May (2011:225-6) describes as a "contextualist position" to "forge a middle ground between generalization and particularization." Thus, the organisations formed the boundaries and contexts within which the research methods were employed and the empirical material collected. Whilst I did not purposely select contrasting case studies, diversity of involvement was considered in the recruitment stage (3.4). Rather than setting out to compare the two organisations in the study, I approached the fieldwork looking for similarities and appreciating difference.

I considered the case study organisations to be an interface where the structural and the interactional somewhat 'converge'. For example, participants brought their lived experience, including more structural experiences of stigma, discrimination and being treated differently, to the organisation (which was a social structure in itself and influenced by socio-political concerns considered later in this section in 3.3.4) where they experience relationships of support and are party to interactions with others. Furthermore, the two organisations and the staff are enmeshed in mental health policy, their own organisational policy, and performed a professional role which they occupied to interact with members. It is therefore important to look more closely at the 'set up' and context of both case study organisations using the pseudonyms of 'Bright Futures' and 'Creative Mindz'.

3.3.2 Bright Futures

Bright Futures is a service which is run by, and is part of, a regional registered charity. The Bright Futures service is based in a city centre in the North East of England supporting adults who experience mental distress to develop their skills, confidence and self-belief. The service is jointly funded by the local Clinical Commissioning Group (CCG)[3] and the local authority. In terms of staffing, there is a service manager, a deputy manager, and around five link-workers who work directly with members. Bright Futures also have one or two student social workers on placement at any one time and around four sessional volunteers. Most referrals to the organisation come from mental health professionals, social workers and GPs, but self-referrals are also accepted. On referral a member is allocated a link-worker who supports them to identify activities/groups they are interested in pursuing and provide ongoing support for them to take part. Staff also work with members to identify other opportunities outside of the Bright Futures environment e.g. Open University, volunteering placements etc. Members are not charged any fee to attend the service and

[3] CCGs are NHS organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in England.

may participate in a range of activities including learning work related skills e.g. computer training and CV building; training and education courses e.g. food hygiene, literacy, numeracy and mental health first aid; therapeutic groups e.g. hearing voices; and community activities e.g. photography, fishing and other social groups. Many of the groups and activities take place in public spaces whilst others are held in various rooms on the Bright Futures office-like premises. Although members are welcomed into the building for a particular activity, group, meeting with their link-worker, or to use the computers, it isn't a social space for members to simply drop by and 'hang out' with staff and/or other members. Bright Futures must report to their funders on a number of outcomes including, members who continue with activities independently after using the service, those continuing with education/training, people in voluntary work, and people in employment or work related activity.

3.3.3 Creative Mindz

Creative Mindz is also a registered charity and also based in a city centre in the North East. The bulk of their funding is provided by the Big Lottery Fund to deliver creative based services and run an art studio for those who experience or have experienced mental distress. The service Creative Mindz provides includes an art studio, music group, ceramics, puppet making group, debating group and a creative writing group. In terms of paid staff, Creative Mindz has a studio manager, a deputy manager and an involvement officer. There are also around five paid sessional artists and four volunteers who assist with general support and/or deliver creative sessions. Unlike the set-up of Bright Futures, members of Creative Mindz do attend the studio to socialise with other members and/or get on with their own art work; they don't have to be attending a particular session or group. Most referrals come from mental health professionals and social workers but members can join without a referral. It is usual practice for prospective members to be given a tour of the studio by a member of staff, often accompanied by the referring mental health professional. Once they sign up as a member, they can come along to use the facilities and join in with the groups whenever they please. There is a daily fee of £22 for attending the studio which can be paid for out of a member's personal budget[4] or direct payment; attendance is incentivised and so the daily fee is reduced the more times a member attends. If a member does not have a personal budget and provides supporting documentation from a GP or mental health professional, their membership can be subsidised by grant funding. A subsidised member pays £10 for each 4 week period of

[4] A 'personal budget' is a sum of money allocated to a person from the local authority as a result of an assessment of social care needs.

membership and during that time they can attend as little or as much as they choose. Creative Mindz are required to report on the following outcomes to their funders: developing independence by learning new skills, knowledge and the development of employment/education/volunteering opportunities, members demonstrating ability to manage their mental health, developing self-confidence, and independence.

3.3.4 "Shadow state" organisations?

Typically both organisations fall within what Wolch (1990) describes as the "shadow state" i.e. a third sector providing the sort of health, welfare and social care objectives once provided by the state (Billis, 2010:9-10). Such "semi-institutional spaces" are common in contemporary health care and welfare provision (Parr, 2000), and Billis (2010) describes organisations such as Bright Futures and Creative Mindz as 'hybrid organisations'. For example, Bright Futures is directly funded by government contracts and could be said to provide "public services" (Harris, 2010:29) or be a "public sector spin-off" (Cornforth and Spear, 2010:83-4). Creative Mindz, although funded by a Big Lottery grant, provides the services once provided by the NHS funded art therapy room in a local psychiatric hospital. Literature suggests that this "mixed economy of welfare approach" is based on the premise of enhancing individual choice (Oliver and Barnes, 2012:134) with the by-product of blurring lines between the public, private and third sector, and formal and informal 'care' (Glendinning et al., 2000).

Both organisations receive referrals from similar 'types' of professionals such as GPs, CPNs, psychiatrists, social workers and occupational therapists, and the emphasis on the services they provide is less about therapy and more about learning new skills and activities. The outcomes both organisations are funded to provide relate to employment, volunteering and education, along with independence and confidence. These goals are directly reflective of mental health policy which centres on the notion that 'recovery' from mental ill health as indicated by:

> greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live…
> (Dept. of Health, 2011a:6).

When I first approached the staff at Bright Futures and Creative Mindz about being involved in this research project, I asked them whether they thought their organisations had any role in reducing or mitigating mental health stigma and/or discrimination and/or its effects. Both organisations explained that tackling stigma and discrimination and its

effects was within the general remit of their work. This response formed part of the rationale for inviting them to take part in the study, as it suggested to me that they subscribed to the idea propagated by policy that mental health, particularly tackling stigma and discrimination, was "everybody's business" (Dept. of Health, 2014:35).

A difference to emphasise at the outset is that Creative Mindz is much more of a 'building based' service, whilst Bright Futures operates outside of its building base as much as it can. There has been a move away from building based services, particularly day centres, in the name of personalisation throughout all social care services (e.g. Dept. of Health, 2010). The ethos behind this was to discontinue the 'one size fits all' approach offered by a welfare state of yesteryear which was not 'person centred' (Duffy, 2010:7). Neither Creative Mindz nor Bright Futures is a day service/centre per se but it should be noted that Bright Futures used to run a day centre on their old premises and the manager informed me that at the new premises they are trying to move away from its legacy and encourage as many activities as possible outside of the physical building and in public social spaces such as galleries, coffee shops, etc. Creative Mindz began to provide their service when the art therapy room was closing down at a local psychiatric hospital; many of the staff at Creative Mindz had worked at the art therapy room and encouraged patients to come along to Creative Mindz studio when the art room closed. Attendance at the studio is still encouraged and there is less emphasis of doing things outside of the building base; although there are regular excursions to the local beach, galleries, exhibitions etc., it was less of a focus for Creative Mindz.

From a sociological perspective Martin et al (2015) highlight how sociologists of health and illness have largely overlooked the role of buildings in health care. Although buildings and space are not a focus of this study per se, following Martin et al (2015) the rationale for delivering services outside of a building-base seemed to feed into the rationale that members of Bright Futures ought not to become dependent on a particular building and thus contributed to members becoming "responsibilised citizens." Furthermore, exploring the differences in spatial contexts in relation to how the support environment is shaped, and the power dynamic within that context, was a key difference between the two case study organisations and discussed further throughout the findings chapters.

The research questions were exploratory in nature which suggested I required a multiple methods approach which was flexible enough to investigate any social phenomena at play. Whilst I have established the rationale for a case study approach as providing an important context to explore stigma and discrimination, and introduced the organisations and their 'place' in the socio-political climate, it was important that the methods I

employed at each organisation were flexible to enough to capture the subjective experience of the people participating in, and working at, Bright Futures and Creative Mindz. For example, exploring how participants made sense of the relationships at the organisations, how experiences outside of the organisation impacted on their thoughts and feelings, and how I experienced some of those interactions and 'being' at the organisations. For this I selected three qualitative research methods; participant observation, semi-structured interviews, and focus groups, which:

> are particularly suited for exploring subjective views on an issue. They put the subject and its perception of the world at the centre of their attention. The lived experiences of those studied or their accounts of it serve as the basis for data analysis.
> (Schulze and Angermeyer, 2003:301).

Before I go on to explain and justify the use of these methods I will discuss how Bright Futures and Creative Mindz were recruited to the project, the rationale for their recruitment, and how I recruited participants within each organisation.

3.4 Recruitment of, and within, Bright Futures and Creative Mindz

The North East of England presented a critical focus for and backdrop to the study because of its high rate of people reporting mental distress (see Mental Health Matters, 2013; North East Public Health Observatory, 2013; ONS, 2013). That said, the rationale for recruiting organisations in the North East also involved a certain degree of practical convenience given it is where my institution is located and I also live, and have worked, in the North East of England.

I initially undertook a purposive sampling strategy via the local Council for Voluntary Service where most charities are registered. Using their search engine, I searched for organisations providing "mental health services" in a selected city in the North East. Twenty three organisations were identified in the search results and, having worked in the sector for many years, I pragmatically relied on my existing professional networks to approach and access a number of possible organisations (Payne and Williams, 2005). I did contact some organisations I hadn't worked with and who I was not known to in a professional capacity, but they didn't get back to me.

I began individual meetings and negotiations with five prospective organisations in early April 2013 which, in our initial conversations over the telephone and via e-mail, I

identified broadly worked towards reducing or mitigating the effects of mental health stigma and discrimination. These five organisations provided a range of services from supporting people via creative services, physical health, advocacy, skills development, therapy groups and service user groups. Thus, diversity was a consideration when selecting case study organisations in terms of the services they provide. Following initial conversations three organisations, including Bright Futures and Creative Mindz, were interested and enthusiastic about being involved in the project. After discussion with my supervisory team, selecting three organisations was considered to involve too much work for a Ph.D. project and it was agreed I would select two organisations to work with. It was with regret that I had to refuse a service user group's involvement in the study but this was done on the basis of practical convenience of when they could host me and when I was available to conduct the fieldwork which I wanted to carry out sooner rather than later. After outlining my research proposal to both organisations, I obtained authority from the respective service managers at Bright Futures and Creative Mindz. This ensured I was authorised to collect data via participant observation and to recruit participants to the focus groups and interviews from their members and staff (see Appendix I).

Recruitment of individual participants for interviews and focus groups at each organisation was also purposive. The manager of each organisation circulated the staff invitation to participate via e-mail (see Appendix III) and staff put up copies of my invitation to participate/information sheet on notice boards (see Appendix II) and circulated copies via e-mail to members. I was clear that staff members were not to advocate participation in the study and simply informed members of the opportunity to participate. In practise I did get some queries from members and staff about being involved in the interviews and group work, but it was only when I began to attend the organisation to participate in the groups and sessions (see 3.5) that most participants expressed more interest in the study. I ensured that when I first began attending each organisation I explained why I was there and handed out information sheets to ensure participants were aware of the study and they could participate voluntarily. This worked well, no one objected to me observing (although they were given this option, see 3.5) and I was able to interview everyone who expressed an interest in being involved and could also accommodate their involvement in the focus group work.

In terms of the diversity of the participants I recruited to the interviews and focus groups my sample was, as far as possible, reflective of the demographic (in terms of age, gender, and ethnicity) of the staff and member population. The demographic of participants in the focus groups and interviews is detailed in the table on the next page.

Name (pseudonym) of participant	**Organisation:** Bright Futures (BF) or Creative Mindz (CM)	**Status:** Member (M) or Staff (S)	**Gender:** Female (F) or Male (M)	**Age**	**Ethnicity**
Aaron	CM	M	M	20s	White European
Abdul	BF	M	M	20s	Bangladeshi
Amanda	BF	M	F	20s	White European
Bethany	CM	S	F	20s	White European
Carl	BF	M	M	40s	White European
Daniel	CM	S	M	40s	White European
Dave	BF	S	M	40s	White European
Deborah	BF	S	F	50s	White European
Derek	CM	M	M	70s	White European
Faye	BF	S	F	40s	White European
Felicity	CM	M	F	50s	White European
Grace	CM	M	F	50s	White European
Graham	BF	M	M	40s	White European
Greg	CM	S	M	20s	White European
Ian	BF	M	M	20s	White European
Jake	CM	S	M	40s	White European
Jane	BF	M	F	20s	White European
John	BF	M	M	30s	White European
Kathy	BF	M	F	50s	White European
Keith	CM	M	M	50s	White European
Linda	BF	M	F	50s	White European
Lucy	BF	S	F	20s	White European
Maria	BF	M	F	40s	White European
Nicola	CM	S	F	20s	White European
Owen	CM	M	M	50s	White European
Patricia	CM	M	F	50s	White European
Peter	CM	S	M	30s	White European
Sarah	BF	M	F	40s	White European
Sid	CM	M	M	70s	White European
Steve	BF	S	M	40s	White European
Stevie	CM	M	F	40s	White European
Stewart	CM	M	M	40s	White European
Susan	CM	S	F	30s	White European
Thomas	CM	M	M	50s	White European
Yvonne	BF	M	F	40s	White European

I was able to interview all of the permanent three members of staff at Creative Mindz who were all White European, between the ages of 21 and 50, and male. I also interviewed three out of the six sessional artists who were all White European, two of who were female and the other male between the ages of 21 and 35. At Bright Futures I interviewed five out of ten staff; two male and three female between the ages of 25 and 50. Most members at

both organisations were White European[5] and above the age of 35 with an approximately equal ratio of male to female members. Thus, most of the members participating in the focus groups and interviews were White European, 18 were male and 17 female.

3.5 Participant observation

Participant observation is a method rooted in anthropology and ethnography; understanding ethnography as "the attempt to understand another life world using the self- or as much of it as possible- as the instrument of knowing" (Ortner, 1995:173). Ethnography focuses on the "meaning, functions and consequences of human actions and institutional practices, and how these are implicated in local, and perhaps also wider, contexts" (Hammersley and Atkinson, 2007:3). Participant observation has been employed in the past to explore mental health and mental distress, for example, in exploring the use of community treatment orders as a form of "policy ethnography" (Jobling, 2014). I used participant observation to try to "build a picture of the lifeworld of those being observed and an understanding of the way they ordinarily go about their everyday activities" (Stringer, 2007:75). Whilst participants' "everyday activities" are not the focus of my study per se, how stigma and discrimination may impact upon and influence them are, along with exploring the interactions which take place in the support environment. Thus I spent around 12 weeks at each organisation attending different sessions for the equivalent of three days each week. During this time I also conducted interviews (see 3.6) and focus groups (see 3.7). Practically speaking, participant observation also enabled me to develop relationships with participants and as a result they became involved in the interviews and focus group work.

Observing and participating in the sessions at the organisations and spending time at each organisation afforded me the opportunity to observe and experience interactions in context; both interactions between members, and between staff and members. Participant observation enabled me to gain a deeper understanding of the perspectives of participants (Becker and Greer, 1957) and I experienced first-hand how meaning may be constructed in the interactions within the organisation; experiences which were considered alongside the interview and focus group material. Moreover, participant observation provided me with an opportunity to problematise interview data and cross reference my

[5] It was surprising that more BME groups were not represented as members and staff in each of the organisations given the high representation of BME groups as recipients of psychiatric services, particularly in secure mental health settings (Mind, 2009). I spoke to the managers at the respective case study organisations and they reported that many BME groups attend dedicated BME services in the City and thus, they were not well represented in the services provided by the case study organisations.

observations during interviews (Snow and Anderson, 1987; and for example see Ortner, 2003). For example, when I observed an interaction I inevitably drew conclusions about what had gone on and the effect of the interactions; during the interview I was able to ask the participant outright about the effect of something that had happened. Furthermore, involving more people in participant observation also helped to ensure as far as possible that exclusions and barriers are not reinforced (Beresford, 2007a; 2007b); this is particularly pertinent to researching stigma and discrimination and speaks to theoretical concerns regarding 'power.' I also employed participant observation with the intention to involve and engage more people in the research than I was practically able to in the focus groups and interviews.

To ensure, as far as possible, participants were consenting to my presence, I introduced myself and my area of study to members at members' meetings at each organisation before each period of fieldwork. I also introduced myself to the staff team at a full staff meeting before I carried out the fieldwork. This provided potential participants with an opportunity to ask me questions, and gave them some time to consider whether they might object to my presence over the three months which would follow. Additionally, before the beginning of each session I observed and/or participated in, I introduced myself and my work to any members I had not met before and asked their permission for me to be there. I did not encounter any objections to my presence but I often encountered many questions at the beginning of each new session I participated in. The questions frequently related to the research itself, and many participants wanted to know more about the topic of 'stigma' and/or were keen to provide me with their contact details so that they could be involved in the interviews and/or focus groups.

My role at the organisation was overt and I saw my position as a mixture of 'participant-as-observer' (when everyone was aware of my research and I was engaged in regular interaction at the organisations), and 'observer-as-participant' which involved more observation rather than participation (Gold, 1958). I relied on my preliminary encounters over the first fortnight to build a strong rapport with staff and members during my time at each organisation. My role certainly changed throughout the research process (Gans, 1968) and at varying points in the research I was engaged as 'total participant', 'researcher participant' and 'total researcher'. My role also changed between active and passive. For example, in situations at Bright Futures such as the hearing voice group I observed and said very little, yet in the group making a DVD I was invited into the discussion and contributed much more actively. There were also situations in which I 'helped out'; for example in one particular members' meeting at Creative Mindz I was asked to assist chairing the discussion. The 'effect' of me being present at the organisation also changed throughout

my time at each organisation. To begin with I was careful to consider the effect of me observing sessions and being present at the organisations (Patton, 1999:1201-5) and what are considered 'observer effects' changed throughout my time at each organisation. For example, when I first joined a particular group such as hearing voices, creative writing groups etc. and I introduced myself, staff and members often asked me a lot of questions about the research. As we interacted in the group and worked on various activities over the weeks we got to know one another, and the atmosphere became more relaxed as participants got used to me being there. As a result we chatted much more informally, exchanged stories about ourselves and developed relationships which gave me greater insight into the lives and experiences of staff and members. I consider this, and the effect exchanging stories might have had on the data collected, in more depth in 3.9.

At the end of each day I typed up my fieldnotes in Word documents which were later entered into Nvivo (ver.10) (see 3.10). Depending on what was going on each day and what I was taking part in, I had some opportunity to write things down in my note book during the day. However this depended on the social acceptability of doing so. For example, making notes in a situation such as the hearing voices group where all the participants knew my purpose and in which I observed, rather than participated, seemed acceptable. However, writing things down when I had a personal one-to-one conversation with someone about an experience of child abuse when I had been in the field a while felt insensitive and so I waited until lunchtime to record the encounter along with my thoughts and feelings in my notebook (Emerson et al., 1995:19-26); for an example of a similar discussion see Atkinson (1981:131-2). I tried to record my encounters in as much detail as possible because I did not know what may or may not turn out to be unexpectedly important (Tjora, 2006:433).

3.6 Semi-structured interviews

Semi-structured interviews were selected in order to promote opportunities for participants to make connections between actions, interactions, feelings and beliefs; all important elements of the stigma discourse. The interview centred on participants' life-world to explore the meaning and experience of stigma and discrimination from their perspective (Kvale, 1983). Although the interview schedules for members and staff differed (Appendix V and VI), each interview provided the opportunity to ask participants directly about their thoughts and experiences, and (re)construct and interpret their experiences and behaviour. In doing so my aim was to gain insight into the experience of wider social structures, such as the staff/member relationship which involves a power

dynamic which may produce or perhaps mitigate stigma and discrimination. Furthermore, semi-structured interviews allowed me to pursue topics participants felt were applicable and interesting to them (Leidner, 1993:238) and develop new areas of enquiry (Oka and Shaw, 2000) whilst using my own position as researcher to steer the discussion (Davies, 2000:91). In practise this meant we explored experiences of employment, claiming welfare benefits, other mental health support services and family life etc., and topics which became significant such as 'self-stigma', relationships in the support environment and the way support was 'performed' or 'enacted'.

A purpose of the interviews was to assist me to understand how people define and assign different meanings to the terms 'stigma' and 'discrimination' (Sahin, 2006). Therefore I elicited participants' personal definitions in an attempt to understand what they meant to each participant by exploring examples from their experience. Thus, the meaning of 'stigma' and 'discrimination' was developed during the interaction of the interview process (Arnd-Caddigan and Pozzuto, 2006). I considered whether participants should be informed that we would specifically discuss stigma and discrimination but as the exploration of stigma and discrimination is 'nested' within the exploration of the experience of mental distress I felt there was no requirement to be more detailed than that. This guarded against anyone coming to the interview with a 'model definition' of stigma and discrimination prepared. However, to mitigate any distress or difficulty participants may have experienced when asked to articulate a definition of stigma or discrimination, I had a 'working definition' to hand for the interview. I didn't need to use this definition, and rather than it be my own overriding definition, its purpose was simply to ensure participants who were unable to think of a definition or what stigma and discrimination meant to them didn't feel uncomfortable in the interview. We then moved on to explore how or whether experiences participants cited as stigmatising and/or discriminatory impacted on the support context, and how or whether support affected the lives of members beyond Bright Futures and Creative Mindz.

The research topic may be considered 'sensitive' (Renzetti and Lee, 1993:5) because I was asking participants, particularly member participants, to talk about experiences which may bring back negative emotions about being treated badly, along with recalling experiences of distress more generally. For this reason it was important that the interview process was collaborative, diminished of hierarchical power as far as possible, and built upon rapport and reciprocity (Oakley, 1981). To build rapport I drew on my professional experience to attempt to make participants feel comfortable. As most participants I had interviewed had met me at sessions and groups, it made rapport building easier. I was transparent throughout the research process, answered any questions

participants asked and provided the opportunity for participants to ask me questions. I was particularly keen, given the importance of power and labels in the stigma discourse, to ensure that participants were supported as unique individuals and not as illnesses (BASW, 2012:8). Following this principle I did not ask member participants to disclose their diagnosis (although it frequently came up in conversation) as literature suggests stigma and discrimination is often attached to psychiatric diagnoses (see Chapter 2). This method has much in common with social care values in terms of respect and acknowledging worth and dignity (Gilgun and Abrams, 2002).

Practically speaking I exercised caution in the over-use of general questions to avoid going 'off track' and only used them as introductory enquiries or to contextualise more specific questions (Mason, 2002). Nevertheless, I relied on the notion that "interviewees frequently know that they are expected to be expansive in their answers", (Bryman, 2008:44) and they have selected to take part in interviews because they have something to say. There were two interview schedules (see Appendices V and VI) which were slightly different for staff and members. For example, members were encouraged to explore experiences where they may have been treated differently as a result of experiences of mental distress. Conversely, staff member participants were asked to reflect on occasions when members may have been treated differently with an emphasis on their own actions and observations. I wanted the interview format to be loose and conversational. However the interview schedules I drafted (see Appendices V and VI) served as prompts for me as they related to theoretical concerns which I had attempted to operationalise as interview questions. Thus, when I came to conduct the interviews I focused on more practical questions and the participants' everyday lives which could be considered an "open-questioning technique" drawing on the schedule to structure the accounts (Rickard and Purtell, 2013:28). Interviews tended to follow an iterative approach of refinement (Beardsworth and Keil, 1992:261-2) where lines of thought were followed and there was scope to be reflexive during interviews and between sessions of fieldwork.

I conducted 10 interviews with members at each organisation (20 in total) and 5 interviews with staff members at each organisation (10 in total). Each interview lasted between 50-90 minutes and was digitally recorded. As mentioned in 3.4 I carried out the interviews whilst I was spending time at the organisations participating and observing which meant it was more convenient to arrange interviews and for prospective participants to ask me about being involved. I obtained written consent from participants at the beginning of each interview, talked them through the consent form (Appendix IV), and asked them to sign the bottom confirming that they understood. After the recorder was turned off, one or two participants disclosed a different story or an account which I was

able to note down which served to problematise my interview material. Whilst I wasn't able to record this verbatim, I was able to write this up in my field notes immediately after the interview ended (Parker, 2000:236). To do this ethically, I explained to the participant that what they had said was interesting and asked permission to note it down.

Interviews can be viewed as a one off event and considered intrusive. Asking participants to recall events and feelings some may suggest I am relying on the memory of participants which is not 'trustworthy' and will therefore yield inaccurate results. However, respecting each person's experience and 'different expertises' considers each participant's account 'real'. I also acknowledge that "respecting the diversity of madness experiences often requires making room for perspectives that are disconcerting to our own sensibilities" (Hornstein, 2013:36). My research is not about assessing the accuracy of what has been stated e.g. whether stigmatisation or discrimination *actually* occurred. Instead I focus on the interview as "a vehicle of identity construction" (Yanos and Hopper, 2006:233) and an opportunity for participants to interpret experiences. Both the focus group work (see 3.7) and individual interviews allowed me to create an opportunity to develop meaning via interaction. In doing so I accepted that equivalence cannot always be constructed (Mills et al.., 2006). Nevertheless, the data remains 'factual' despite the fact it is malleable and cannot be rendered statistically.

Semi-structured interviews were useful because I was able address the research questions in a straight forward way and ask participants directly about their experiences. However, the interview itself could be considered "unusual" because "interviewees are forced to speak about specific things they might not have raised had they been asked about them openly in everyday situations." (Barlosius and Philipps, 2015:14). Thus, for exploring everyday routines and to gain other perspectives on interactions and power in the support environment I felt it was integral to the study to observe participants in context and experience the environment for myself to gain greater insight (see 3.5).

3.7 Focus groups

Focus groups rely on the explicit use of group interaction to provide insights on particular topics which would be less accessible without this interaction (Morgan, 1997:2). I have already highlighted the relevance of interactionist concepts in my research and therefore focus groups seemed an appropriate method to explore. Morgan (1996:131) explains the rationale for selecting focus groups:

> First, it clearly states that focus groups are a research method devoted to data collection. Second, it locates the interaction in a group discussion as the source of

> the data. Third, it acknowledges the researcher's active role in creating the group discussion for data collection purposes.

Focus groups are often used in the sociology of health and illness as a common research method (Schulze and Angermeyer, 2003:301). Particularly in situations where participants may find individual interviews intimidating (Morgan, 1997). This was a particularly important consideration given the potentially emotive and sensitive topic of my research; for an example of using focus groups for a similar sensitive topic see Cohen and Taylor (1972). Following Schulze and Angermeyer (2003:301), this study sought to:

> place those who experience stigma and discrimination in their everyday lives in the role of experts whose knowledge and experience is essential to advancing the theoretical discussion on stigma. In addition, focus groups create multiple lines of communication and thus offer participants a safe environment where they can share experiences, ideas and beliefs in the company of people which have a central element of their experience in common.

I held three focus groups at each organisation which included a small number of staff and member participants (no more than 8 participants in each group) where I defined the topic and issue for discussion in each one (Cameron, 2005). Staff members were not invited to the first group because we were creating a character of a member with experience of mental distress to be used again in the remaining focus groups where up to two staff members would be present. The rationale was that members would take the lead on character construction and would 'own it', and so staff weren't be present in the first group. Addressing group composition in the subsequent two groups was important and I considered whether I simply involved members with the rationale that member participants would be more honest, open and 'freer' to say things they may not say if staff were present. However, as a result of my interest in the dynamic of 'power' in the stigma discourse, along with interactions, it seemed more appropriate to include a small number of staff members. Furthermore, the approach of involving staff builds on the principles of learning together and strengthening relationships.

The activities within each group were carefully planned (see Appendix VII) and based on a fictional composite character created by member participants in the first focus group. Primarily, this was so participants didn't feel as though they had to share personal experiences if they didn't want to or felt uncomfortable doing so. It is important to note the necessity of a 'safe environment' and the group work also helped foster a space, and perhaps a stronger sense of agency, for members to explore, clarify and construct their

own views, using their own vocabulary and pursuing their own priorities (Kitzinger, 1995:299). We all sat in a circle or square around a table to ensure maximum interaction and engagement. To contribute to the safety of the space we discussed and set ground rules at the beginning and made it clear that everyone should have the opportunity to express their opinion, leave the room if they would like, and be respectful of others. As facilitator I ensured each person had a chance to talk, kept discussion relatively focussed and explained what will happen after each focus group (Stringer, 2007:74-75). Explaining confidentiality, safeguarding and informing participants of the chance to withdraw at any time was of vital importance and I did this both as I was recruiting participants and at the beginning of each group. Participants were given an information sheet (Appendices II and III) to keep before the session so they could spend some time thinking whether they want to take part and signed a consent form at the beginning of each group (Appendix IV). There was further consideration to ensure that the composite characters were not developed to resemble an individual member in the focus group itself or the organisation more widely. Firstly, this would defeat the object of the exercise in terms of drawing from each participant's experiences. Secondly, it would run the risk of persecuting and/or 'setting apart' a particular member. Whilst the characters the participants built did not resemble one particular member, it was important to be aware of this eventuality from an ethical perspective.

The aim of the first focus group was to create a character with personal experience of mental distress and who was a member of the organisation to be used again in the remaining focus groups. Participants gathered around a large piece of flip-chart paper with the outline of a body already drawn on it. Through discussion amongst themselves they were encouraged to name the character, decide on the age, occupation, friends, history etc. Individual participants were invited to use post-it notes to write down what the character might feel, what they might do and where they might go. I did give some prompts but member participants seemed to find this fun and creative. I asked for permission to 'write up' the character (see Appendices VIII and IX) to use in the subsequent focus groups and explained we would be putting the character through a number of scenarios. These exercises had links with interactionism in that the members quite literally created a character via the individuals in the group interacting and talking to one another; the only stipulation was that the character had experienced some form of mental distress and was a member of the organisation. This method was creative and became a site of empowerment (Magill, 1993; Race et al., 1994) and a way of approaching the topics of stigma and discrimination 'differently' (Hese-Biber and Leavy, 2006). Similar to McLaughlin and Coleman-Fountain's (2014) approach to research with disabled young people, the

rationale for using a non-clinical and a more creative way of working makes possible to elicit complementary insights whilst also drawing on more traditional methods such as interviews. Moreover, such arts based practices are said to be useful for research projects like this study which aim to describe, explore and discover, particularly relating to experiences associated with difference, diversity and prejudice (Leavy, 2009:12-13)

In the second focus group, up to two staff members were invited to contribute to the discussion. We began by reading out the biography of the character, which members were keen to do. A number of questions were on flipchart paper to prompt discussion: How does the character feel coming to the organisation? What doesn't the character like about the organisation? How does being at the organisation help the character? Has the character ever been treated unfairly because of his mental health? Has the character ever stopped himself from doing things because of how others might respond to him having a mental health problem? Has the character ever overcome stigma and discrimination? Has the character ever been treated more positively or received special treatment because of a mental health problem? These questions were all adapted from the DISC-12 (Discrimination and Stigma Scale) (Indigo Study Group, 2008) survey which was developed and is used to measure stigma and discrimination quantitatively.

Initially I had thought that the final focus group would involve me talking about themes I had been thinking about and developing during my time at each organisation but I was quite naïve to think I would have any idea of themes at that stage or time to formulate them. Therefore I decided that the final group would be about involving staff and members in looking forward using the character. Four questions were posed on flipchart paper for discussion: What things does the character want for the future? How might the character want to be supported by professionals? What could the character do about mental health stigma and discrimination? What help does the character need to tackle mental health stigma and discrimination? Similar to creating the composite character in focus group 1, we also created another character of the 'ideal support worker' at each organisation. Towards the end I asked what participants would like to see from the study and whether/how they would want to be involved in any tangential projects, particularly relating to dissemination of the findings (see 3.12).

The order of the focus groups was progressive; the character was created, it was used to explore issues of stigma and discrimination, and we used it to look to the future and how the character would want to be supported. Looking back there certainly wasn't a 'standardized' approach to the group work; my prompts sparked discussion and the process could be considered iterative and "emergent" i.e. letting the "questions and

procedures shift from group to group in order to take advantage of what has been learned in previous groups" (Morgan, 1996:142).

Focus groups are usually a one-off meeting between a group of individuals (Bedford and Burgess, 2001:121) but many members were keen to attend all three focus groups and this worked out well and a dialogical element to the study developed. As I was recruiting from the staff and members at each organisation the 'pre-existing group' tended to instigate a more 'natural' discussion given the participants already knew one another (Kitzinger, 1994a). This was an advantage to the discussion as they shared a sense of "common social identity" (Holbrook and Jackson, 1996:141) and didn't pose a problem at all because I was concerned with the 'types' of interaction within the organisation given the research is framed by the case study. Participants seemed to feel confident talking to one another but I was concerned that if there was any particular 'history' between participants I wasn't aware of the group discussion ran the risk of exacerbating that. However, as I had already got to know the members and staff in the weeks previous this didn't seem to be an issue.

Participants were able to use the vehicle of a fictional character to use to 'de-personalise' any points they had to make which may have been personal. Moreover, in relation to any concerns over 'freedom to be honest', I also had the data from my observations and the interviews to cross reference what was said in the groups. Different results from the different interactions as a result of group and individual interviews provided a focus for analysis (see Banks, 1957). This is particularly important for my work in exploring how different meanings and interactions may or may not produce different results within different 'power' contexts in the stigma discourse.

Initially the plan was to hold one focus group at the beginning of my time at each organisation with members only, and then invite two staff members to the second group in the middle of my time at the organisation and hold the third group towards the end. In practise participation in the groups was contingent on the case study organisations (May, 2011:138) and it wasn't viable to hold the first focus group in the first and second week of me being at the organisation. Firstly, because members weren't interested in being involved because they didn't know me and weren't clear about what they were getting involved in. Secondly, I required space at the organisation which had to be organised around existing commitments and room bookings. At each organisation the three focus groups were held in the last three weeks of my period of participant observation, lasted between 1 and 1.5 hours, and attended by no more than 8 participants. One group only contained three participants but, similar to Longhurst (1996) I didn't view this as a 'failure'; it was a useful form of data collection with the opportunity for more in depth discussion.

I recorded each session digitally and kept a note of who sat where and transcribed straight after the group whilst I could still remember who was who (see Bryman 2008:476). Whilst transcribing discussion was important, I also took photographs of the flipcharts and post-it arrangements. The photographs were entered into NVivo and revisited during the analysis stage.

3.8 Triangulation and interaction of methods

In social sciences triangulation is "the attempt to map out, or explain more fully, the richness and complexity of human behaviour by studying it from more than one standpoint" (Cohen and Manion, 1986:254). In qualitative research, triangulation aims to enhance the credibility and validity of the results; "triangulation gives a more detailed and balanced picture of the situation" (Altrichter et al.., 1996:117) and formed the rationale for using three qualitative research methods and triangulating those methods.

Whilst interviews are a useful and direct way of gathering information, I also wanted to guard against what Bourdieu (1999) describes as "false collusive objectification"; participants presenting themselves 'falsely' or as a 'model' story of 'success', or how participation in the organisation has helped them 'overcome' their experiences of mental distress, or staff presenting themselves as 'model professionals'. Being present at the organisation to chat more informally and observe interactions enabled me to make critical correlations between what I was experiencing in the day to day interactions and interview data. Moreover, the focus groups and composite characters gave participants the chance to tell different 'stories' if they so wished. Adjusting my own position by "active and methodical listening" (Bourdieu, 1999:608-609) helped guard against the telling of one story, and using three methods enabled me to develop my own ear and eye to better tune into the participants' position (Davidson, 2003). Watching for tensions between my interpretation and meaning participants attribute to experience (Millen, 1997:5.6), for example, in observations and interviews, enabled me to reinterpret findings in terms of the conditions and contexts which provide this tension (Anderson, 1981).

In terms of 'validity' of the material I gathered from the different methods, particularly the focus groups and the individual interviews, I followed Kitzinger (1994b:173):

> Differences between interview and group data cannot be classified in terms of validity versus invalidity or honesty versus dishonesty....The group data documenting macho or sexual harassing behaviour is no more 'invalid' than that

> showing the research participants' relatively acceptable behaviour in interview settings.

And Morgan (1996:139):

> What is said in individual and group interviews is as much a statement about our culture as our methods.

Although I was not concerned with 'pure truth' or 'authenticity' my material would be of little use to the study if participants only presented a replication of what they think 'people want to hear'. Having said that, a situation where interviewees (particularly staff members) describe a rhetoric which I problematise via participant observation or in focus group work was of use to explore the tensions between the different contexts. Furthermore, I was able to look for critical correlations between interview data and how a member or staff interpreted a situation I observed; this helped me not to read meaning into things, and if I did, the methods I used challenged my inferences. Differences between what I was hearing in the focus groups, participant observation sessions, and interviews provided further insight into how participants created meaning in different contexts and further highlighted how social realities pertaining to stigma, discrimination and support, could be different for people in different contexts.

When I first designed the research I intended to use the initial focus groups at each case study organisation as a way of 'brainstorming' and then the interviews to explore specific opinions and experiences of stigma and discrimination in more depth (Duncan and Morgan, 1994). However, this did not happen. This would have been useful because themes arising in first focus group could have been included in the interview schedule where appropriate and explored in more detail. That said, the overriding aim of the focus group related to group interaction and discussion which could be correlated with the interview and observation data which became important at the analysis stage (3.10).

By triangulating methods (Denzin, 1970:310) and employing an ethnomethodological approach (i.e. using the method to try and shed light on how the social order is accomplished in terms of stigma, discrimination and support via talk and interaction) I encouraged more diverse involvement from anyone who may have experienced stigma and discrimination. For example, if I hadn't been observing at, and participating in, the organisation, many of the member participants wouldn't have been willing to take part in the focus groups or interviews. Participant observation and being able to interact with participants in the context of the organisation added to the richness of

the research process too, particularly in terms of the theoretical backdrop of interactionism where meaning is constructed via interaction. Participant observation provided another way to analyse stigma and support because I could experience for myself what members and staff were telling me in the groups and interviews. Thus, triangulation of methods contributed to a richer capturing of the participants' experiences relating to the issues of stigma, discrimination and support at the case study organisation.

3.9 My position as a researcher

There is a clear personal connection between myself and the topic and location of this research (Marcus, 1998:239). As a professional I have been employed as an advocate and legal representative for disabled people and people who experience mental distress in the North East of England. I have also worked with a range of professionals providing support to individuals such as social workers and mental health nurses. Thus, I have some experiential knowledge of performing and occupying a professional role which involves an element of support imbued with a degree of power. I have also been on the receiving end of psychiatric support and services, and have some personal knowledge of what it feels like to experience a sense of stigma and disempowerment, primarily as a result of mental distress, and secondarily as a recipient of psychiatric support where I often, but not always, felt somewhat powerless. This research project is not autobiographical, nor do I wish to make it so, but notions of stigma and power were issues I had become aware of in my experience as a professional and patient/service-user in addition to my position as researcher and should be acknowledged. As a result it could be said that both my experiences and the existing literature in the field informed the research design.

Within each case study organisation I saw my role as researcher to "co-construct perceived reality through the relationships and joint understanding we create in the field" (Simons, 2009:23). Using myself as a valuable research resource was inevitable both in terms of practicalities such as gaining access but also being able to connect with members and staff and build rapport. As Church (1995:136) suggests, it is a way of moving the line between a "public" and "private" life, rather than dismantling it completely. To not be reflexive and to ignore or neglect my own voice in favour of others would have had the ironic consequence of marginalising my own self (Butler et al.., 2007:294-5); a self which can be viewed as an asset to the research rather than a hindrance and may offer important insights. As a result the question was not about excluding any bias but coping with it, hence the rationale of acknowledging my own experiences outside of and during the research process (Pyett, 2003:1171). Particularly in my field notes where I tried to position

myself in a space of "betweenness" (Katz, 1994) i.e. between service user and professional, and between personal field notes and `the literature.'

Ethnographic methods usually give rise to the 'insider/outsider' debate and my position ought to be acknowledged. Following Naples (1996) I argue that there is no static position of 'insider' or 'outsider'; instead positions of the researcher are permeable and ever-shifting. Thus, the binary of 'insider' or 'outsider' is a false binary where an ethnographer/researcher is neither inside nor outside a community. I prefer to consider the insider/outsider debate as a continuum between two elusive absolutes and used the practice of reflexivity to negotiate the challenges presented at varying points on this insider/outsider continuum at any one time. I did not feel ever wholly an outsider or insider. I did draw on myself as a resource, using my experiences as a professional and as someone who has experience of mental distress, at instances I felt it were appropriate and which I talk a little about below. In doing so I share Church's desire to do academic work that is "intellectual and emotional, empirical and subjective" (1995:38).

When I began my fieldwork I didn't realise how much my own experiences of madness and distress would become relevant, but as I got to know the participants I often recognised myself reflected in their stories. Via this recognition, over a period of weeks, I talked about my own experiences when participants asked explicitly and I felt comfortable replying, or when it was appropriate- usually in day to day interactions rather than interviews. What I chose to disclose to participants depended upon the context of the interaction and conversation. For example, a particular participant I had got to know quite well recalled a suicide attempt in a conversation one afternoon; her experience struck such a chord that I spoke of my own similar experience. More openly, I talked with some participants about coping with anxiety, panic, and other 'unusual' experiences, along with our diagnostic/psychiatric labels which some of us disagreed with. I didn't go into the organisations with an agenda to talk about myself in this way, yet I didn't have a blanket policy of not sharing my experiences at all. However, it had to 'feel' comfortable for me and I had to feel that the participant would be comfortable with the conversation and that it would benefit rather than burden them in some way. Thus, I negotiated disclosure by taking into account the context of the conversation and the interaction, and my relationship with the participant. I can't *know* exactly what the effect this disclosure (or non-disclosure in other circumstances) had on the empirical material. However, it is likely to have shaped participants' interactions with me, whether that was that they were more 'open' with me or that they didn't tell me certain things because they assumed or took for granted I already understood because, for example, our diagnoses or experiences were similar. The impact on the data is difficult to ascertain. However, the findings must be

read through this lens and the notion that the empirical material was collected by me, serving as a subjective filter.

Some staff knew me from my work with them when I occupied previous employment roles and at times there was a tendency to slip into "coded language and communication" with staff participants (Kanuha, 2000:443). Whilst my research diary and regular supervisions enabled me to keep a check on this and question what might have appeared to be "self-evident" (Jobling, 2014:54), this no doubt occurred because of the dimension of my 'professional' identity. On reflection, at times, I felt I drew on my experience in previous professional roles and my role as researcher to disrupt power relations between staff and members. For example, a staff member and member were experiencing difficulties in their relationship; the staff member felt that the member was always trying to 'push the boundaries' and each reported that they found the other party frustrating. In a particular focus group, both participants were present and the staff member referred to the composite character as being "quite difficult" and always trying to "push the boundaries", the member turned to the staff member and said "you're talking about me, aren't you…?" The staff member responded and what ensued was a short conversation where, through the vehicle of the composite character, each party to the conversations could see themselves in a different light. Both participants commented to me afterwards, on separate occasions, that this had really helped them see things differently.

I approached the study primarily as a researcher, not as a practitioner or as a service user. That said, the practise of reflexivity meant that my other experiences could not be entirely side-lined and were, as suggested above, an asset. For example, participating in the writing group and writing poetry (see Appendix X) with the members about personal experiences and sharing stories (Foster et al.., 2006) with members helped to extend my understanding of the experience of support in those organisations. This fed into subsequent analysis because I was unable to view any of my empirical material dispassionately; there were always many sides to a story. I 'felt' staff members' frustration at some members because I sometimes experienced feelings of frustration, particularly in situations which were beyond our immediate control such as housing or benefit problems. Most importantly it made me experientially and personally aware of the subtlety of topics such as stigma and discrimination, particularly as it pertains to the support environment, which is nigh on impossible to quantify in black and white. The importance of context for stigmatising and discriminatory interactions, along with how this can be mitigated, is vital to understanding stigma and discrimination, and the impact of support. Furthermore, the fact I often felt unable, at times, to talk about myself because some experiences are too

personal and painful made me acutely aware that many of the participants wouldn't/couldn't either. In doing so I became much more cognisant of the importance of relationships and the role of supportive relationships which enable this sort of disclosure. Finally, by acknowledging my own position, identities, thoughts and feelings in the aforementioned ways spoke methodologically to the project's theoretical approach relating to interaction, power, and the importance of foregrounding individual experience.

3.10 Analysis

Having carried out an extensive literature and policy review, I was already aware of the major themes running through the stigma discourse, thus making tentative links between the literature and the empirical material was unavoidable from the outset. I transcribed the interviews and focus group recordings myself as soon as possible after they took place. I made notes in my research diary after each one, summarising the interview and commenting on any key issues which arose, and my thoughts on how that fitted or didn't fit with what I already knew about stigma and support. I also used my research diary to comment on common themes which kept arising during the course of the fieldwork.

Once I finished my periods of fieldwork and transcription was complete, I went about systematically analysing all of the empirical material, including my field notes and research diary (Lofland and Lofland, 1995). To do this I put all of the empirical material into NVIVO (ver.10) and I used the list of initial themes consolidated from my research diary to form nodes which I used to code the material. Initially, coding was conducted very loosely; i.e. I coded large pieces of text to keep comments in context to avoid narrowing down my lines of inquiry too early on in the analysis process. I also read each transcript and fieldnote in its entirety to immerse myself in the details and to develop a sense of the "bigger picture" before breaking it into parts for coding (Agar, 1980:103). NVIVO was particularly useful to keep my data organised and later enabled me to access material and cross reference empirical details linked to particular themes.

No strict consensus exists for analysis of forms of qualitative data. Creswell (1998:140) identified three general analytic strategies by Bogdan and Biklen (1992), Huberman and Miles (1994), and Wolcott (1994), involving noting down ideas in margins, highlighting information in the empirical material, and contrasting and comparing different pieces of material whilst noting patterns and categories. I found the aforementioned approaches to analysis useful and I went through each transcript (interview and focus group) and fieldnote systematically and coded it. Via this process new nodes and child nodes emerged (see Appendix XI for full list of nodes and child nodes). Findings within and between the different organisations were also critically compared to develop analysis

further, and at this stage I also reflected on the documents each organisation provided e.g. their mission statement, code of practice for members and staff etc. After I had been through all of the material I tried to link it back to the formalised body of knowledge relating to stigma (Miles and Huberman, 1994). During this time I began to list the preliminary main themes and discussed them with my supervisory team to guard against 'claims-making' and to counter any bias that may have arisen during the process (Heritage, 1984:238). After developing initial themes and thinking about the findings chapters, I revisited the material to read through it again and further code text to the nodes I had developed. Largely due to time constraints I wasn't able to return transcripts to participants for them to comment on, or return to participants to discuss how themes in the research had developed. On reflection, this would have been useful to develop a further dialogical element to the work.

I was not primarily concerned with whether my findings could be generalised to a wider society or to produce data that could be easily standardised or to universalise personal viewpoints. Instead I focussed on generating theory relating to mental distress, stigma, discrimination and support, from the findings (Mitchell, 1983; Bryman, 2008:57). In doing so, I tried to understand that people assign different meanings to different things, can experience stigma, discrimination and support differently to others, and explore how those meanings and experiences impact on the way participants understand the world and interact with those around them- particularly in the support environment. Via the processes of interpreting the qualitative material, gathering themes using systematic coding and rereading the empirical material I realised 'self-stigma' was a compelling phenomenon. However, discussion in terms of self-stigma only arose because of the relationships between staff and members at the organisations. Although I wanted to write about 'self-stigma', it was imperative to do so as a concept for exploration nested within the relationships at the organisations and within the context of the organisations. It was only via my methods, particularly the complementary nature of the participant observation alongside the interviews and focus groups, which helped me retain the bigger view and see the research as a whole. For example, the detail participants relayed to me in interview, if taken out of context, could tell a different story. In this respect, and following Walcott (1994), on reflection I took an ethnographic approach to the analysis process. This began by me describing what I thought was happening at the case study organisations and analysing my material accordingly i.e. exploring 'self-stigma', relationships between staff and members, and between staff, and then drawing connections between the 'culture-sharing group' (the members and staff at the organisations) and larger theoretical frameworks of the stigma discourse and support relationships. Although data from the

ethnographic findings may not be evenly spread throughout the findings chapters, the significance of the ethnographic element of the fieldwork became particularly clear during the analysis process. This is because, as discussed above and in 3.8, participant observation provided an opportunity to explore more deeply the critical correlations between the focus group and interview material. For example, in relation to self-stigma discussed in Chapter 4 which predominantly relies on interview and focus group data, my own experiences as a result of participant observation enabled me to explore the nuances of the support context which are given more weight in Chapter 6.

To distinguish between different sources of empirical material in the thesis I use the term 'int.' to refer to interview material, 'FG.' to refer to focus group material along with a number (1, 2 or 3) to indicate which focus group in the series I am referring to, and 'FN.' to refer to a fieldnote which is followed by the fieldnote number (each fieldnote was simply numbered in order of when I wrote them at each organisation). I also distinguish whether the empirical material in each instance comes from a member or staff member of the organisation, and specify which organisation they are from.

3.11 Ethical considerations

The project follows Durham University's School of Applied Social Sciences research ethics policy and the plan for the fieldwork was submitted to the Director of Postgraduate Research and approved before any work was carried out. The study also follows the British Sociological Association's statement of ethical practice (BSA, 2002) particularly in terms of being actively aware of the power differential which often accompanies researcher-participant relationships. Following the ESRC's Framework for Research Ethics (2012) I undertook a two day training course delivered by the North East Doctoral Training Centre (DTC) on research ethics. Although this research is not a piece of Participatory Action Research (PAR) I am committed to the ethical principles of participatory action research including principles of mutual respect, equality and inclusion, democratic participation, active learning, making a difference, collective action, and personal integrity (CSJCA, 2012).

Separate information sheets for staff and members (see Appendices II and III) clearly outlined the research to ensure participants made an informed and voluntary decision to participate. The sheets also detailed the right to withdraw at any time and participants were informed of this at appropriate points throughout the research e.g. before focus groups, individual interviews and during participant observation sessions. This was to ensure, as far as possible, that participants proceeded with "eyes wide open, to implement meaningful and informed consent" (Johnston, 2010:244). At interview stage, participants were also informed that, should they wish to withdraw, any interview

information collected up until that time would be stored and used, or destroyed and not used, in compliance with the individual participants' wishes (Melville, 2005). In practise no one chose to withdraw and written consent for the interviews and focus groups was obtained (see Appendix IV). In terms of the participant observation sessions, I had already introduced myself at members' meetings before the fieldwork commenced to give members an opportunity to ask questions and object to my presence. In addition, a notice was put up in the communal area near the sign in sheet to let people know I would be participating and observing, along with details of the project. The purpose of this was to encourage people to speak to a member of staff or me if they had any objection or wanted to ask me questions.

There was the possibility that participants who experience mental distress would find discussing their experiences distressing as the subject matter has the capacity to evoke powerful emotions (Gilgun and Abrams, 2002). Therefore I was required to ensure there were adequate safeguards in place. For example, to avoid any harm to the participants and provide required aftercare the information sheets (Appendix II) included contact details of the duty social work team and the emergency duty team at the relevant Local Authority along with my contact details and those of my supervisory team. In my professional capacity I have completed levels 1, 2 and 3 safeguarding adults training and have experience as Safeguarding Adults Lead for Shelter from 2008-2010. My professional experience ensured, as far as possible, I created a research environment that was supportive (Gergen and Gergen, 2000). To ensure the safety of participants I also ran through the interview and focus group guides with an ex-colleague. Participants understood via the information sheets and by me talking them through the sheets that although discussion during the interviews was in confidence, disclosure was required if they said anything that potentially indicated they or anyone else was at risk of harm. Participants were informed, if they did mention any information of this type, I would indicate this to them and they could choose whether or not to continue with discussion, what the next steps would be and my duty to disclose if I believed someone would be at risk of harm. During a small number of the interviews member participants became emotional and/or upset but not in a way that I believed any harm had been inflicted or that harm would be inflicted as a result of the interview. Furthermore, it is important to recognise that there is a difference between harm and getting upset or feeling distressed.

Before commencing the fieldwork I clarified with each organisation whether a DBS (Disclosure and Barring Service) check was required. Both Bright Futures and Creative Mindz required me to apply for a check and I did so via Durham University. I considered whether there were any identified issues relating to mental capacity which affected

participants' ability to consent to their involvement in the project. I clarified this via conversations with the respective managers of each organisation during the initial recruitment period and they were clear that the members attending did not have any issues under the Mental Capacity Act 2005; this was confirmed by my own conversations with members and prospective participants.

Confidentiality was maintained throughout the project. I have ensured that I have not identified any organisation or individuals by name or by any other that would unveil their identity (Griffith, 2008). For ethical reasons and due to the sensitive nature of some of the stories participants shared, I have distorted, omitted, and generalised some of the details in the subsequent chapters. Although this alteration does not change the material meaning of the observations and interactions, it does ensure as far as possible that participants cannot be identified. Whilst I emphasised confidentiality and anonymity from the outset, both organisations were happy for other organisations to know about their involvement in the project and talked about their involvement freely to other organisations and stakeholders in their organisation. I needed to ensure all participants were aware of this. Furthermore, it is likely that whilst I have anonymised the people within the organisation it is likely they may still recognise one another (apart from where I have purposefully distorted details as above) and I needed to ensure participants understood this too. A pseudonym is used for each organisation and participant, and each organisation and staff role was generalised apart from when the staff role was relevant to the empirical material e.g. if it was spoken by a manager or a previous member who had become a staff member. Transcripts were anonymised straight away, the recordings are stored on an encrypted data stick and will be deleted after completion of the Ph.D. Although the recordings will be destroyed, the anonymised transcripts will be retained.

3.12 Dissemination of findings and potential 'outputs'

As a fledgling academic I am interested in publishing in academic journals and presenting at academic conferences. Whilst one of the aims of the study is to contribute to the theoretical debate within the stigma discourse, following Shakespeare (1997) I also approach the work with the intention that it will contribute to tackling stigma and discrimination in some way. Furthermore, I want to publish and/or present the findings in a format and in places which may be useful to the participants and the case study organisations. As a result, and after my viva, it has been agreed with the case study organisations that I will produce a report for each of the organisations detailing the findings and how they apply to their specific organisations. I have also agreed that I would attend

staff, members', and board, meetings at the organisations to talk about my findings and discuss the themes arising from the research.

During the fieldwork, I tried to ascertain other ways in which the study may be beneficial to participants and the organisations. There was some discussion in the third focus group at each organisation about what they would like to develop from the research and I discussed ideas more informally with individual participants whilst attending sessions. At Bright Futures members expressed some interest in making a DVD related to the findings, and staff members were interested in any training opportunities which may arise as a result of my time there. The DVD idea has not been realised as the DVD group can only take on one project at a time and were continuing with the shared decision making project. At Creative Mindz a number of members wanted to create composite characters 'Mickey' and 'Simone Garfunkel' as puppets and develop a script to perform a puppet show. However, the volunteer facilitating the puppet group began to focus on other mediums at Creative Mindz so that idea is on hold for the time being. Furthermore, my time was/is limited in terms of how much I am able to lead on these projects. That said, following my period of fieldwork I continue to work closely with Creative Mindz on a number of other projects and evaluations, and I have been involved in a number of events relating to films, animation, collaborations with other art studios and mental health organisations etc. I intend for these relationships to continue, and evolve, beyond my Ph.D. study.

As a previous employee of CSV (Community Service Volunteers, Now 'Volunteering Matters') I have already developed and delivered some training sessions around stigma and discrimination in conjunction with them. Some staff from the case study organisations also attended this training. Following the viva, I intend that the findings from this project will form the basis of policy briefings and contribute to informing the practice of support in the mental health field. Using my existing links with Volunteering Matters I will work with them as a national and local platform to talk about the findings arising from this piece of research.

3.13 The research journey: reflections and challenges

Critical work on community care often disturbs "the cosy picture of civility and its wholesome certainties about the nature of community imagined as 'community mental health'" (Knowles, 2000:5). Before each period of fieldwork I was particularly concerned about arriving at each organisation, explaining my research, and unsettling relationships or making staff and members feel 'on guard' or uncomfortable. Not only would such a situation skew my findings, it would also go against the ethic of collaborative working and

building relationships. As a result, and mirrored by the conceptual elements of stigma (Chapter 2 and 3.1), I regularly reflected on my own 'power' in the researcher-participant relationship. In particular, this prompted me to consider my approach to the project and how it was presented to participants. I explained to staff and members that I was coming to their organisation in the spirit of 'collaborative inquiry' (Bray et al., 2000). As a doctoral researcher, I had already designed the research project after considering the literature and policy framework pertaining to stigma, discrimination and support. However, I made it clear that whilst I had some theoretical knowledge which I brought to the project, I also explicitly acknowledged the limitations of this "expert knowledge", and emphasised the "primary relevance of the experience and know-how of people in their everyday lives" (Stringer, 2007:186). I recognise that participants are experts in their everyday lives and experience; in particular they may be experts in experiences relating to stigma and discrimination and support, or they are likely to have an opinion on stigma and discrimination based on their own experiences. On reflection it may have enhanced the project to employ the creative skills of many of the participants. For example, this could have involved using visual methods by asking participants to take photographs and asking them to discuss them with me (Bryant et al., 2011), or asking participants to make a photo diary of their experiences which could also include material about their life outside the organisation (Conradson 2005). If I were to conduct the study again I would certainly try to create a more collaborative and participatory study, involving participants in all stages of the project from design to dissemination (see Faulkner, 2004; Sweeney et al., 2009; Staddon, 2013).

The fieldwork itself was enjoyable and went relatively smoothly, but I found leaving the field at the end of the 12 weeks participant observation at each organisation difficult. I had built relationships with members and staff, and shared many personal stories, activities and experiences with them. Many members and staff said they would miss me and I have kept in touch with some via Facebook and e-mail; others I bump into in the city centre from time to time. I also keep in touch with some staff who I update with progress reports relating to how the Ph.D. is progressing, and I have since worked with Creative Mindz on a number of other projects. After being totally immersed in each organisation for three months, being able to keep in touch somewhat soothed the 'shock' of leaving each organisation to return to working alone on the Ph.D. and beginning the analysis process.

During the analysis process, I spent some time reflecting on the 'reliability' of my data. As Diefenbach (2009:877) articulates:

> qualitative research and social sciences are more vulnerable to the possible downsides of subjectivity that may influence the research negatively…In qualitative research one can only draw analytical but not practical lines between research and researcher, 'reality' and making sense of it, data and their interpretation, social science and social practice.

Thus, I didn't attempt to draw 'practical lines' between myself and the research, and the data and its interpretation. As Cook (1997:146) explains, qualitative research, in particular field notes and ethnographic diaries as data is "no more nor less `objective' or `subjective' than any other forms of information brought back from the field." However, reflecting on my methods overall, I did consider carrying out two interviews with each participant to enhance relationships and rapport between me and the interviewees (Malbon, 1999:3). Repeated interviews would also provide the opportunity to test and revise accounts to obtain less contrived accounts on sensitive issues (Wiersma, 1988). However, time constraints made this untenable and rather than conducting more interviews, I felt it was worth exploring different methods such as participant observation (which also helped develop rapport) and building alternative methods such as focus groups into the study instead.

Considering intersections of age, gender, ethnicity and class in my sample made me wonder whether my sample was limited. That said, I stated from the outset that the sample is purposive, not representative. The purpose of the research is to offer insight into the experiences of people within the community support context, and therefore the themes which emerge could be considered to gain 'moderate- generalisability' (Payne, 2007). The sample of participants reflected the staff and members at each organisation as far as possible; involving equal numbers of men and women, participants from every age bracket present at the organisations, and although the sample was predominantly White European, this is something which is reflected in the members attending the organisations. Perhaps including a larger number of case study organisations and dedicated organisations set up to support BME groups and/or young people would yield a more diverse sample and a different or more nuanced set of findings which could be considered for further study.

Setting out on the research journey, I had little idea about what I would find. With the benefit of hindsight it is easy to critique your own research design, questions, methods etc. However, whilst writing up my findings I did muse over whether I might be reaching the conclusions I have done in this thesis because staff members and members don't have the distance I have as a researcher. This could be considered in both a negative and positive way; positive because I could perhaps see things staff and members may not and

draw conclusions which may be useful for practice, but negative because that distance between me and the participants may leave open the possibility for misunderstanding. I was also concerned whether I had been led by the issues which concerned staff members given that I often spoke to and interviewed staff first as they were essentially the 'gatekeepers', controlling member participants and avenues of opportunity to some degree (Hammersley and Atkinson, 2007:27). Furthermore, despite the ethnographic nature of the fieldwork, I am not employed as support staff at the organisations day in and day out and dealing with the pressures they do, and so my perspectives on what is going on is likely to be different. The same goes for members, it would be impossible for me to experience the support environment the same way that the members do. I think such concerns are important for the reader to keep in mind in the following chapters. Whilst they don't devalue the findings or the conclusions I draw from the empirical material in the proceeding chapters, these 'methodological realities' do demand a critical reading of themes developed in the remainder of the thesis.

CHAPTER 4:

The importance of relationships for minimising stigma and providing support

The political landscape concerned with stigma reduction and the body of literature asserting that stigma and discrimination are significant features in the lives of people experiencing mental distress provide the backdrop to this study. Whilst a starting point for the project was to explore experiences of stigma and discrimination with members, given the already vast literature, such discussions provided the context and a route into exploring whether negative experiences may or may not be mitigated by interactions occurring in third sector organisations providing support. This chapter begins by detailing member participants' reports of when, where and how they have experienced stigma and discrimination. It also includes instances, described by participants, when they have been 'treated differently', which they attribute to them having experienced mental distress, declared details of a 'mental health condition', or acted in a way which meant mental distress was 'obvious'. It is these personal experiences and how participants make sense of these experiences, often by referring to them as experiences of stigma and discrimination, which they bring to the support environments provided by the organisations I worked with. A range of different 'types' of stigma and discrimination experienced by members were identified, particularly experiences in institutional settings designed to help them. Member participants did not feel stigmatised and discriminated against in or by the two case study organisations, and I examined how and why members consider the support they receive at Bright Futures and Creative Mindz to be non-stigmatising. Therefore in this chapter I begin to build a picture of what might be considered non-stigmatising support by specifically exploring the relationships which develop between members, and staff and members at the organisations. In doing so I contemplate what makes the relationships which develop at the organisations *so* different and *so* supportive in contrast to members' reports about other services providing support. Tentatively discussing where such relationships and organisations may be located in the stigma discourse provides the foundation for discussion in subsequent chapters.

4.1 Significance of stigma and discrimination in the lives of members

All of the member participants I interviewed and many of the members I conversed with during my time at the organisations reported that they had experienced stigma and/or discrimination, and described being 'treated differently', in their lives outside of Creative

Mindz and Bright Futures, which they attributed to their experiences of mental distress. The contextual subcategories of when/where/how members experienced stigma and discrimination varied but can be broadly categorised as occurring in institutional settings (work, volunteering, education, psychiatry and mental health support services), personal relationships (friends, family, intimate relationships) and interactions with the public. These findings are reflective of the literature and the underpinnings of current policy which suggest mental health stigma and discrimination permeate all areas of social life; for example see Link and Phelan (2001) and Dept. of Health (2011a; 2014). The empirical material in this section explores in further detail the different contexts of social life in which members report feelings of stigma and discrimination to highlight how, for the members, stigma and discrimination is or has been a significant feature in their lives. It is important to note the issue of 'causal attribution' at this point; in many cases there may be other contributing factors to why an interaction was 'played out' in a particular way, but what I am concerned with is that members attribute stigma to these interactions. For example, there are likely to be other contributing factors to an interaction which involves a member's retold experience of not being offered a job because they declared experiences of mental distress. Other reasons may include not being the most suitable person for the job or not having relevant work experiences or qualifications. However, I am interested in how meaning and feelings of mental health stigma and difference are created via, or attributed to, that interaction by members.

In terms of stigma and discrimination occurring in an institutional or work context; many members reported experiencing stigma and discrimination in employment or whilst job seeking. For example, Grace (member, int., Creative Mindz) described her experience of job interviews:

> *I think when I've been to interviews like for jobs and whatever, if you say that you've got mental health problems, they don't want to know you and they don't give you the job…and I'm thinking well you've never give us a chance, you should let us try and just give us a trial.*

Susan (member, int., Creative Mindz) talked about going back to work after spending some time in a psychiatric hospital:

> *I went back to work and like people didn't know what to say and it was taboo and no one would ask how I was, you know what I mean, everyone knew but they didn't really want to mention it…one guy I was really really friendly with, and he'd say to my friend, 'how's Susan?' She'd come and see me and stuff, and she'd be like, 'she's*

doing all right', and then the next week, the next day he'd ask 'how's Susan' and she'd be like 'she's all right', and in the end she went 'why don't you go and see her', and he never came to see me, when I got out of hospital he never came to my flat to see me.

Derek (member, int., Creative Mindz) recalled being bullied at work which he attributes to his experience of hallucinations, particularly after his mother died:

When I was in the work situation and I was confused, people used to exploit me. Things like, I was, after me mother died I was feeling quite weak and this guy used to bully me and used to say things like 'it's Woody Allen here', and 'hello Woody', and things like that.

Similar stories of stigma and discrimination came from other members who were volunteering or looking to volunteer. For example, Jon (member, int., Bright Futures) described the process of applying and being rejected for a voluntary role which left him feeling upset and dejected:

The only time I've faced direct stigma was trying to get a voluntary job… I said 'I have manic depression', and he said 'well you know', I came back and seen him and he said 'it made it really complicated', he said, 'if we created a scenario around you and see how you reacted' and he says, 'well, we don't really have any insurance for people with problems'.

A further experience of a stigmatising or discriminatory interaction in the context of volunteering was mentioned in one of the groups I attended:

Cassie (member) says a lot of people understand it [mental distress] but some don't and when she was volunteering in the charity shop she heard someone talking (she didn't say whether staff, volunteer or public) and they said 'she's not normal her, I'm glad I'm not her' and she said it made her feel 'rotten' - Cassie said she stayed and persevered as long as she could but had to leave. Cassie later mentioned it was a mental health charity shop where this incident occurred. (Bright Futures, FN14)

A few member participants described experiences of stigma and discrimination in education but the references tended to be historical i.e. interactions which occurred in the 1980s or before. That said, the experiences reported by participants seemed to continue to have a significant effect, particularly for members aged 40 and over. For example Kathy

(member, int., Bright Futures) described how her experiences at school and applying for college affected her:

> *In the early 80s they had me down as somebody with problems and got sent to a special school and that didn't do anything for me. The fact I hated it, I didn't like it because I didn't learn anything, so I got no nothing like qualifications…I mean now they wouldn't have done that, maybe they would have given us special lessons in an ordinary school, well that's what they should have done then…and the college at that time they weren't interested, as soon as I said that, the college said 'there are places for people like you'. So that really sickened me and I just lost all my confidence…*

Other examples of institutional stigma and discrimination reported by members involved experiences with psychiatric and/or mental health support services. For example, Jon (member, int. Bright Futures) said he felt stigmatised by psychiatrists because he felt psychiatrists want to push him out of his "comfort zone" and he doesn't always want to be "pushed":

> *They're [psychiatrists] obviously goal oriented in terms of like career and being productive and I think you lose grasp of the fact that, wait a minute, as somebody who suffers like I do, just being in a comfortable place and with my life is enough for me. You know so, dealing with different psychiatrists, you're dealing with different levels of stigma towards how active a person you actually are and whether you can cope with more.*

Yvonne (member, int., Bright Futures) described feelings of being discriminated against when she was on section[6] in a psychiatric hospital as being 'violent' even though she had never been violent:

> *It's like everybody in the hospital is the same, so probably the trigger is the same like everybody's, I had been allocated as violent, usually because the people when they go psychosis they are violent, so I got this stigma [as a] violent aggressive person. I've never performed this.*

Other members reported interactions they found stigmatising and discriminatory in other mental health support services. For example, Ian (member, int., Bright Futures) recounted

[6] 'on section' refers to patients who are compulsorily (and very often, involuntarily) detained in hospital under the Mental Health Act 1983

a time when he felt 'different' as a result of overhearing a conversation between staff at accommodation designed specifically to support people experiencing mental distress:

> *When I was at XXXX hostel, I overheard a member of staff saying 'there doesn't seem to be much wrong with him'…it felt like they were judging me…*

Susan (member, int., Creative Mindz) said she had felt irritated at staff assumptions about her intelligence whilst attending a mental health support service:

> *I think some people assume that because you've got mental health problems that you're thick or that you're not very educated. Like someone I met within the mental health system, I think he worked, was he a support worker or something, I can't remember who it was now, and he just said, 'someone said you had a degree', and I was like, 'I do have a degree and I've got a PGCE' and he was like, 'you have?' And I was just like, 'yeah, I'm probably more qualified than you', do you know what I mean and it's kind of like, that stigma.*

The majority of members reported feeling stigmatised in personal relationships, particularly by their friends and family. For example, Patricia (member, int., Creative Mindz) described her awareness of stigma crystallising when she was admitted to a psychiatric hospital:

> *I mean people can understand about physical illness and that but they're not as understanding with mental illness, people don't know what to say do they? I mean when I was in hospital, the normal way of things would be for people to visit you in hospital but I didn't have any visitors at all…I think there's stigma attached to my having this diagnosis…*

Stewart (member, int., Creative Mindz) reported being made fun of because of his acts of self-harm:

> *Yes…I've had it done by friends, I've been round at a friends' and, cos I've self-harmed very very very badly, I nearly died because of it and I've had the rip taken out of me.*

Jane (member, int., Bright Futures) described her parents being less than understanding about her experiences of mental distress and belittled her aim to work in the mental health sector:

Even now, even now when I tell my parents you know, 'I want to be working within mental health, in the mental health sector', they're like, 'this is so silly', blah blah blah blah

Carl (member, int., Bright Futures) explained how the perception of his mental health diagnosis affected intimate relationships:

I went to a club and I managed to get friendly with a girl in there and ended up taking her back to my place, and she saw my medication on my work surface and said 'what are they for?' and I said 'oh bipolar', and she said 'bye' and walked out…so people do judge.

Finally, a few members had experienced members of the public behaving cruelly towards them. For example, Clive (member, FG2, Creative Mindz) explained:

One of the things that annoys me, what has happened to me, is when you get nice people and they say some of the most nastiest things, like there was a Christian who came up to me and said I was possessed by demons.

The *Stigma Shout* report (Time to Change, 2008) identifies the prevalence of significant stigma and discrimination in all of the areas of social life in which members describe negative experiences- institutionally, personally, and publicly. The recent review of *Time to Change* indicates only modest, if any, reduction in mental health stigma and discrimination in the areas of employment, mental health services and personal relationships (Corker et al., 2013; Hinshaw, 2013, Smith, 2013). The literature suggests, as do these initial findings, that stigma and discrimination continue to have a negative and restrictive impact on people who have experienced mental distress pursuing opportunities in the areas of employment, health and housing (Link and Phelan, 2001; Sartorius and Schulze, 2005; Callard et al., 2012). Collating and detailing how members understand stigma and discrimination from their experiences demonstrates that the recollections of the members I spoke to are broadly reflective of contemporary literature and research informing political agendas.

Members' experiences of stigma are an important context to this study. These experiences are what members bring to the interactions with the staff at Bright Futures and Creative Mindz; these are the experiences that staff must 'work with' if they are going to make a difference. The snapshot put forward in this subsection forms the foundation to begin exploring what support *does* for the members and how feelings of 'difference' or

experiences of being treated differently may be impacted or reduced by the support of the organisations in this study.

4.2 Significance of support in the lives of members

As acknowledged in Chapter 2 (2.2, 2.3.4 and 2.5), there is literature (e.g. Schulze, 2007; Dept. of Health, 2011a; Corker et al., 2013) indicating that mental health professionals can often be stigmatising or discriminatory towards service users. Systemic discrimination has been identified in the mental health system and service users may often feel like they're not taken seriously (Sayce, 2000:64-5). There are also claims that people who know more about mental health issues are just as discriminatory as those who know less (Wolff et al., 1996). Although members reported negative experiences in other support services and psychiatry (above 4.1) none of the member participants reported or indicated that they felt stigmatised or discriminated against at, or by, the staff at Creative Mindz and Bright Futures. Conversely, the members I spoke to directly described the significant and positive impact that attending Creative Mindz and Bright Futures had on their lives. Members talked specifically about the importance of practical support, combined with the caring approach of staff, the personal qualities of staff, being around other members and sharing experiences, the pace of organisation, and how attending activities at the organisations made many members feel less isolated in their lives- both physically and mentally.

Kathy (member, int., Bright Futures) explained how practical support and help to do things is important and contributed to her feeling more confident:

> *These [staff at Bright Futures] really just help me do things. That's what the organisation has done for me. And of course, if I have a problem they'll listen. They would listen…I'm doing more things now, thanks to these. They get me into these groups and organisations and things …they've helped me a lot, erm, with getting into groups and getting confidence and all that…So I'm a lot better than I was in that way. Now, they helped me getting into college, which I always used to think that I didn't have the brains…I've got support here, they took us there…went with me because at the time I was a little bit unsure about it, not as much confidence, but I soon built up confidence from that.*

Whilst practical help is important, all of the members I spoke to felt that it was much more than practical support and also about the approach of the staff and being with other members. For example, Linda (member, int., Bright Futures) felt similarly to Kathy in terms

of confidence building and put that down to being both in a non-judgmental environment and the activities:

> *It's because staff don't judge you…in the working environment you always get somebody who is trying to take advantage…Here everyone's different, one person can be suicidal and another person can take drugs or alcohol because they're depressed. Everyone's different…in the walking group, cos you're out in the fresh air you feel better, and I love the walking group, cos I love getting out and going to different places and that kind of helps your mental health, getting out.*

Jane (member, int., Bright Futures) explained how the staff at Bright Futures let her be as autonomous as possible and allowed her to do things at her own pace which is important, as is being with other people with similar experiences:

> *Being in an organisation that lets people do whatever they need to do to recover is actually really gratifying, and that's what they did for me as well, they just allowed me to do what I wanted to do, and it helped, it really helped me recover because you get to talk to people, it's sort of in a unpressurised situation where you don't have to talk about yourself, because sometimes when you're coming out of, well when you're in mental health…It's got me out my shell…cos sometimes when you are in the really bad place you want to withdraw, you want to hide, and just taking a leap out, and being in a place where people understand mental health, being around people who have mental health, so you initially wipe all that fear and stigma and discrimination out.*

The importance of being in a non-pressurised environment and spending time with others who have experienced or are experiencing some form of mental distress was important for many of the members. For example, Stevie (member, int., Creative Mindz) pointed out how it was important for her that Creative Mindz was not too demanding and how it was essential to her well-being to be around people in a community setting:

> *Well it's not demanding. I need that because I don't do art that often, because I can only do what I have the mood to do when you have the mood to do it, I can't even make myself do it, but you're welcome to still come here and it's not like you must be busy getting on with whatever and if you're not, then out you go. It's nice to be among people and you can do your own thing in your own way… it's a great benefit where you've got somewhere where you're with a group, we're like a community, we can be ourselves, there's no demand for us to conform, no fear that*

we've got lots of normal people being funny the way they are, or they can be, when you're not like them and it's nice to be in safe environment without all that as well.

Thomas (member, int., Creative Mindz) reiterated similar points and emphasised how being made to feel welcome and treated as equals contributed to the significant impact Creative Mindz had on his life:

It's very relaxing, you're not pressurised into doing anything, there's no hurry, no pressure, the staff are very kind and helpful, it's restful you know… Staff here are great, very supportive, very, always there to help if you want, they're very supportive here, we're welcome here, we're treated as equals… it's not like a formal class where you've got to keep up with the others or work under pressure. Staff are kind and helpful, they don't mind if you have an hour on the easy chair and just doze for an hour, you just do your own thing, I mean they help if you ask but they don't pressurise you.

Similarly, Grace (member, int., Creative Mindz) who had had a bad experience at school said she enjoyed Creative Mindz because:

You're not forced to do anything that you don't want to do and erm, you can come and go, how many days a week that you're not busy, and we're all friendly… we don't have to do anything that we don't want to do and don't get forced to do anything…

Many members commented on how the activities at the organisation were important to them because it prevented them from feeling isolated, and got them out of the house. As Sarah (member, int., Bright Futures) explained:

Yeah, it keeps you out the house a bit longer, I don't like being stuck in the house for days on end. You see I've got nothing on in the morning cos there's nothing on in the summer holidays.

Ian (member, int., Bright Futures) reiterated similar sentiments:

I don't really like staying in the flat, not because I am not comfortable in my flat, but I love being out and about. But I don't like getting the bus…if it wasn't for here, I don't think I would have a social life…I've met a lot of people.

And as Abdul (member, int., Bright Futures) explained:

It's got me out the house, got me doing something at the moment…

Physically getting out and away from the home environment was important for members, but equally, it was the people at the organisation (both staff and members) who had such a positive impact on the lives of the members I spoke to. Moreover, it was not simply the practical guidance which was important; the other members and the attitude and approaches of staff made the environment particularly supportive. Patricia (member, int., Creative Mindz) described how it is the people who really make the organisation:

> *It's been a fantastic life save for me really, to come along and meet the people here who are all dead friendly and everything and to erm, just come along, it gives you a purpose really to get up in the morning…the people, the like-minded people, and erm, I keep saying non-judgmental but I don't mean that but they're just welcoming and just creative, I mean it's just lovely how…you can see with someone, I've witnessed people who have just come for the first time and they've done a piece of art work and they get praised for it and you can tell that it just makes them feel great about themselves...the staff facilitate, they don't say 'you do this this this and this', they just facilitate you being creative.*

For many members, such as Felicity (member, int., Creative Mindz) the organisation was their only support. Felicity's comments highlight how it is the practical support combined with the visceral experience of being with the staff and members which contributed to her feeling more positive:

> C*oming in here it has been in a way my saviour also. In a way I can be myself in here, and also because my husband doesn't support me, or my studies or my work at all, so I have been feeling this is my spiritual home in a way. I have been seeing people who have been having issues with their lives also and they have been, this art has been helping them enormously and I have been always doing art and all kind of things and also, when I was stuck with my studies, they gave me a helping hand also*.

Focusing on activities combined with the supportive approach of staff seems to help members concentrate on the things they can do. The members I spoke to frequently commented on the positive way that staff supported them and most member participants thought highly of staff members' approach to, and administration of, support. Members cited 'autonomy' as being important and at this point it is worth returning to the literature. 'Autonomy' is consistent with studies which suggest service users making their own choices and being able to contribute is conducive to supportive atmospheres (O'Brien, 1990).

Concentrating on members' strengths can be, as Scheyett (2005) asserts, a way to challenge stigma. The relationships between staff and members and between members were regularly referred to by members as being of a 'caring' nature. Concurring with Burns (2004), the personal skills of staff such as compassion, enthusiasm, and empathy staff exhibit are a substantial contributing factor in what members consider to be good non-stigmatising support. A further ingredient identified by members as contributing to positive experiences in the support environment is contact and support from other members or 'peers'. As Shaw (2013) claims, this can lower the sense of stigma and the feelings of being marginalised.

The evidence in this chapter so far suggests that members of Creative Mindz and Bright Futures have experienced stigma and discrimination and that those experiences are described by members as having had a negative impact on their life. However, when it comes to interactions and experiences in the context of support provided by Bright Futures and Creative Mindz, members speak of caring relationships and feel positively towards many of the other members and the staff. Prima facie the members I spoke to had very positive things to say about the organisations and the members attributed this positivity to the relationships which developed as a result of activities and/or attending the organisation. Emerging from the initial analysis process there were a number of areas to explore in more depth. As 'relationships' seemed to be key to what makes the support at the organisations so positive, how were these played out and negotiated in the support environment? As stigma and discrimination emerged as being significant factors in the lives of members I spoke to, how did staff members work with members who have had such negative experiences? Did staff members mitigate experiences of stigma and discrimination? If so, how? How did the wider socio-political context permeate staff roles in supporting members? What was it about the way professionals manage their own role in the context of the organisation which made interactions between members and staff supportive in the face of more negative experiences of stigma and discrimination? Can support, and the relationships which develop in the support environment, reframe negative experiences and/or perhaps reduce feelings of 'difference' which members describe as stigmatising or discriminatory? These are all questions to be explored in the remainder of this chapter and subsequent chapters. What is notable from what I have delineated so far is that members reported stigma and discrimination occurring in other institutional settings, yet in the context of the case study organisations they report something different. Part of that difference seemingly relates to the two 'types' of supportive relationship which emerged from analysis of the empirical material; relationships between members and relationships between staff and members. By

exploring those relationships in more depth, particularly what characterises them, I begin to shed light on their role in non-stigmatising and non-discriminatory support provision.

4.3 Supportive relationships between members as 'peer support': reducing feelings of difference by caring, sharing, and doing

Members' descriptions, experiences and interpretations of stigma and discrimination in 4.1 can be summarised as other people's negative reaction to difference, how others 'treat' difference, and 'feeling different'. That said, the members I talked to during the fieldwork described how support provided by Bright Futures and Creative Mindz had a significantly positive effect on their lives. As introduced above in 4.2, a compelling element of the 'positive impact' members describe emanates from the relationships which develop at, and through, the organisations. Supportive relationships regularly develop between members in the context of the organisations, and this section illustrates how those relationships are often characterised by a combination of 'caring interactions', the sharing of experiences and the practical provision of advice and/or guidance. These relationships will be discussed with reference to what is regularly referred to as 'peer support' by the literature (see 2.5).

Thomas and Stevie (members at Creative Mindz) said they became friends 5 years ago as a result of attending Creative Mindz; I witnessed many interactions between them which indicated that they cared for, or about, one another. For example, when a number of us gathered for the debating group:

> *Thomas asked me where Stevie was and I said I didn't know. He brought a chair over for her and said he would save it. Thomas then got up from his chair and announced that he was going to try and find Stevie in the other room. He returned after a few minutes and said he really hoped Stevie comes through to join us and that it's her birthday today. I really got the feeling Thomas wanted to make sure Stevie was there so he could try to ensure in some way that she enjoyed her birthday.* (Creative Mindz, FN11)

Observations like the one above were common and they suggested to me that many members felt a sense of care towards, or concern for, each other. At other times Thomas appeared to care and support Stevie more practically for example when she had locked herself out of her flat:

Whilst chatting to Joanne (member) over lunch I heard the word 'emergency', and Stevie was rushing around and appeared to be flustered. I asked Peter (staff) what had happened and he said Stevie had locked herself out. Stevie was talking loudly to herself about having to get the bus as soon as possible. With that I noticed Thomas follow her and said he would go with her. Thomas apologised to me for not being able to do the interview we'd agreed to and said that he had to go with Stevie because she was upset and he didn't want her to go alone. (Creative Mindz, FN7)

The above excerpts demonstrate two typical day to day interactions which seemed to involve a sense of care and support between two members; these sorts of interactions were common amongst members attending the organisations. A further discernible supportive interaction involved the death of Denise's (member, Bright Futures) mother and I noted the sense of care and concern amongst the members in the photography group:

Turned up and Neil (staff) was there along with Jimmy (member) and a guy called Graham (member) I had never met before. Sarah (member) and then Jon (member) joined us. Deborah (staff) had told me that Denise's (member) mum had recently died. Sarah seemed concerned about whether Denise was going to come and kept asking the group if anyone had heard from her. Whilst we were waiting Sarah always seemed to be looking around, she said she was trying to spot Denise. Jimmy called Denise to check she was coming. I felt as though everyone really wanted to see Denise to make sure she was okay. Denise arrived about five minutes late and both Jimmy and Sarah gave her a big hug. Denise hugged them back and said 'thank you' to them. I felt really touched by the whole thing. (Bright Futures, FN8)

The majority of the relationships I experienced and talked to members about appeared to be mutually supportive. In the group developing a 'shared decision making' DVD at Bright Futures, I observed and experienced the group members' respect, care for, and acceptance of one another in the sessions. Each member, Jane, Maria, Fred and Jon played a part in the discussion and the way they interacted with one another indicated that they respected each other's thoughts and opinions as they contributed in turn:

Jane suggested they do a timeline for the DVD. Jane suggests an introduction to depression. Jon takes the lead and describes the symptoms. Fred said it should be a brief sketch and Jane asks the group whether they think medical terms go in here.

> *They have a brief discussion and agree they could do two introductions- one from a GP perspective and another from a patient. Jane suggested that this would help people understand the GP's role. Jane takes the lead and suggests having two characters, Maria chips in and suggests the characters both go through their day. Fred interjects and says there should be more emphasis on the patient because they are the experts in their own feelings. Jane says she really likes that line and Jon and Maria nod in agreement. I am impressed with how democratic and respectful the whole process is; there is no animosity or anyone overly controlling. Whilst Jane takes the lead, everyone else looks relaxed but also engaged. It's actually really nice to listen to and be part of- some of my ex-colleagues could learn a valuable lesson here!* (Bright Futures, FN10)

The above conveyed a democratic process imbued with a sense of mutual respect. Later in the session Jane offered practical support to Fred to help him set up an e-mail account so he didn't feel left out of group e-mails:

> *Jane says she will write up the meeting notes and send them to the group via e-mail. Jane asks Fred if he has an e-mail account yet. Fred says he does not. Jane offers to help him set up his email account so she can send him stuff because she says she feels bad he doesn't get all of the stuff they circulate by e-mail. Fred nods and said that would be really helpful. It's really nice to see that they actually give a shit about each other and Jane is going out of her way to help Fred.* (Bright Futures, FN10)

The way members provide support to, and care for, one another whilst attending the organisations suggested an element of 'peer support'. Morgan (2014:208) describes peer support as being:

> …where one disabled person draws on their own experience, knowledge and skills to support another disabled person. Peer support recognises the value of shared lived experience of disability and the contribution disabled people can make to one another.

'Peer support' is often used to describe people with experience of mental distress being paid or volunteering to support and advise others who also have experience of or are

experiencing mental distress. However, it can also be much more informal and can refer to a sense of 'mutual support' as Davidson et al. (1999:168) explain:

> …mutual support as a process by which persons voluntarily come together to help each other address common problems or shared concerns… and may offer participants acceptance, support, understanding, empathy, and a sense of community.

Peer support, paid or unpaid, is endorsed by national mental health policy (Dept. of Health, 2011a) and Solomon (2004) suggests mutual support offers a sense of belonging, and the perception of being valued and cared for. Much of my empirical material relating to relationships between members reflects similar sentiments to those found in existing literature indicating that peer support promotes a sense of inclusivity where compassion and care permeate the environment (Gillard and Holley, 2014).

Having noted how members care about, and for, other members, there was also substantial evidence of members sharing experiences and practical tips with one another. The following excerpt, taken from my observations at the hearing voices group, suggests that it wasn't necessarily the content of the 'tips' which was important but what the sharing signified and the rapport it created:

> *Dave (staff) asked the group what tips they would give each other. Chris (member) said he would be kind rather than be instructive, try to help out other people who hear voices and not turn against them. Dan (member) looked up from his hands and said he would be the same as Chris. I felt that just saying what the members said out loud was a way to let each other know that they were there to support one another and saying so contributed to the friendly and supportive environment.* (Bright Futures, FN31)

Generally speaking members reported that being around other people who experience or who had experienced mental distress was beneficial to them. Derek (member, int., Creative Mindz) described the importance of being alongside and talking to "likeminded" people:

> *Erm, being with people who are like minded, people who have had similar problems to meself, people who talk to you on a one to one basis…*

Many members stated that being around others with comparable experiences of mental distress made them feel accepted which suggests feelings of 'difference' may be reduced i.e. their experiences don't make them feel 'different.' This may be because their peers have similar experiences and that 'difference' in the context of the organisation and between peers wasn't always seen in a negative light as it is in the case of stigma and discrimination (4.1). As Jane (member) explains in FG2 at Bright Futures:

> *Erm I think it's also the fact that he [Jim- the composite character] doesn't feel alone here and he's where there are other people with the same sort of conditions…so maybe less of a freak, less of a mental freak…*

Many members emphasised how it is the small things that make a difference, such as sharing food with fellow members and making cups of tea for one another at the organisations. As Grace (member, int., Creative Mindz) highlights:

> *We just like to talk and share biscuits and cakes and fruit and that, because people bring it in and that's what you're supposed to do, share and it makes it nice...*

This sense of togetherness and community acceptance is said to be key to supportive relationships between peers (Wong et al., 2010) and members described a degree of comfort as a result of sharing experiences and hearing other people's stories about what they'd been through. Sharing experiences through talking is the ethos of the current anti-stigma campaign 'Time to Change' (2015b) and it seemed to make members feel less alone in the world. For example, Maria (member, int., Bright Futures) described how knowing about others with similar problems made her feel less isolated and provided her with motivation to keep coming to Bright Futures, even when she didn't feel like it:

> *There's so many people that's got similar problems, so you feel like you're not on your own, you don't feel isolated, you don't feel like you're going mad you know. It seems to, it makes you realise I think how many people are out there with similar problems and coping and managing and I think, the deeper you sink back, into that, and your emotions, it's harder to get back again, but once you get back, it's nice to stay…*

Owen, (member, int., Creative Mindz) explained how he liked to help other members and from our conversation it seemed as though helping others made him feel useful. Owen

described trying to help people who may be experiencing distress by not subscribing to psychiatric labels or understandings of 'mental illness.' Owen was the only participant who tried to support others using his understanding of mental health politics to help others; a role traditionally associated with peer support related to collective action or political advocacy (e.g. Chamberlin, 1978; 1996; Deegan, 1992; Diamond, 2013):

> *By listening, not to judge them and not to say 'ah well it's your illness' because I know for a fact if you're having a problem in your life, and people say 'you're just paranoid, it's your illness', that makes you worse, so the way I go about helping people, is not being judgmental, but being there as a friend and trying to help them feel more safe and then, if they have a delusion, being able to talk through the delusion with them, in a way that hopefully sometimes will make them feel as if what they were thinking perhaps wasn't real. But one of the mistakes I don't make is to say, 'ah well you're deluded and you're paranoid', as I said because that makes some people worse, because you know, it's like a negative thing, but I have got the ability now, sometimes with some of my friends to be able to, as I say to talk them out of their delusionary thoughts…*

Owen's comments suggest how he uses his own experiences to help others and in another part of our interview Owen said that he enjoyed that role, implying that the relationships he developed by supporting others were beneficial to him too. Many members gained strength from helping others which illuminated how the bond between peers can help address social isolation, a notion recognised by other studies (Coatsworth-Puspoky et al., 2006; Repper and Carter, 2011). As Ian (member, int., Bright Futures) illustrated:

> *If it wasn't for here [Bright Futures], I don't think I would have social life…I've met a lot of people, I've exchanged numbers with two people and two years ago I wouldn't have done that because I was the new guy and there were twelve other people at the group I didn't know, but because I've been here longer, it's like, I'm like helping these other people really.*

Kathy (member, int., Bright Futures) describes her shock, but also realisation she wasn't alone, when she attended a mental health course and that sharing experiences, along with attending the course itself, helped her:

> *I started the mental health course, I got a shock, at how many people there, in that group, had, got problems, just the same, so that was helping me a little bit, some of*

them have problems and are maybe even worse. I thought I may as well explain a bit about myself, just a little bit…so that made us feel better and of course, there was other people there who were training for university and stuff like that, which helped, I was like amongst good intelligent people, at the same time, mixed in with people who know what it's all about. So it was like a mixture, so that made me feel better.

Kathy's comment emphasises the importance of reciprocity and suggests that it is a combination of the sharing and the 'doing' of the activities which makes the difference. Thus, whilst caring for, or about other members and sharing similar experiences is important, I also found that the 'doing' of activities and practical exchanges of skills between members to be significant in supportive relationships between peers. For example, Felicity (member, int., Creative Mindz) not only described exchanging practical skills, but also explained how providing and receiving practical support had helped her learn from others how to help and how to ask for help. It seemed deeper meaning was attributed to the practical interaction:

There is lady [another member] who knows everything about sewing so she has been helping me cutting the pieces for my coat, and then, it's so funny, she was saying she felt exhausted afterwards but a great way exhausted but by giving help is at same time healing themselves…I've helped people that way in here and I know…And also I have learned how to ask for help, because my middle sister was saying to me, 'you never even ask for help', and I say 'I know because I have been in here <points to head> so long that I have learnt to cope on my own'...but now is different

Support from another member helped Felicity develop her own skills; her sentiments about reciprocating support seem to follow the "helper therapy principle" whereby the non-passive role of 'helper' makes an individual feel valued (Riessman, 1965; 1990).

Generally speaking, empirical material considered in this section follows the literature in this area. For example, comments from the members are consistent with Mead and MacNeil's (2006) claim that:

…people who have like experiences can better relate and can consequently offer more authentic empathy and validation…helping people rebuild their sense of community when they've had a disconnecting kind of experience.

Moran et al. (2014) also suggest sharing personal experiences as a resource in the way many of the members I spoke to did help people with experience of mental distress to connect with one another. However, it's not just the experience of 'impairment' which cements new friendships (Hewitt and Pound, 2014); it is just as important for people to 'hang out' with "exiled others" (Pound, 2011). The empirical material emphasises the importance of 'reciprocity', this is consistent with literature which suggests the notion of 'reciprocity' is key to supportive relationships (Bracke et al., 2008). The empirical material also supports the argument that the exchange of skills leads to members feeling important to each other (Taylor and Turner, 2001), increasing feelings of competence and usefulness (Skovhiolt, 1974) where other members help one another develop their own skills (Salzer and Liptzin, 2002).

The relationships which develop between members seem characterised by interactions which are deemed supportive by members (whether they be practically exchanging skills or sharing stories etc.). Thus, it is important to emphasise the integral significance of the support context which enables these interactions to occur. The staff members are also instrumental in providing a context for these interactions to occur which will be considered below (4.4), but without the context of the organisation as a place to meet other members engaged in similar or joint activities, it is unlikely these interactions would occur. Thus, the context of the support environment seems to enable these interactions which members find supportive and non-stigmatising. Furthermore, members' descriptions of stigmatising experiences in other contexts (and not at the case study organisations) highlight the importance of context to the stigma discourse. The only nuanced difference between the organisations that I identified that is relevant to member relationships relates to Creative Mindz being a building based service. Whilst members regularly attended the studio for particular sessions such as water colours, ceramics, creative writing etc., they often spent the whole day in the studio working on their own art pieces and talking to other members. Bright Futures is not a building based service; some sessions such as hearing voices, bipolar support, DVD group etc. are held in the building at specific times only and most activities take place outside of the building and this was actively encouraged. As a result there was more scope for members to mutually support each other at Creative Mindz in the ways described above and more opportunity to engage in mutually supportive interactions on an informal day to day basis. The significance of this difference is important when we think about designing mental health support services; having a place for members to come along and 'hang out' creates more opportunities for care and support between peers. Implications of this difference in the 'set-up' of Bright

Futures and Creative Mindz reoccur and thus will be revisited at appropriate points in the remainder of the thesis.

The relationships members developed between each other and described as positive and significant were about caring about or for one another, sharing stories and space with one another, and taking part in activities together along with providing each other with practical advice. Consistent with other studies (e.g. Faulkner and Layzell, 2000) I have emphasised how it is important to members to feel accepted, share experiences, be emotionally supported, and feel safe, secure and relaxed. Whilst I have described how many of the relationships which develop amongst members are caring and supportive, there were a number of limits to those relationships which are important to explore and relate to the context of the support environment.

It was evident that in most cases the relationships developing in the support environment remained within the support context. For example, during our interview, Patricia (member, int., Creative Mindz), explained how a friend helped her settle in at the organisation during the first few weeks she attended. Patricia only saw her friend at the studio and that relationship didn't extend much further, apart from a few texts which she felt reluctant to send:

> *It's unfortunate XXXX <friend and member> who introduced me to the studio, she hasn't been well, I heard that she's been in hospital but I don't, I haven't heard from her so…I hope she does come back…I don't know what's happened to her…*

V: *Do you speak to her outside of the organisation…Like would you text her or anything?*

P: *Not really just an odd text …it's funny, well not funny ha ha, but it's funny with mental illness I don't know her well enough to know whether my texting her might pressurise her in some way or make her feel bad that she hasn't been in touch so I just left it. I'm sure it'll be fine when I see her here again but erm, yeah…*

In this particular instance, Patricia's reluctance to get in touch stemmed from being sensitive to how her friend might be feeling with the implication her friend will come back when she is ready and then their relationship will continue. This perhaps accentuates the limits of their relationship in terms of how well Patricia and her friend know each other. Similarly, other members describe how their relationships with other members they get on with well and often describe as 'friends' are conducted via organisational activities only. For example, Linda (member, int., Bright Futures) said she made friends with a member she

met on a course and they exchanged numbers but they only see each other at organisation activities:

> *Well she was getting her food hygiene and first aid and we met there and got on really well, and she comes on Monday for the social and I just see her there…*

Sarah (member, int., Bright Futures) reiterated Linda's comments and explains she has made friends but doesn't see them outside of organisation; telephone calls are usually made in relation to what they're doing at the organisation rather than anything else:

> *I do have a friend that I hang around with in photography, XXXX. She's not here today…I didn't know her at first, when she appeared I thought, 'who is she?'…but yeah, she's lovely.*

V: *How long have you been friends with her?*

S: *Oh it'll be a good few months.*

V: *Do you meet up outside of the photography group?*

S: *Not really no, sometimes she rings me, if, she's done that before. She rang us when I was on the toilet in the library <laughs> I was like 'excuse me' <laughs> but she was checking that I was still coming…*

Previous studies suggest that people who have experienced mental distress avoid disclosing their involvement with a supporting organisation (Camp et al., 2002) and that as a result, peers are reluctant to identify with one another outside of the organisation (Hall and Cheston, 2002). The participants I spoke to did not suggest any similar reasons for not extending their friendships beyond the support environment and nothing the member participants said indicated that these 'in-situ' relationships were particularly problematic for them. Perhaps members I spoke to have enough friends and family to socialise with outside of the organisation? Maybe members saw the organisation as an extension of their social life anyway, so there was no reason to see other members outside of that? It is not clear from the empirical material but perhaps it does represent an example of the limited reach of the relationships formed in the context of organisations like Bright Futures and Creative Mindz. This led me to consider other possible limits to the relationships between members, particularly in terms of the tension between members.

Many members flagged up tensions in some of their relationships and talked about problems they experienced getting on with particular members. An example of this is demonstrated in the following fieldnote:

> *Spoke to Joanne (member) about the puppetry sessions and asked if she fancied joining us. She said Stevie (member) has put people off going because she sings and plays music throughout the session. Joanne then said her and Stevie had a run-in last week. I asked what it was about and Joanne said that she had brought in hot dogs and mustard for everyone to share and Joanne spilt mustard on her shirt and she went to the toilet to clear it off. Stevie was banging on the door saying 'hurry up' and causing a scene. Joanne said that she doesn't like using the bathroom, it makes her nervous because of her experiences of being abused. Joanne added that she is bulimic, and when she has to be sick and feels it, she has to make herself sick. Joanne starts crying and I ask if she's talked to anyone else about it. Joanne says she told Bella (staff) and also said that Felicity (member) won't use the toilet on this floor because of Stevie, and that Stevie 'just doesn't think'…* (Creative Mindz, FN19)

The above example illustrates how Joanne did something which was characteristic of care and mutual support at Creative Mindz; bringing in food to share. However, this was spoiled in Joanne's eyes by the lack of care that Stevie demonstrated which created tension and upset. Kathy (member, int., Bright Futures) recalled an experience when a relationship she developed through the organisation didn't go very well and tension ensued:

> *Well it was a man anyway, it was somebody who I thought seemed canny and it wasn't anything like that, like relationship or personal, wasn't like that, more of a friendship, I knew he had problems too, didn't realise how bad they were. We met at the computers here, we met doing the same thing, and…we went out for a coffee and stuff like that, like friendly coffees and stuff like that, and I give him my phone number and, things like that, just to make a friend really…He was interested in doing drama and all, and I said 'well actually I go to a drama class' and I got him in it…I took him in, I did their job <points to office>... That's where I got the idea from, and I took him down and helped him sign in and fill the things out and then…he said he liked me and all this, then he just wanted to be friends, he didn't know, his mind was confused and then, I went near him, like as if I was affectionate, not affectionate in that way, but like you would may be with your family or your friend, not like in that personal way, and he got the wrong idea because it happened at me drama group and he rung me up, no he didn't, he avoided us, he was ignoring us,*

avoiding me phonecalls, I thought it was something that happened here, and I felt really awful, there's something I've done and I was a little bit upset about that and I came here and explained here and that was a little bit…By giving him a friendly peck on the cheek like I would give to me son, or give to me mother or me sister, he got the impression that it was something more and I thought, it really hurt me, the way he said it, it wasn't in a nice way like that…I thought well you know, that is really hurtful, that if someone goes near you like that they think you want a relationship, if you look at it that way, I'm not in a relationship with me brother and mother- if you like…I think it's best to keep away, not to get really involved and that of course, he's still at my drama group, I've got to put up with him but I don't go near him, I just get on with my own business, he frightens me a little bit you see.

There were other times when it seemed members weren't keen to share stories, or perhaps didn't want/require the support of their peers, highlighting that it is important for members that the sharing of stories is voluntary. For example, in the DVD group at Bright Futures:

Jon (member) questioned whether IAPT [Improving Access to Psychological Therapies] *work in the same way i.e. working out how depressed you are without medication. Fred (member) asked Jane (member) if she was ever in touch with them, she said 'no' and looked down at the paper in front of her. I noticed a change of atmosphere; Jane said it was the crisis team she first spoke to, they were forced on her and that she had no choice. She said, 'mine was a different route unfortunately.' Jon opened his mouth as if to say something but I noticed he didn't. It went quiet for a few seconds and I got the feeling Jane didn't really want to discuss it any further and sensed she felt uncomfortable.* (Bright Futures, FN13)

When some members reflected on their relationships in the support environment, they reported that they didn't always feel they could get on with everyone. Maria (member, int., Bright Futures) said she initially felt unable to get on with people she thought were more educated than her. However, Maria described how tensions and negative expectations turned into a positive experience for her via attendance and the DVD group and helped her overcome barriers:

I was a bit nervous around them <the DVD group members> at first…I think they're more educated than what I am, so they come from…We were just discussing it you

know, and they seemed to be coming from an educated background and things like that and we were just talking and I just thought 'I haven't done anything', you know what I mean? And I felt a bit out of it and then I thought 'well no, I'm still proud of who I am and where I've come from' and I just think, 'I'm Maria from the block', you know <laughs> and we just start laughing. So, just things like that, it's that barrier as well you know but we're all the same, we just come from different backgrounds.

Other members felt similarly. When describing composite character 'Jim' in FG2 Jon (member, Bright Futures) said:

Some users he has problems getting on with, particularly people from a completely different social background…

This suggests how other identities other than those associated with mental distress are important (Wong et al., 2010), particularly in terms of forming meaningful and supportive relationships. In our interview, Jon (member, int., Bright Futures) explained a little bit more from a personal perspective about friendships with other members. He highlighted how some friendships often only last for the duration of a member accessing the service:

I've made a lot of friends but the thing is, when you're with, when you're with people with mental health problems as well, or some of the relationships are a bit tenuous, a bit dubious, you know, a lot of the friendships don't really work out in the long term, because of the problems people have and you know, if you've got problems and another person's got problems it is difficult to establish like long term relationships…My long term friendships did last a few years but they have sort of petered out as these people aren't accessing Bright Futures…

Jon's comments suggest that whilst relationships which develop in the support environment between members can be a source of mutual support and comfort, relationships often remain in context, or decline because of people's problems or when members stop attending activities at the organisations. Thus, although relationships between members can be positive and transformative, positive relationships don't automatically ensue simply because members spend time together in the same place. There can be tensions, just like there would be tensions in any other area of social life.

The empirical material indicates that the relationships which develop between members in the support context are often very valuable to them. The findings begin to suggest that meaning, care and support in this context can be developed through mutually

supportive interactions between peers. Moreover, these interactions and ensuing relationships seem key to supportive and inclusive environments where, to borrow from Link and Phelan's (2001) concept of stigma, members do not feel 'set apart' from one another. The empirical examples demonstrate how members develop a 'sense of purpose' by reciprocally providing practical and/or emotional support to their peers and by sharing experiences. Members' comments strongly suggest that such relationships can reduce feelings of isolation and 'difference'. Before attempting to conceptualise the phenomena at play in 'member to member' relationships and their part in the mitigation of negative feelings associated with stigma, I will explore how similar concepts of care and the sharing of experiences are also important for supportive relationships between staff and members.

4.4 Relationships between staff and members: 'caring' support and sharing stories

In 4.2 I introduced the reasons members gave as to why they found Bright Futures and Creative Mindz such supportive organisations. Members overwhelmingly reported that staff had a positive and profound impact on their lives and said this was because they felt staff members weren't judgemental, bossy or always telling them what to do. Members also described how staff members were enthusiastic about members' lives, empathetic and let them progress in their own time providing guidance on practical skills and emotional support when required. This approach is reflected in each organisation's code of conduct governing the staff-member relationship. Bright Futures' principles included being compassionate and hopeful, open and friendly, inclusive and fair, valuing experience and expertise (including staff experience of mental distress), being creative and innovative, and going the extra mile with people to achieve the right outcomes for the individual member. Creative Mindz' core principles include ensuring a safe, inclusive, respectful and friendly environment through the practice of art and creativity. By considering interactions between staff and members in the support environment, along with what staff and members had to say about those relationships, I will use this section to explore *how* staff achieved this sort of support. In doing so I consider the interactions which characterise the relationships and how staff sharing their own experiences of mental distress is particularly significant for many members.

Similar to the findings relating to 'member to member' relationships explored in 4.3, the notions of 'care', 'concern' and/or 'compassion' were important ingredients of a supportive relationship between staff and members. Members emphasised the

importance of feeling that staff 'cared' about them as they were carrying out their support role. As Maria (member, int., Bright Futures) explained:

> *Knowing that these care and understand, cos sometimes I think when you've got depression and you're going to do something and you don't do it, it's like, don't bother with them they won't bother coming back, it's that sort of thing as well, you know what I mean? And because when you've got depression you tend to not go to appointments and you tend to, and people think you're mucking them about and you're wasting their time and I suppose you are, but it's not intentionally. But here they understand…it's nice that they ring you up the next day as well*.

Maria's comments, like many others, suggest that the way staff support her makes her feel cared about. Maria's further comments hinted at how she appreciates staff members' approach to support:

> *I think cos they make it just so matter of fact, they don't make a big deal of it. They don't sort of like, you're not mollycoddled, you're treat as an adult, an individual and it's your choice, you're not obliged to, you're made to feel that it's all your choice and they're just helping you, giving you that little bit of support.*

In FG2, Jon (member, Bright Futures) described how the organisation helped composite character Jim and gave an example of how members feel that staff care, particularly when members may feel other people in their lives do not:

> *It's nice for him to expect a phone call now and then, you know, cos obviously here do chase you up on the activities…Instead of, you know, maybe just waiting for his family who don't contact him much or something like that, there's also somebody else there to phone him...*

Ian (member, int., Bright Futures) recalled a time when the approach by staff helped him through a difficult time by providing the right amount of practical and emotional support:

> *I mean, there was a time when I was isolating myself, I wasn't going out at all, me mental health was deteriorating, they didn't give up, they kept ringing me and asking me how I was or do you fancy doing this group and all that*.

Other members, such as Derek (member, int., Creative Mindz) told me about a time when he felt he had been supported in a more practical way but indicated that this was associated more generally with the positive approach of staff:

> *I was doing a picture of Guinevere for someone in church…I got a picture from the internet and I used that as the basis of a painting, this guy had heard a song by Crosby Stills and Nash, they did a song about Guinevere and it had inspired him and he asked me to do a painting of her based on this song, so I looked on the internet with the help of XXXX [sessional artist], he got the image from the computer and I used that as the basis of me painting, because I didn't know what Guinevere looked like you see, so I selected what I thought was the most appropriate image, because there's quite a lot of pictures of Guinevere on the computer, contemporary actresses and old paintings and things like that. So I'm, I wanted to do this painting, and XXXX [sessional artist] suggested I do a tracing to get the proportions right of the figure of Guinevere, from the print out we got from the computer and I used that and XXXX [assistant manager] has helped me with colour mixing because I'm a strong draw-er but I'm not very good with colours. So people are helpful, erm, it's a positive attitude, I mean XXXX [manager] is extra specially positive...*

Owen (member, int., Creative Mindz) explained the importance of the environment created by both the staff and the members. He identified that the environment promoted positive relationships which are not focused on "illness", which is the "mistake" staff at other services make. Owen emphasised the importance of a space just to 'be' and Creative Mindz provides the physical and mental space to do that:

> *If I was somebody else, I would think it was like, a little bit like a social club in a way, I mean there's like, since it was open, the studio, it gradually progressed from just kind of doing art to being able to sort of talk about difficult issues that you want to talk about or you know, mental health problems or anything that's bothering you, people are starting to gradually realise that XXXX [studio manager] can help them and start talking to XXXX [studio manager]…you see the mistake the services make, in the past all of the time, was to concentrate and focus on the person's illness all the time; when that happens, the person don't ever get the opportunity to develop themselves as a person that could be well because it's all focussed on the illness*.

Particularly important for the 'staff-member' relationships for most members was the notion that staff 'knew what they were talking about' from personal experience. I have

already explored how members found sharing stories and experiences of mental distress with one another specifically supportive and there are some parallels to be drawn with the findings in the previous subsection. However, there are some additional key complexities around the power differential of staff and members when it comes to disclosure and it is important to begin to explore how that 'plays out' in the support relationship.

Carl (member, int., Bright Futures) felt that staff members with experience of mental distress provide a different perspective to the traditional professional/therapeutic relationship, by comparing Bright Futures and his experiences of psychiatry:

> *Steve who started to run this group, he was running the group when I came and his bipolar experience has, it gives you a different perspective…knowing that he's been through it… I think Steve in particular, I like him very much because he's using his experience of bipolar to help people come to terms with their own, so I think that should be more promoted, people who have suffered mental illness and recovered from it, or at least learned to manage it, maybe not recovered from it, but learned to manage it successfully, erm, should be more, more able to get into a position where they can help others to understand …I find people are more open here because they're more comfortable, if you're more comfortable you're more open…not that I'm not open with pretty much everyone, it's just sometimes I'm just guarded with what I say, like with my new psychiatrist today…this morning, I was quite guarded with what I was saying because, well like I say, I couldn't google him, I didn't know who he was and what qualification he had, where he studied and he had read all my notes, so he already had the upper hand…so I was like, howay, a two way street…a lot of them are about control as well…I feel the psychiatric evaluation should be a negotiation not a consultation, you know, it's a two way street, you can't completely close yourself off from someone and expect them to open up to you*.

Carl's comments highlight how many members believe that the more open staff members are with members, the more members open up and feel comfortable; members appeared to enjoy the element of reciprocation and sharing with staff. Like Carl, members often compared their experiences at the respective organisations to experiences of the psychiatric profession with their 'stricter' professional boundaries. Staff sharing their own experiences seemed to bring staff and members together rather than create a barrier or a sense of separateness which is likely to emphasise difference.

Members believed lived experience of staff members to be an asset to the performance of the support role. For example, when member participants in FG3 at Creative Mindz constructed the ideal member of staff, members felt it was important for staff to have some experience of mental distress (the character members had created was transgender support worker 'Simone Garfunkel'):

V: Right so what other qualities and experiences does Simone have?

D: Lived experience…and experience of discrimination…and being confused

V: How does Simone help Mickey?

St: A lot of people who are transgender, they've gone through the mental health system they've had to go to countless psychiatrists just to prove they want the sex change, so she will have some empathy for what he's gone through. I had a friend who went through it, they have to wait, it's like psychological torture…but it's to make sure they want it done.

V: So has experience…

D: They could compare experiences, talk about and compare experiences…

Being able to compare experiences with staff and for members to feel confident that staff members know what they're talking about was reiterated by the member participants in FG2 at Bright Futures when constructing composite character of a member the group called 'Jim':

Jon: He has also witnessed how people who suffer from the illness can progress because people who work here suffer from certain illnesses…Erm, he sees that there is a lot of positive light in the world because you know, a lot of people are much friendlier than he thought about his illness…Jim has more chance of working in some sectors such as Mind charities and stuff like that because of his, he's got a better chance in some jobs than others, because like here could help him get voluntary work in MIND and other mental health organisations…so in essence he's using his illness to his advantage to get work…

The idea that staff know, or may have experienced, what members go through is important for the staff-member relationship and for members to feel that staff have a sense of integrity. As Kathy (member, int., Bright Futures) explained:

Actually, what I think, I'll say this, probably half the majority of staff in here, I think probably have problems themselves and that's why they're so brilliant because they know what it's like themselves. You know…Just sometimes you just think one knows each other, you know what I mean, without saying, you can tell…like I said before, we've all got some kind of hang up, everybody has, some kind of vice. But of course, they've got qualifications…which even people like me, apparently, can get qualifications you know.

Kathy thinks staff members being personally familiar with what mental distress is like makes support staff better at their jobs. Kathy's remarks about gaining a qualification to be like the staff indicate how staff with experience of mental distress can set an achievable example. Rather than qualifications creating a barrier or feelings of difference, because of the sharing of experience Kathy sees herself as similar to the staff and not different. Yvonne, (member, int., Bright Futures) made a similar comment about how the member of staff leading some training talked about their own experiences and set an example as somebody Yvonne might aspire to be:

I complete anxiety management with XXXX and she's amazing, she's a great personality person, very trustful and genuine, because when she talks about subjects she exactly knew, because she passed this, she is not shamed telling about her experiences with her mental illness but she's fully independent and fully active. She is like my, somebody I always, when I was younger, I wish to be, as an adult.

During my time at each organisation there were a number of occasions when I was participating in a group and a staff member spoke about their own experience. For example, in the writing group, Kirsty, staff member at Creative Mindz, used her own experiences and encouraged us all to do the same. It made me feel as though I wasn't in a traditional 'staff-member' or 'professional support' relationship because of what Kirsty spoke about and how Kirsty talked about herself which seemed to stimulate a certain way of working:

Kirsty collected the other members from the other room after our break and says she is going to read a poem. Kirsty says she is trying to get across to us how we can write about a situation where we might have felt vulnerable by thinking about what a situation tastes, sounds, looks, feels and smells like. Kirsty read her poem, everyone listened intently with their eyes fixed on Kirsty. When she finished she

said the poem was about reporting a sex crime and it was based on her own experience. Kirsty suggested we think of a situation where we might have felt vulnerable and do some free writing on it. Kirsty said for us to think about four metaphors and similes, she says hers were quite dark but she used it to illustrate vulnerability and encouraged us to write something that is emotionally charged. (Creative Mindz, FN12)

Members in the writing group seemed to be 'with' Kirsty as she read out her poem; Kirsty doing what she was asking us to do was of key importance and made me feel like there weren't any obvious barriers between Kirsty and the members in the group. Kirsty's approach seemed to create a safe space to discuss personally uncomfortable and emotional subjects through the medium of writing.

Listening to what members were telling me and experiencing staff disclosure for myself was integral to the study. However, it was also important to take into account what staff thought about talking about their experiences of mental distress to make sense of the 'sharing dynamic' between staff and members. Four out of five staff I interviewed at Bright Futures said they had experience of mental distress which they would talk about under the 'right conditions' with members. The organisational ethos of Bright Futures is that staff should only disclose details of their own experience if it will help a member and not to meet the emotional needs of a member of staff. At Creative Mindz two out of five staff I interviewed said they had experience of mental distress. There was no specific policy at Creative Mindz about disclosure but the approaches of staff were often similar in each organisation.

Staff with and without first-hand experience of distress said that employing staff with personal experience of mental distress was important and, in the opinion of staff members, it is good for members to know that 'mental health problems' can affect anyone; experience seemed to be heralded as a useful tool to "teach people" by example. Daniel (staff, int., Creative Mindz) expressed this sentiment in our interview:

I talk to everybody about it because I think it's really important to show that, or to teach people that mental health, doesn't discriminate in any way, it can affect anybody at any point in their life...

It could be said that staff members who experience mental distress such as Daniel use their personal experiences as a resource to help others and connect with others (Moran et al., 2014). Steve (staff, int., Bright Futures) felt sharing his own experience of being a service

user of Bright Futures helps members see themselves in a less negative way and not different or separate from other people. Steve describes it as a way of gaining respect and using himself as an example:

> *The majority <of members> probably sort of look at their mental illness and see that it sets them aside from other people in a negative way, and part of our job is to use purposeful and meaningful activity to sort of get them to achieve things and get them engaged in that so the self-stigmatisation isn't as strong…in the bipolar support group I always tell people that I'm bipolar myself, and that makes people feel easier in the…and I think people have a bit of respect that I actually managed to get a job and stuff and that I was a bit of an example maybe, I'm not sure, they didn't say that, but they felt more at ease and that I knew what I was talking about, and it's turned out to be quite a good group…*

Steve's quote highlights how many members may feel 'set apart' and different from other people in society and so when staff tell members about their own experiences members may feel more confident in themselves and more confident in staff because 'they know what they're talking about'. Faye (staff, int., Bright Futures) explained how telling members about her experiences can give them space to think differently and open up to staff:

> *I have OCD, I find that people who come here, for all we're a mental health organisation, are a little bit shy and don't know how we're going to treat them because they have a mental health diagnosis and sometimes I feel it appropriate to sort of say to them, oh yeah I understand that, I've got problems, or I've had problems in the past with anxiety or, I've had experiences with mental health myself, and I think that allows them that space to think, well, if it can happen to you it can happen to me and a little bit disclosure can help them to disclose themselves*.

The above accounts demonstrate how staff experience can be used to set an example, help members with their own confidence and to mitigate feelings of difference, gain respect, deepen staff empathy, and provide members with the space to think differently about themselves. Staff members I interviewed were particularly keen to talk about how using their own experiences can help members. For example, Dave (staff, int., Bright Futures) told me about how he uses his experience of helping his brother:

> *I use me brother as an example in the hearing voices group…and he has voices, so it's an example in the voices group where someone says, 'I hate having voices, I*

hate it, it's nasty it's horrible.' So I'm like, 'has there ever been a moment in your life where you've had voices and they've actually been quite positive?'…my brother hears four voices and he classes them as his brothers, he took an anti-psychotic and one of them disappeared and he mourned the death for a while. He couldn't get used to not hearing it. So, it's like 'well, he doesn't suffer with voices, he quite enjoys them, some of them are nasty but not all, what about you guys?' And then eventually, you pick away at things, and there'll be some sort of, 'oh, actually once, I drew a picture and voices were sort of complimentary'.

Dave's comments suggest that he uses his life experience to tease out positivity in members' experiences. Faye (staff, int., Bright Futures) discussed how she disclosed details about her own experience to get members to open up to her a little more:

You test the water. It's a little bit of disclosure, a very small amount. I've had people say to me 'well you won't understand because you don't know'. And I've said ;well I have had experience of that', and they've went, 'oh yes?' and I went, 'yes, I had a family member who had really bad anxiety', which I did, it was my mother but I never told them that, and I've lived with that for a long time, so sometimes I do say I've had experience in the past of it, but not disclose too much and sometimes I do say…I met someone who had OCD, and was very tense and then I'd said, 'actually I have OCD aswell' and they're so relaxed, their body language changed, their attitude changed, they gave me lots of information, lots of things about themselves, and it was a really good conversation. But I'm always aware of not giving too much information and turning it into a bit of a mutual counselling session <laughs>…I've got a balance with, I do say to people, 'you know things are possible, but you have got to work at it, it's not going to come to you, you do have to do something, but at the same time I can understand that you're not in the right place to do it, because a few years ago, I wouldn't have been in the right place to drag myself out of it…'

Faye explains how disclosing details of her own diagnosis can have the effect of making members feel at ease and more comfortable with the support relationship; disclosure seems to aid the support relationship and a way to build trust between staff and members. Trust is widely recognised in academic studies of professionals as an integral element of a successful supportive relationship (Banks, 2004: 167-9) and it is said to be extremely important to good and supportive 'person centred' relationships between practitioner and service user (Beresford et al., 2011:248). However, as Faye's comments illustrate, staff

members carefully manage the information they disclose. For example, Faye says she doesn't 'disclose too much' or information that is too personal to her all the while ensuring she is disclosing information for the benefit of the member and not herself which is consistent with Bright Futures' policy. This is a careful negotiation and staff think carefully about what they disclose as to not compromise a 'professional position' and consider what they think will be most useful to particular members, recognising that some members may not be in the 'right place' to hear it. Daniel (staff, int., Creative Mindz) said he was willing to talk about his own experience of mental health difficulties "to a point", but then he would pull back:

> *I don't say if I'm having a day where I'm struggling personally for whatever reason, and my private life, me, my partner, but I talk about my family, and my brother and my two nieces who I absolutely adore, so I make conversation like that, but that's slightly detached from, although it's your personal life, it's not as personal as how you're feeling on a day to day basis. I think, if for whatever reason you did fall out with a member, they've then got something that they can….it just doesn't feel right.*

Staff members take into account a number of things when they are talking about themselves to ensure they don't say anything too personal and nothing too present/immediate. Staff members provided different reasons for this, for example Faye suggests, following the organisation's policy i.e. she is aware it shouldn't be a "mutual counselling session" and Daniel because he believes that information may be used against him. Most staff with experience of mental distress found it easy to keep to what could be described as 'boundaries' between themselves and members; part of that negotiation was selecting what is 'relevant' and 'appropriate' to talk about. As Steve, (staff, Bright Futures) explained:

> *Obviously I do respect the professional boundaries but, I'm quite open about myself to people I think it is relevant for them to know about that and, aside from that, I think boundaries are really important, not to get too involved, not to form too strong a relationship with someone, just a therapeutic relationship is what it's all about, that's why we're here….I don't come in and put a professional front on at work, but like I say, I do know when to pull back. It's hard to explain…*

Steve describes negotiating what is relevant for members to know and emphasises the importance of not getting too involved and pulling back where necessary. The reservations staff have about disclosure and their decisions to disclose parts of their story has the

potential to create, or make apparent, an element of separation or distance between staff and members. Furthermore there are nuances to disclosure, which refer back to Faye's comments about members being in the 'right place' to listen to staff talk about themselves, as Deborah (staff, int., Bright Futures) elaborates:

> *I think it's easy for me to say because I've got a job where, people think well she's the manager, with that one, it's fine for me to say I've had mental health problems because people think well it hasn't stopped her getting that job…if I was unemployed and I hadn't been employed for a lot of years, I could easily think, if people knew that about me then people would assume that was the reason why I hadn't been employed…. the danger is that the celebrities come out, saying it's fine, is like it's fashionable now to say that, it's fashionable to have a mental health problem…erm, and I suppose, I try and be careful with it because it's not the first thing I would say to any of our members, oh yes I've got, I've had a mental health problem…*

Deborah reflected on the idea of using yourself as an 'example' and hints at the idea that the disclosure of people in more powerful positions, such as staff and celebrities, may not be the most useful way to support members. Deborah warned against everyone talking about their own experiences as being fashionable and was conscious that her disclosure might be viewed as it 'being easy' for her because of her social position.

It is clear that staff members think much more deeply about what they choose to say about themselves and their experiences of mental distress than members do when talking to other members. Many of the reasons for this seem to relate to an element of keeping within the boundaries of a professional role which includes considering whether talking about their own experiences will necessarily be helpful for a particular member in a particular context. Staff members' intentions when they use themselves in this way stems from the belief that telling members about some of their own experiences encourages members to feel more at ease, less different from others, more confident, more likely to open up and accept help etc. In this respect I would like to suggest that staff telling sharing experiences in this way can be used as a tool or resource to support members and enhance the professional relationships i.e. disclosure is, in part, a 'support device.' This 'support device' seems to play a role in promoting non-stigmatising interactions (and perhaps helps mitigate the effects of stigma experienced elsewhere) by reducing the perceived distance between some staff and members. In this respect, experience of distress may even be considered to be an asset to their role. For example, Susan, once a member of Creative Mindz and now employed by them on a sessional basis, explained in her interview that she

thought it was good for members to see she has made progress and she tries to operationalise her experience in a positive way:

> *Yeah, like, who was I telling, someone came and they were quite unwell, I can't remember who it was now, and I try to wear long sleeves but sometimes like I forget, like today, so people notice and I just said 'oh yeah I used to self-harm or whatever' but they don't expect, I think I come across differently to how I really am, you know what I mean, I have this front that a lot of people don't see until then they'll see my scars or whatever…and this one lady, I said to her, 'you know I was like you a few years ago, I never left the house I spent all year in hospital, this that and the other', and she was like 'oh my god, really?' and I think, they don't expect people who work in mental health to actually suffer from it themselves, I think some people…but it was quite nice because then, I said to her, 'you know you might not see yourself getting better and you'll not wake up one day and be better, it's such a slow gradual process, that it's only in time you'll look back and think that's when things started to change, but you can't see that at the time'…but I think because I've got quite a good insight, I think some people, again, it might be better for me and I've got more of an insight than XXXX <studio manager> that people actually think, 'yeah, Susan knows what she's talking about'…you know what I mean?*

In summary, members felt that staff members care as a result of interactions such as helping a member draw a picture or telephoning a member when they haven't attended for a while. Attention is not on any 'symptoms' or 'symptom reduction'; the focus at each of the organisations is on 'doing' or taking part in an activity, and any emotional support is delivered concomitantly. Members don't report feeling disempowered by the approach of staff, instead members report that they feel autonomous, that they are given choice, and feel 'cared about' because staff members are 'being caring'. That said, relationships between staff and members are inevitably characterised by a power differential; most distinctively, one is employed and paid to support the other. An important component of stigma (Link and Phelan, 2001) is that stigmatised people are 'set apart as different'; this difference is something that has the potential to be reinforced by professional relationships and a power differential. Staff talking about their own experiences of mental distress with members seems to have the effect of breaking down more traditional barriers in the client-support relationship, reducing the significance of the power differential, and can encourage members to 'open up'. Members report that staff talking about their own

experiences is a positive thing and contributes to staff integrity, respect and trust. Thus, I have suggested that staff using their own experiences as an asset to provide support could be considered to be a 'support device' to help reduce feelings of 'difference'. Nevertheless, I have also described how disclosure and information is carefully managed by staff; this suggests that, despite good intentions, there remains some sort of 'distancing'. For example, staff members may choose not to talk about certain details relating to their family and friends, or make a decision not talk to members about specific details if they're struggling personally. It seems that whatever the intention, staff members do try to put some distance between members and their personal lives, and it is important to explore the significance of this for the support relationship. It should also be noted that whilst the attention has been on staff members' negotiation of what they will and will not disclose to members, it is also possible that members also selectively negotiate what they share with staff. However, members did not report that they were selective in the same way that staff were. On the contrary, they commented on how easy it was to talk to the staff at the case study organisations and instead, spoke about being particularly selective in other contexts which I explore later in 5.2. Secondly, whilst members share stories with other members (4.3) they are not expected, by virtue of any role, to provide that support, and so it became important to explore why it became such a common theme. Finally, staff members, by virtue of their role and payment for performing that role, occupy a relatively more powerful context/position and that's why the negotiation matters and is relevant to discussion relating to 'distancing,' difference, and stigma.

4.5 How supportive relationships can reduce feelings of difference and contribute to mitigating the effects of stigma and discrimination

In 4.3 and 4.4 I detailed how support is performed amongst members, and between members and staff. This section offers a deeper understanding of stigma and support provision by exploring the conceptual underpinnings of interactions in the support environment which are considered by the members to be supportive and not stigmatising, along with their implications for mental health support. The findings suggest that care, compassion, and mutual concern characterise supportive interactions. Members report that relationships which develop in the support context contribute to the significant value members place on the support they receive from Bright Futures and Creative Mindz. Caring interactions cannot necessarily be pinned down in order to provide a blueprint for support; what is caring or compassionate in one context may not be in another. What constitutes a 'caring interaction' is context dependent, and the support context is explored

further in Chapter 6. However, members' comments suggest that the 'caring approach' of staff and members is constituted by a combination of interactions, often taking the form of conversations, which offer empathy and choice, and reinforce autonomy, along with practical actions such as accompanying a fellow member home when they've locked themselves out of their flat, or a member of staff guiding a member to improve artistic technique. These types of interactions seem to be integral ingredients of a support environment which is "person centred" (Beresford et al., 2011) and foster a sense of belonging. Compassion, care and concern are necessary components of support in the context of the organisations and do not appear to be sources of oppression or stigma.

Goffman's proclamation that stigma is a "blemish of individual character" (1963:13) echoes the ethos and title of his book, which boldly asserts stigma leads to one managing a "spoiled identity" (1963). For Goffman, stigma ensues when interactions, disruptive to the day to day expectations and rules of social interaction, result in the bearer of "undesired differentness" being rejected, particularly where there is discrepancy between an individual's "virtual" and "actual" social identity. In 4.1, empirical examples of interactions that members described as stigmatising or discriminating which emphasised 'difference' were presented. In those contexts, difference based on experiencing mental distress was construed by the parties involved in the interaction as 'negative' or 'undesirable'. However, in the case of members supporting one another, members could be said to share the 'stigma' of mental distress, and their 'actual social identity' is known by virtue of their membership of the organisation. There is no discrepancy between their virtual and actual social identity because they are to each other, in Goffman's terms, one of their "own" (1963:31-41). The supposition that interactions between members are not of a stigmatising nature may also be explained by using the much-cited contemporary model of stigma put forward by Link and Phelan (2001). Link and Phelan (2001) indicate the complex nature of stigma and delineate its four components; labelling, stereotyping, setting apart and forms of disapproval (discrimination, rejection, exclusion), in a power differential that allows for the unfolding of these processes. Following Link and Phelan's model, the findings suggest that when members are together and supporting one another, they can't reject one another on the grounds of experience of mental distress, because in some way they've all experienced mental distress. That said, it could be possible for a member to reject another member on the grounds of a judgment made about that members' management of their distress, but this wasn't an issue raised by the empirical material. Instead, it seemed that a members' attendance at the organisation confirms they have experienced some mental distress and so there isn't a 'setting apart' or a creation of an 'us' and 'them' category that may happen in everyday social life or other services where

members report negative experiences. Arguably there isn't an obvious power differential and all members are in the 'them' category. That's not to say there aren't nuances or hierarchies within the category of 'mental distress'; particularly related to different diagnoses. The tensions between peers highlight how people who experience mental distress are not an homogenous group, and support, as provided by the organisations, is not a panacea for everyone all of the time. It seems that when members are together and party to caring and supportive interactions (whether it's between themselves or between themselves and a staff member), they feel 'less different' and are not 'set apart' as different based on their experience of mental distress.

The interactions described in 4.2, 4.3 and 4.4 are very different from those described in 4.1 because they do not obviously accentuate difference. Quite the opposite, they emphasise togetherness on the basis that people have had similar experiences and they share their stories of mental distress knowing that their peers have experienced distress too. Literature relating to 'member to member' or peer support which supports my findings usually originate from a health, therapeutic or psychiatric research source and from a symptom reduction perspective. The 'sameness' involves finding solace in knowing others have experienced distress, learning techniques from each other, reducing symptoms, coping etc. The findings in this chapter suggest that members sharing experiences, about 'symptoms' or 'problems', and/or experiences of marginalisation, reduces feelings of difference and so members don't feel 'set apart' as different in the support context. Instead they report feeling a sense of comfort and inclusion amongst their peers. Arguably, stigma is transient and not a permanent spoiler of identity in this context. If stigma is born of negative reactions to difference, and a formerly stigmatised person experiences more positive or validating interactions which don't emphasise difference negatively, then it could be that those supportive interactions mitigate the negative effects of stigma. If this is the case, interactions in the support environment between peers do have the capacity to reduce feelings of difference and the effects of stigma and discrimination. Moreover, these sorts of relationships provide a focus on support which staff members are unable to provide because being a staff member, as explored in 4.4 and below, introduces a power differential that does not occur between the members.

There is an obvious and unavoidable power differential when it comes to exploring the member-staff relationship, not least because one is paid to support the other. However, staff members sharing their experiences of mental distress appear to be actively striving to dissolve the 'us' and 'them' divide by intentionally reducing the distance members are 'set apart' in the support environment. Staff members often use their personal experiences as a device to support members, improve their relationships with

them and engender the trust necessary for a flourishing and supportive relationship. That said, staff purposefully hold back details about their experiences and their lives because of their status as 'staff member' and in the interests of 'being professional'. This performance of a 'professional role' indicates that there is some sort of 'distancing' from members. Staff members often don't want to talk about themselves for a range of reasons, from not wanting to put pressure on members to concerns that the information they disclose may be used against them. It seems an element of distance, which could form the foundation for 'setting apart', is created by the power differential between staff and members. That's not to say staff are instrumental in stigmatising members, but it ought to be recognised that staff members do have a degree of 'micro-power' to distance themselves from members and that this provides an important avenue of further inquiry in relation to 'self-stigma' which I consider in the next chapter.

4.6 Concluding comments

The relationships and the component of care which characterises those relationships discussed in this chapter appear to be a significant constituent of non-stigmatising and non-discriminatory support because members do not feel labelled or stereotyped, set apart far enough or excluded (pertinent components of stigma and discrimination). Instead, the relationships help to reduce feelings of difference. However, it seems that there are professional, organisational, and personal boundaries to contend with between staff and members involving a separating out of information which can be shared by staff in the context of providing support. Negotiating information in this way seems to be both a support device, and may potentially result in a form of separation or distancing. Although staff disclosing their experiences of mental distress can be seen a way of reducing feelings of difference and thus, reduce feelings of stigma, the fact that such a negotiation goes on and only certain details are disclosed runs the risk of presenting sanitised stories and creating a barrier which is perhaps more insidious than an obvious one.

Does it suggest that staff believe there is still a degree of stigma attached to disclosing more details or talking about how they feel? If so, isn't that one of the stigmatising attitudes policy and practice is trying to overcome? Is the support device of disclosure somewhat paradoxical i.e. when the point of staff disclosure is to break down boundaries and make members feel at ease, if the result is to only tell certain stories, is a barrier surreptitiously introduced? Are there any negative 'side effects' of setting an example in this way? If so, how does this affect the provision of care and support? Conversely, could this negotiation of information also be construed as staff performing

their role appropriately i.e. by not 'burdening' members and abusing the power differential that is there by virtue of them being paid and performing a supportive role? Exploring the answers to these questions will form the basis of the next two chapters, the first of which looks at what happens when staff members attribute self-stigma to certain behaviours of members, and in doing so introduces a more socio-political element to the discussion.

CHAPTER 5:

Attributing 'self-stigma' and misrecognising self-management techniques

In Chapter 4 I established how member participants experience stigma and discrimination, particularly with regard to interpersonal interactions within institutions and support environments (other than Creative Mindz and Bright Futures) designed to help them. I considered the relationships that developed at the case study organisations which, in the words of the members, make the support provided at Bright Futures and Creative Mindz very different from other experiences of support, as this support doesn't appear to the members to be stigmatising. Towards the end of the last chapter I deliberated whether 'support devices' such as staff disclosing details about their own experiences of mental distress may inadvertently create distance or set members apart as different because staff members hold back the extent of what they say and disclose. This led me to contemplate whether an element of distance, which may or may not be 'setting apart' (an important component of stigma), is necessary to support members, or an inevitable by-product of support relationships. To explore this 'distancing' in more depth, this chapter considers staff members' attributions of 'self-stigma' to certain members and how members' conceptions of 'self-stigma' seem substantively different to those of staff. It must be noted that I might be reaching the conclusions I have done in this chapter because staff members don't have the distance I have as researcher. Moreover, despite the ethnographic nature of the fieldwork, I am not employed as a member of support staff at the organisations day in and day out and dealing with the pressures they do, and so my perspectives on what is going on are likely to be different. Thus, I am not proclaiming that staff are necessarily stigmatising particular members in the support environments of the case study organisations via the attribution of self-stigma. Instead, this chapter focuses on exploring behaviours and attitudes associated with self-stigma and its attribution; in doing so I provide a different perspective for considering how stigma is linked to discrimination by rethinking what is thought of as 'self-stigma'.

The empirical material unequivocally suggests most staff members I spoke to believe 'self-stigma' to be a significant barrier to members receiving support and 'moving on' with their lives following experiences of mental distress. Most staff participants described, as Steve (staff, int., Bright Futures) explains, 'self-stigma' to be:

A bigger problem, possibly more now, than the public stigma.

As introduced in section 2.3.3, literature indicates both a distinction and a relationship between public and self-stigma (e.g. Corrigan and Watson 2002a; Corrigan and Watson, 2002b; Rusch et al., 2005). Broadly speaking, 'public stigma' is considered to include reactions of the general public based on stigma about a particular group, in this case a group of people who experience mental distress, which is often based on stereotypes. 'Self-stigma' relates to people who experience mental distress turning these negative attitudes and/or stereotypes against themselves. For example, Corrigan et al., (2009) explain self-stigma as arising when people are aware of a stereotype, agree with it, and apply it to themselves.

This chapter begins by exploring how staff members conceive 'self-stigma', particularly in terms of how and when 'self-stigma' is identified by staff and attributed to members. I also consider how staff members reflect on socio-political concerns and in what ways those politics become incorporated into individualised notions of 'self-stigma' attributed to members. These are perspectives and issues not covered in any depth in contemporary 'self-stigma' literature. Following on from discussion in the last chapter relating to staff using their own experiences to support members, I consider how staff members use themselves and stories of 'overcoming'. In doing so I begin to question whether support such as that provided by Bright Futures and Creative Mindz always instigates a mitigation of the components of stigma or, in some cases, inadvertent exacerbation. Staff members' conceptions of self-stigma are juxtaposed with members' interpretations, the latter tends to involve some experience of actual discrimination and ensuing behaviours which are enacted to avoid further discrimination. As a result I explore in more depth the relevance of the power differential between staff and members and ponder whether staff attributing 'self-stigma' in the way they do reflects an individualisation which can be potentially harmful and stigmatising in the support environment. In doing so I highlight the cost of self-management techniques in relation to notions of self-stigma, and suggest that self-stigma is better recognised within the context of discrimination.

5.1 How staff members identify 'self-stigma', its effects, and what staff *do*

During discussion about stigma in our interviews, the majority of staff members raised the issue of members stigmatising themselves. It became clear from their comments that staff didn't always think it was stigma or discrimination from external sources which prevented members from 'moving on' (although this was thoroughly acknowledged); instead, it was

'self-stigma' which staff reported as being the barrier to members getting the most out of support and/or moving on with their lives in some way. When staff members reflected on this notion of self-stigma, staff members identified that self-stigma manifested itself in the attitudes of members e.g. members were blameful of society for their predicament and/or felt powerless to change their circumstances. Staff members also identified that self-stigma manifested itself in the behaviours of members e.g. avoiding situations or shying away from opportunity. The comments from staff also suggested that attitudes and behaviours were closely interlinked. The specific examples of self-stigma which I explore in this chapter were identified by the staff member participants and include members 'holding on' to their 'mental health identity'; a negative attitude towards society; 'self-defeating behaviours' (particularly self-defeating behaviours which relate to the support environment and what support has to offer); and members using their mental health as an 'excuse'. Furthermore it seemed that many staff members considered self-stigma to be a 'choice'.

Many staff members often regarded self-stigma as a 'choice' because, in the opinion of many staff members, a member is not compelled to stigmatise themselves in this way. As Dave (staff, int., Bright Futures) illustrates:

> *Some people sort of go around looking for it, they look for the stigma as something to blame, blame society, 'well it's not me, I've got a mental health problem, it's not my fault I can't do it, they're not letting us do it.' So, although stigma, if you asked them are you being stigmatised, they'll say, 'oh no no', but they're kind of self-stigmatising… And I think it's a self-fulfilling prophecy, that's how I would sort of define it, because you can only be stigmatised if you let it…*

Dave's comment captures the attitude of the majority of staff participants in the study and he goes on to describe a member he believes is self-stigmatising:

> *XXXXX who you might meet, he is like, 'I can't do it, I lost my job 20 years ago I can't'…that's all he says, 'I lost my job I can't do it… 20 years ago when I lost me job because of having bad nerves, erm, the help I could get now I would have been back into work but nah, I'm too, it's gone now, there's nothing I can do. I've got a bad heart, nah nah'…he's always making excuses up. He wanted to do some sort of fitness, I looked into him doing some walking football, because he has got a problem with his heart but nothing that would make him sort of, collapse and die. So I got a health trainer to come in and have a chat about it who was running it and he was shocked at how much he could do at the gym, and so you say, 'actually you*

can do things', and he says 'no, I've had this for 20 years, they'll not take us'…He said I worked in a warehouse, 'I can't do warehouse work now, I'm getting too old', so you say, 'well retrain'…and he actually did go to college to do the ECDL [European Computer Driving Licence], so he was starting to come round a bit but then when things aren't going too well, he tends to back off a little bit.

By comparison, Dave explains what he identifies as non-self-stigmatising behaviour which, in common with most staff respondents, is readily defined by someone who 'tries' and takes advantage of what the support environment is able to provide them with. Dave describes a member who took advantage of computer courses, despite negative experiences of education in the past which included bullying. Dave worked with this member by talking to him encouragingly and attending the course with the member when he first started:

D: …it took a bit of time to kind of get his confidence back up and to give him the self-belief that actually, you can go and do it.

V: So going back to what you were saying before, do you think he didn't self-stigmatise?

D: I don't think he did, because he realised, he'd done the course, got the certificate, I was like 'look, here, you've done it, you're the same as the rest of the guys, you're the same level as everyone else here, there's nothing different, in fact you've completed some bits some of these guys haven't completed and probably won't' and sometimes I think also people not wanting to get well… 'I don't want to get a job, I'm quite happy being like this', again that's like using mental health, using self-stigma to stop themselves progressing any further… I think that's a one as well. There's quite a few people who want jobs, but I don't know if, they're sort of saying because it's expected now, but deep down they're thinking, 'I'll never get one'…

It seems Dave believed the member who undertook the computer course did not 'self-stigmatise' because he completed the course and satisfactorily responded to, and utilised, the support on offer. Dave compared this particular member to others who 'don't want to get well' or get a job, which seem to be more passive characteristics, and are also features commonly attributed to self-stigma by staff participants. I use Dave's comments together because they provide a good and clear demonstration of how most staff members typically

consider the components of self-stigma and how it plays out in the support environment. Common remarks such as Dave's led me to consider whether the attribution of self-stigma in this way occurs when members don't comply with, or take advantage of, the help or support staff members are able to provide. Thus, there seemed to be a strong link between attitudes of members which are construed as self-stigmatising, and their behaviours. For example, Steve's (staff, int., Bright Futures) comments below suggest that a contributing factor to 'self-stigma' is a negative attitude which can be countered by certain behaviours which are not construed as self-stigmatising i.e. by complying with 'help' or 'support' provided by professionals:

> *There was a gentleman came once and he had bipolar disorder, he still has bipolar disorder and he had got himself into this cycle of self-stigmatising, and sort of believing he was depressed when he wasn't really depressed, if that makes sense, not as depressed as he was making out and really that was stopping him from getting involved in things. What we were trying to help him with, and he was just wound up in this cycle…He wouldn't do anything physical, he would just talk himself out of situations, saying well 'I'm not going to do this because I'm feeling like this and I've got bipolar and it's the most horrible disease in the world and it's stopped me and it's ruined my life'. Where in fact it hasn't ruined his life, it's impacted on his life and he's still self-stigmatising, that is a negative way of looking at things on his part. It's stopping himself from progressing and making moves to having a better life really…so there was a lot of talking, getting him involved in the bipolar support group, which helped him quite a lot in educating him about bipolar, so he's had good spells, since that time he's had good spells and bad spells, the way he sees himself, his sort of self-perception…But he's recently sort of fallen down a little bit, which is quite natural for someone with bipolar, to have a dip in mood, but then again, he is going to go and see a psychiatrist, which he would have refused to do before, he wasn't on medication before, but he's going to see them about medication now. So perhaps he's not stigmatising himself quite so much…*

The findings in Chapter 4 did not indicate or reveal distrust between staff and members, and negative attitudes towards members are not inherent at Bright Futures and Creative Mindz. Yet it seems that behaviours which do not indicate a relative degree of 'compliance' with support i.e. members taking advantage of the support provided in order to 'move on', and/or subsequent 'independence' i.e. members trying to 'move on' with their life, is labelled by staff, often as 'self-stigma'. The comments by Dave and Steve could

suggest, via compliance with what's on offer in the support context and other help available (such as psychiatry in this case) a member can become less self-stigmatising or display the right 'kind' of attitude which is then construed by staff as less self-stigmatising. Thus we see support in this context potentially augmenting the medical/psychiatric model of support (Fabris, 2013). Prima facie, it seems that when members don't take advantage of, or conform to, what support has to offer and other help available (psychiatry, talking therapies, back to work/skills training) they are labelled by staff as 'self-stigmatising'. A critique commonly levelled at psychiatry is that psychiatric support assists to regulate those who disrupt hegemonic social relations and institutional processes (Diamond, 2013:74) and it appears this may be going on to some degree in the support environments of Bright Futures and Creative Mindz. Furthermore, the attribution of self-stigma by the staff matters because of the relative power of the staff to label members as self-stigmatising in the support contexts of the case study organisations. Nevertheless, self-stigma attribution seems nuanced, particularly when it is attributed in this way and in this context, and demands further exploration.

Conversations with many staff indicated that they felt that members 'holding on' to their 'mental health identity' are self-stigmatising because it makes it more difficult for them to take full advantage of the support on offer. As Greg (staff, int., Creative Mindz) explains:

> *their mental health identity is something to cling on to…I do get a feeling, that maybe there's a sense of comfort, like I'm not like that guy over there, why is that, that's because I've got this, and then, maybe this danger you might grab that tag and then cuddle it or cling onto it somehow and not want to let go of it just to justify somehow, to yourself.*

The idea of using a mental health problem or diagnosis as an 'excuse' for not seeking out or taking opportunities for things like work, education, socialising etc. was common amongst staff. Not behaving in line with the support rules or rules of the organisation and 'bad behaviour,' was also considered by many staff participants as a facet of 'self-stigma'. As Faye, (staff, int., Bright Futures), describes:

> *They see themselves differently or use it as an excuse… We had a gentleman who, I don't know what his diagnosis was because I never really worked with him, he was a nice enough, very polite man but you always knew, you always felt as though he was going to kick off…He was always I suppose a bit intense and you got that feeling that you would tread a little bit carefully around him and he did kick off this*

one day, someone had said 'you know there's no need to shout and scream and swear at people', <raises voice> 'I'm allowed, I've got a mental health problem and it's your job to deal with it'…<back to normal voice> so I was like, 'is it?' Oooo…so is that part of our job description to just deal with people kicking off when really it's their attitude…

Faye describes a situation in which she believed the member behaved badly and used his mental health problem as an 'excuse'. She attributes this to his 'attitude' but there is no other understanding or explanation offered to explain why the member behaved in this way. Such staff explanations of 'self-stigma' and ensuing excuses or bad behaviour may be considered to be a way in which staff conceive of and individualise the 'problem' of self-stigma.

Most staff members readily considered instances of clinging to labels or diagnoses, bad behaviour or refusals to join in as a 'choice' rather than the mental health problem itself or systemic discrimination. Jake (staff, FG2., Creative Mindz) explains this as the group were developing the composite character 'Mickey':

I can imagine that he's built up such a chaotic lifestyle, that actually, making choices that weren't chaotic were perhaps particularly difficult because it was almost like, I don't know if this is answering the question so much, but it's almost like the mental health issue is so much part of his character that his choices are defined by the fact he's got mental health issues, rather than he's making situations better for himself…perhaps, an opportunity to do something with his skills, maybe play in a band, and because he felt that you know, he would have to follow certain rules of the band, like the songs they did, he had to drop out of it because he didn't feel able to be that person.

The above excerpt raises the question of what is considered to be part of a member's 'mental health problem' and what is bad behaviour or self-stigma, and how that is distinguished. It is not my task to identify this and any such distinction would be contestable in any case. However, I am interested in how responses of staff members play a role in constructing ideas of 'self-stigma' and how that impacts on the support environment and ensuing interactions.

It is important to note how particular staff members seem to place a lot of emphasis on choice and self-determination. Nicola (staff, int., Creative Mindz) describes a member who she considers to be 'self-stigmatising' and 'self-pitying' because the member believes

she is unable to work as a result of her mental health and is particularly vocal about it when she is attending the organisation:

> *I think she's just very self-pitying, like she feels sorry for herself... Sometimes I do want to sit her down and be like, you know what I mean like, everything is a decision…I think she's too keen to play the victim, of like everything's hard…she could get a job, she could work…*

This labelling of certain behaviours as 'self-stigma' often occurs because, according to staff, members don't try, they appear passive, and/or they make excuses which is not in line with what support has to offer; this could also be seen as a way of putting some distance between staff and members, and perhaps 'setting apart' members as different. Nicola, (staff, int., Creative Mindz) describes a divide between those who try not to stigmatise themselves and those who do:

> *There are the members who are actively trying to you know, better themselves and get jobs, and actively trying to do things, but…I think there's kind of a divide, there's some members that I don't know, I just don't think that they ever want to go further than this, erm, like XXXX <member> I think he's here and that's it…which is a shame…*

The empirical examples suggest what staff consider 'self-stigma' to be such as 'holding on' to their 'mental health identity'; a negative attitude towards society; self-defeating behaviours (particularly self-defeating behaviours which relate to the support environment and what support has to offer); using their mental health as an excuse or as a choice; and often staff, such as Dave (staff, Bright Futures) believe self-stigma to be a "*self-fulfilling prophecy*". Thus, the empirical evidence in this chapter is suggesting that the way staff attribute self-stigma may be part of the wider 'stigma problem' and, as Corrigan and Fong (2014:112) suggest:

> …focusing on how people might eradicate their personal struggle with self-stigma may unintentionally perpetuate the notion that stigma is *their* problem, that it is another sequelae of the illness for which they must be treated.

The empirical material considered so far may suggest that staff consider 'self-stigma' to be an individual concern and something that can set members apart as different. However, staff members do recognise more systemic and socio-political issues affecting the lives of

their members. For example, staff members were keen to split public stigma from self-stigma, citing examples of public stigma such as media influence which are different to self-stigma. As Steve (staff, int., Bright Futures) explains:

> *Stigma and discrimination generally comes from like society, so that's how the general public in general sort of see someone with mental health problems, the headlines are in the newspapers, all the scaremongering that comes up like this paranoid schizophrenic stabbed someone or carries knives or someone with bipolar is a danger to themselves and others because of their, over the top behaviours maybe and that isn't generally the case with the vast majority of people…*

Loss of entitlement to welfare benefits as a result of recent welfare reforms is, in the eyes of staff, a common contributing factor to why people don't try, and is related to staff members' ideas of self-stigma and its effect on members. Peter (staff, int., Creative Mindz) explains how 'self-stigma' affects members:

> *I would say in a poor attitude towards themselves, in terms of playing down their own ability, erm, but I think a lot of that is done through fear also, because people are terrified of change, terrified of coming off benefits, almost have gone unchallenged because of the mental health issue…I mean this is what I think, erm, and I think that's what we do do here, I think we do challenge people and push people's buttons a bit and kind of put the cat amongst the pigeons a little bit. Kind of the debate group we have, we talk about benefits, bedroom tax, and erm, it's really difficult because the ones who do stigmatise themselves I think always will do so…I think it's through fear, fear of change and I think it's, I think people, although mental illness is an awful thing for them I think it becomes like it becomes a kind of safety blanket al.most, like I have mental illness so I don't have to do anything to change…It's tough, I think we make very gradual gains with people, it's like chipping away at a big block of marble to create a sculpture I suppose… It's a huge joined up problem, because I feel people are people regardless of physical or mental condition and if people are capable of being pushed and of doing something, that, people should be working as optimally as possible. I mean I see people kind of in here, and they're very capable individuals but I think they've becomes so entrenched in that kind of negative thinking and become completely institutionalised through many aspects of society…*

Peter talks about "mental illness" as a "safety blanket" members cling to as result of "fear of change" usually instigated by changes in support or welfare provision, even though people are "capable" but it is likely those who stigmatise themselves "will always do so". However, wider political concerns are open to the interpretation of staff. For example, Steve seems more willing to see media representations as the source of the stigma, where Peter's comments suggest he considers welfare issues to be an excuse. In most cases, staff members continue to attribute self-stigma to members who don't try and other associated behaviours and 'negative attitudes' with 'self-stigma'; more political or cultural matters didn't seem to override individual concerns of self-stigma. Although it wasn't raised by the staff, on reflection I noted that the outcomes organisations report back to funders involve members moving on in some way e.g. into work, volunteering, education etc. (3.3.2 and 3.3.3) and it is therefore less in the organisation's interests to maintain 'dependence'. This may also impact on staff members' frustration and readiness to attribute self-stigma.

In 4.4 I explored how staff sharing personal experiences of mental distress was useful to create trusting and effective support relationships and that this sort of disclosure was a useful 'support device'. Part of the common narrative of staff members with experience of distress involved talking about how they had actively 'overcome' self-stigma or resisted the urge to self-stigmatise. For example, Daniel (staff, int., Creative Mindz) recognised he had stigmatised himself but had 'overcome' it and had this to say of members when talking about the benefits of exercise and mental health:

> *I think a lot of people who say, 'I'm not doing exercise', they should give it a go. I love my job here, but sometimes it's so frustrating because mental health people are just so resistant against change, even if that change is going to help them… obviously in my own personal experience, erm, I think a lot of stigma is inward, I think a lot of stigma comes from within, erm, but ultimately that must be there because of the reaction you believe you will get from other people and I stopped speaking to a lot of friends when I first took ill. Friends who had what I would consider, good professional jobs, teachers, occupational therapists, that kind of thing, a mate who is fireman, these are all decent careers and I just felt I was then on the scrap heap and that they wouldn't want to speak to me because I wasn't at their level anymore. So that was self-stigma I think but I think there's also an element of low self-esteem there, so just because I wasn't working and was on benefits, it didn't mean I was any less of a person, I can see it now, but back then, I felt like scum, having to go and beg for money.*

Daniel went on to describe how he told his story as an 'example' to some members but reported how he found some members frustrating when they didn't attempt to overcome 'self-stigma' or 'try' and perhaps, instead, choose to ruminate on welfare reform which, in members' opinion, were forcing them into work. The comment also suggests how support can lead to frustration, indicating as Bracke et al. (2008:439) also suggest, that staff may require support themselves to deal with these feelings. Daniel explained how he felt at a loss to do anything other than try and move members off the topic of conversation and continue to encourage them individually in the tasks members were doing or interests they have. Participants such as Daniel recognise some stigma is 'inward' but in doing so, and as we have seen previously, staff members don't wholeheartedly link this to the stigmatising or discriminatory behaviour and attitudes of other people or institutions. In most of the conversations with staff about particular members, staff acknowledge members' individual histories, including bullying, abuse, negative experiences with psychiatric services, welfare benefit entitlement, employment etc., yet it is still 'self-stigma' that is seen by some staff as being more difficult to deal with.

Most staff interviewees, such as Nicola (staff, int., Creative Mindz) saw staff members with experience of mental distress as examples to hold up to others. Nicola seemed to compare members to staff members with personal experience:

> *it's so easy to be like 'me, me, me, me, like my life's bad, my life's blah blah blah', so I think I'm quite big on, look at the bigger picture, like you know, 'you come here, actually, your life isn't bad, like actually we all have problems', so I think I'm big on trying to be like, I don't know, even-par, we're all the same. Because I think like, the other thing I've learnt from obviously like being here and talking to like Daniel and Susan who originally were members and now work here, is that what people don't realise, is like people here with mental health, you know like crazy people blah blah blah, but really like we all have it in us…*

Such responses suggest that staff with experience can be used an example to show "we're all the same" which is potentially positive because it suggests mental distress can be experienced by anyone at any stage in life, and so those of us who experience it shouldn't be stigmatised. However, holding up some members or staff as an example as 'overcoming' mental distress and the associated stigma to get a job, move on etc, can put pressure on, and create negativity for, people who, perhaps because of their own particular circumstances (which are unrelated to personal resolve or 'not trying') are unable to follow suit. This is similar to what Saguy (2013) refers to as 'blame frames' in the study of obesity i.e. a concentration of personal choice rather than focusing on society or the distress an

individual may be experiencing. However, it must be noted that there were nuances within this theme of 'setting an example' to overcome 'self-stigma', as Deborah (staff, int., Bright Futures) explains:

> *When I was manager at the other place, in the one in four magazine, I did have an article up about me, and I was upfront about the fact, that was why I wanted to work in that job, because you know it was about getting people back out to work, raising their expectations. I knew I'd been surrounded by people, when I was unwell, that just, they made it very clear to me, that was going to happen, I was going to get better, I was going to, I didn't believe it at the time, but other people's belief around me in that hope. So, you know, that's why this job appeals to me because I know I was very very fortunate in who I had around me and the support I had at the time and I've realised that that isn't the same for everybody for everybody else.*

Deborah recognises that having a job and support system around her made her feel more able to overcome feelings of self-stigma and prepared to tell her story. This demonstrates how some staff members take into account other factors when it came to members overcoming 'self-stigma', such as family support, job prospects, skills, career history etc.

Whilst staff members often use their experiences as a way to help people overcome self-stigmatising attitudes, they also work with members in other ways. For example, staff members report that they try to reduce feelings of self-stigma by encouraging members verbally and spending time with them on a one to one basis etc. As Peter (staff, int., Creative Mindz) describes:

> *I think the environment is a very nurturing one, to begin with, it's kind of very relaxed, very informal, so it's almost about establishing a rapport first through conversations and kind of, yeah, making someone feel at ease and comfortable and then working with them over a period to kind of tease out any ideas people might have, or interests people might have and then kind of forming their practice around that…*

In doing so all staff members explain how they try to support members to overcome 'self-stigma' and address *their* 'self-stigmatising' behaviours by developing skills, having informal conversations, developing self-awareness and confidence building, as Jake (staff, int., Creative Mindz) expounds:

Here we concentrate on other aspects in terms of developing skills, awareness of things that they haven't done before, testing the water, having a laugh, looking into opportunities, networking, finding out what's out there, sometimes it's coming here, it's signposting for us, you know to help people find what's actually best for them…so there's some people it's actually to just get them to sit down at a table and communicate with someone else, with a member of staff or another member, is a big step forward for some people, erm, and then for others, you know participating, getting involved, doing activities, really starting to see their artistic development and that leads to the development stage where they actually start to have something tangible that they can use it for, maybe they're starting to get familiar with using a computer which you know, which helps them to find out what opportunities are out there, potential jobs or volunteering…I think because we, we very much promote the idea that everyone's the same, including public members and staff and volunteers, and there's more of a blurred line, that I think some of the people that perhaps don't have really profound mental health issues, coming here, feel comfortable knowing that they're actually part of an overall group as opposed to a stigmatised group… Stigma is a very strange one because people can stigmatise themselves, they can also promote or do activities that will lead to them being stigmatised.

Staff members clearly don't maliciously 'label' members or attribute self-stigma and despite the suggestion that staff seem ready to attribute self-stigma, staff certainly recognise, as introduced above, that the degree of self-stigma can depend upon members' wider support network and past experiences as Lucy, (staff, int., Bright Futures) mentions:

I think in terms of stigma and stuff, I think for some people it makes them more determined to challenge it and prove that they can do it and for others, well people are going to think 'I can't do it anyway so why try…' I think it can go either way, and I think it depends very much on the stage of recovery that a person is at, and how they've come to terms with it and the support network around them. If you've got a family that's saying 'well you can do it, maybe just do a day a week and we'll support you to do that', where if someone is literally living independently and got no networks or no strong networks, then it's a completely different sort of situation.

Other staff members recognised that experiences of stigma and whether members self-stigmatise will depend on a member's other skills and past experiences. As Deborah, (staff, int., Bright Futures) describes:

It very much depends on their own life experiences and who they know. If you've known somebody who's been very very competent who has had a spell with depression and anxiety, been very unwell and recovered again, then, you don't see it as being any worse than any other illness that you might have.

After a hearing voices group I chatted with Dave (staff, int., Bright Futures) who made a similar point:

Discussed a bit about famous people with mental health problems and Dave mentioned someone who hears voices but she was clever, has had an education and supportive family and there is a difference between that and some of the members. Dave said he didn't think those famous people are always speaking for everyone. (Bright Futures, FN31)

Staff also appeared to support members by prompting and encouraging members to 'speak up' as my example from my fieldnotes and an interview excerpt highlights:

Lucy (staff, Bright Futures) suggests they could each hold up a card for the video on shared decision making- then they will all be in it. Jane (member) doesn't seem keen and says she would rather photobomb it and have a finger in it, she can be like, 'mum mum, it's coming up now.' And we all laugh. Lucy asks if they're aiming for five minutes, Jane says she guesses so, it's to put on the NHS website for GPs to refer to it. Lucy says to Jane so you will want your face on it, and Jane goes quiet and says she is not bothered, maybe a secret finger. (Bright Futures, FN20).

Lucy (staff, int., Bright Futures) later picks up on this in our interview:

I think it was very interesting how Jane didn't want to be in it…See in one of the sessions when they were talking about who they were going to interview, snippets from other people, she said I think it's important that if we are going to be asking other people to share that we share, and I thought that was quite interesting how she understood it was a big thing so maybe she should be in it.

If staff did not encourage members to feel 'empowered' in these ways it is likely that staff members would be criticised for being stigmatising and/or writing members off. Furthermore, the findings in this subsection suggest that staff members negotiate the attribution of 'self-stigma' with some thought, reflexivity, and empathetic awareness of members' circumstances by taking into account the external support structures of members. Staff members also acknowledge that not all members' personal histories and

experiences are the same. However, just as the methods staff members use to support members are individualised e.g. creating a friendly rapport, informal interactions, use of humour etc. (also explored in 4.2 and 4.4 and which makes the environments so supportive) the problem of 'self-stigma' is also individualised. Staff members also appear to be empathetic to the circumstances of members, encouraging members to take advantage of opportunities and speak out about their experiences where appropriate. However, self-stigma seems to be attributed when these methods fail. Similarly, in a study relating to Occupational Therapy, Abberley (1995), following Simpkins (1983), found that "although service providers are only too willing to claim credit for any success, failures tends to be presented as the fault of the recipient" (Abberley, 1995:224). Failure was explained by Abberley's participants as a "deficiency of the client and her situation, not of the practitioner…By doing this it also diverts attention away from the wider social structural determinants of the clients' situation" (1995:230-1). Staff members do recognise social structures, but this acknowledgement is often given less weight when it comes to attributing 'self-stigma'. However it should also be recognised that although support staff can only mitigate what they describe as 'self-stigma' using the tools they have available, some do make efforts to change the support when they think it's not working for particular members. For example, in our interview, a manager at Bright Futures makes an important distinction and describes how they work with people who may display behaviours staff associate with 'self-stigma' and encourages her staff not to simply think of these behaviours as self-stigma or disinterest in support:

> *There are still some people that who don't, you know, don't engage, as I've said, it just might not be the right time, we're also trying to look at, what else can we do for those people who don't have a clear idea about what they want to do. Because keep meeting somebody, to talk about what they want to do when they don't know, that's a pressure in itself and if you're thinking, I don't know what I want to do, and might just say anything to make the interview stop, and get out of here…we're constantly trying to look at for those people who didn't engage… can we offer a bit more, do it differently and is that going to change the outcome for the people that we've sort of reached that bit of an impasse with…you can kind of tell when people aren't taking the information in, and it's easy to believe that it's because they're not interested, whereas it could actually be that it's taken so much effort not to cut and run out of the room, with that one, you're so overwhelmed by it, that, yeah, you can't take the information in, so you go away and you're not really sure what*

you've been to, what it was about and what they were offering, just 'cos it was too much...

The findings in this section highlight the potential danger of distinguishing between public and self-stigma, and selectively applying 'self-stigma'. Attributing self-stigma in any situation indicates that the responsibility for 'overcoming it' is located within the stigmatised person. Staff members do recognise that it might be difficult coming to a mental health organisation and understand that members may avoid certain situations, based on their experiences. However, the overriding impression from conversations with staff was that whilst political and structural concerns are a consideration for staff members, the majority of the findings in this chapter so far suggest how those politics somehow become incorporated into 'self-stigma'. Whilst staff members do encourage debate about more socio-political issues, if members concentrate too much on the political, they run the risk of being seen as 'self-stigmatising'. The agency staff members afford individual members is always in the foreground whilst political issues are in the background; when it comes to 'doing something' it's about the work the individual has to do on themselves, with the help of the support on offer. I will now turn to consider how members 'work' on themselves as a result of experiencing stigma and discrimination.

5.2 'Self-stigma': self-management techniques and misrecognised responses to discrimination

Members, like staff, were keen to discuss 'self-stigma' but they considered it differently to staff. In this section I suggest that the behaviours members associate with self-stigma could be better conceived of as responses to experiences of discrimination, and self-management techniques members have learned as a result of stigmatising or discriminatory experiences. Stevie (member, int., Creative Mindz) describes 'self-stigma' via an articulation of her own experiences relating to a time she felt excluded from a group. Stevie's description reflects the thoughts and feelings of the majority of member participants:

When you stigmatise yourself you're afraid to go out, 'oh I'll not go out, I'll not bother, I won't go in that pub full of normal people', but it's not because you are stigmatising yourself, it's because you don't want to be in a situation where society has separated you as somebody not normal…There's been groups I won't go to and groups I have stopped going to because of that, and you feel well they're all normal and I'm not, they may be nice people, nice with each other, I'm welcome to go there

and do the task, but if one invites the other, 'oh there's a film on in the cinema, isn't it to do with superman or something', and I say, 'oh I like superman as well' says the one who's not normal, and then another one says, 'oh I like superman, oh are you going to come along and see it with me at the cinema', and I say 'any chance I can come', and it's 'sorry no'…because if you were normal they would have been happy about you going along with them and very often it's the one who isn't quite normal who doesn't get included in conversation at breaks, they talk about something and you talk about something relevant to the conversation and they don't look at you and they treat you as though they haven't heard what you said.

V: And that's happened to you?

S: Yeah that sort of thing has happened to me before, and when a group treats me like that I won't go back…I don't want to be where I feel I'm not welcome, I'm not equal and then they put up this invisible barrier, but when it's a case when they are not responsible for you because they're not a relative of yours, it's not within your job, and they're not doing anything spiteful to get rid of you from the group, no issues of policies, laws or conduct is being breached, but people have a right to a choice. You can be somebody's friend if you want to, but you don't have to be so-and-so's friend if you don't want to, but even if you're not wanting to be their friend, you should at least treat them as an equal within the group, but there's people who shut you out because you're not in line with the unwritten rules of normalness of social behaviour, even though the way you behave isn't spiteful or immoral, it's not…but they treat it, equate it as wrong, just because it's different...

Stevie's comments introduce, illustrate and bring together the common threads in terms of how most of the member participants felt about 'self-stigma'. Stevie elucidates the idea that self-stigma is often based on past experiences along with member's own thoughts of what society may think of them. Firstly, Stevie's comments introduce the idea that what we may consider to be 'self-stigma' isn't self-stigma at all, it is a response to experiences of exclusion and she relates this to a time she was excluded from a group she once attended which she believes occurred because she was not 'normal'. The emphasis here is that self-stigma, despite the prefix 'self', is still something that comes from society and not necessarily from the 'self'. Scambler and Hopkins (1986) distinguished between 'enacted' and 'felt' stigma. 'Enacted stigma' refers to actual treatment and/or overt discrimination and 'felt stigma' related to a sense of shame and fear of encountering enacted stigma (Scambler, 2011:225). Stevie's example illustrates (as do all of the examples permeating

this subsection) that what some members may describe as 'felt stigma', seems to always be accompanied by some 'enacted stigma'. Thinking about the distinction between staff and member interpretations of self-stigma, we saw in 5.1 above that it seems staff primarily relate member passivity to attributions of self-stigma i.e. staff attribute self-stigma to members with the attitude of, and behaviours associated with, 'there's little point trying because the world is against me'. However, Stevie's eloquent quote and this subsection demonstrates how members are active agents managing some of the socio-political realities they encounter. Whilst the agency of members frequently seems to be limited and shaped by structural constraints, as I go on to explore below, recognising the work members do is important to capture this notion of agency and highlight the extra work members must do to participate and 'fit in', in both the case study organisations and wider society. Furthermore, Stevie's quote also highlights how stigma can operate subtly at the micro level of social interaction, and so members were left feeling there was little anti-discrimination laws, policies and practices can do; and stigma can lead to some people hiding a problem or condition, or reducing its significance, as we will see below.

When asked about 'self-stigma' most members said that they did stigmatise themselves to some degree. When I asked what made them think that they did self-stigmatise, the behaviours they described were self-censorship i.e. thinking carefully about what details about their mental distress they disclose, and to whom, and avoidance of certain situations where they have experience of being discriminated against (like in Stevie's example above), or where they think they will be stigmatised or discriminated against (also seen in Stevie's example). At this point it is interesting to revisit the issue of disclosure. Chapter 4 considered how staff members describe negotiating disclosure in the support context, not to avoid stigma but to ensure they performed their role professionally and maintain boundaries between themselves and members. The empirical material did not indicate that members negotiated disclosure in the context of the case study organisations, but members were clearly selective in what they shared outside of the support context to avoid stigma, emphasising the importance of context to stigma.

When members and I conversed about self-censorship and avoidance of certain situations, it always turned out discrimination had been experienced in some form and that self-censorship or avoidance was used as 'tactic' by members to limit future experiences of stigma and discrimination in particular contexts. It was clear that the behaviours members and staff associate with self-stigma were different. Firstly, self-censorship was not something staff thought was a big issue in terms of self-stigma. Secondly, whilst avoidance of situations was something that staff did consider to be a behaviour associated with self-stigma, members had slightly different reasons and explanations for their behaviour which

would be better construed as self-management in response to experiences of negative situations or attitudes, and/or discrimination. Both self-censorship and avoidance will be examined in more detail in the remainder of this section with reference to the empirical material.

In terms of the idea of 'talking' and 'self-censorship', member participants seemed to think carefully about the details they disclose to others about their experiences of mental distress. For example Yvonne (member, Bright Futures) explained she tells people she suffers from a digestion disorder to mask binging and purging (FN27, Bright Futures). Sarah (member, int., Bright Futures) said she wouldn't volunteer the information:

> *Unless they ask me but really I just don't talk about it, I just leave it at that…I just leave it*.

At first glance, such findings could be said to corroborate Goffman's (1963) notions of passing and/or covering. For example, Yvonne prefers to 'cover' using her explanation of a digestion disorder, and Sarah prefers to 'pass' and not disclose any details about her experiences of mental distress. Member participants think carefully about what information they disclose to others which suggests forms of 'information management' are occurring and techniques are employed as to not appear 'discredited' (Goffman, 1963). It could be said that most of the member participants are what Schneider and Conrad (1981) refer to as 'pragmatic types'; downplaying their experiences of mental distress and only disclosing where necessary. For example, Thomas (member, int., Creative Mindz) doesn't subscribe to the notion that talking about mental health is always useful for him and assesses the social situation in terms of whether there is a 'need' for others to know:

> *When there's a need for people to know then I'll tell them…only if there's a need for people to know, if I consider it's necessary to tell them, I'll tell them, otherwise there's not any need*.

In the above examples, Yvonne reported that she had been bullied at work and within the psychiatric system, Sarah had experienced domestic abuse which she related to her experiencing mental distress, and Thomas had also been bullied at work because, he said, of his mental health problems. Thus, the perceptions members have of society's perceptions of them are usually born of experience. Any passing or covering seems to occur as the result of the prevalent attitudes or actions of others or society, thus it's the social that creates the stigma (Watson, 2003); an understanding which is implied in Goffman's (1963) work but with little explication of wider social structures or socio-political

concerns as considered here. Furthermore, the aforementioned empirical examples highlight a further distinction between member and staff interpretations of self-stigma. In 5.1, comments from staff members suggested that self-stigma was attributed when members accentuate or exaggerate their difference from others, which can often manifest itself in 'excuse making' or 'avoiding situations', in the eyes of staff. Yet here we see members working to reduce or minimise their 'difference' from others, demonstrating the work they do in order to try and fit in and participate in society.

No participant stated that they had a blanket policy of not mentioning experiences of mental distress. However, what was disclosed and how it was disclosed was very much dependent on the situation, and most participants raised examples of employment contexts, emphasising once again how the social creates the stigma. Both members and staff members who had experienced mental distress spoke about the complications of disclosure relating to work and future job applications. Jane (member, int., Bright Futures) explained how she wouldn't disclose her experiences of mental distress on a job application form:

> *No I wouldn't, not because I'm ashamed of it, but because I don't think it's relevant, just because I've been through it…I've been through it, I myself know now how to cope, so, I mean, yeah, sometimes people have relapses but again, that's something that I wouldn't tell them*.

Similar sentiments were echoed in FG2 at Bright Futures, when participants were developing composite character "Jim", Jon (member) said:

> *Can I, in relation to that, can I say that he's worried about properly talking to his boss about his illness, about depression…*

However, not everyone felt this way. Susan (former member and now staff, int., Creative Mindz) said she would declare she had experienced mental distress on a job application because of negative experiences in past employment:

> *I think I probably would because, and then if I didn't get the job then I didn't get the job, but I would rather have that on the application form, because I think, if they don't want me because I've got mental health problems then I couldn't work in that environment, if they can't accept that, I couldn't work there, because that's what happened when I was teaching.*

Daniel, a member of staff at the same organisation who has also experienced mental distress, negotiated the situation slightly differently (int.). However, Daniel emphasised

that disclosure would depend both upon the job he applied for and whether he was directly asked about his mental health history:

> *I think it would depend, I think it would depend on the nature of the job, so if it was something, like I recently applied for a job with Time to Change, so I did put it. But then if I went back into civil engineering and project management, I don't know, I think it would depend on my perceived response. Which is wrong…It's not because I'm embarrassed, it's because there are so many people fighting for the same job that rightly or wrongly, and even if they say they're not, they will discriminate…So I suppose I am a little bit hypocritical…but yeah, if I went to interview and I was asked about my mental health I would tell them, you know, I wouldn't lie, but I wouldn't volunteer it*.

The examples above suggest that a lot of thought goes into whether members are prepared to disclose details of their mental health history outside of the support context, particularly in a prospective employment situation. It is also worth noting that the latter two examples are from previous members and current staff members, Daniel and Susan. Thus, their extant professional roles perhaps influences their view on disclosure in terms of being more confident to disclose details because they are already employed, and in a more 'socially advantageous' position than an unemployed member. However, it is clear that, what, where and how participants negotiated how to talk about their mental health to others always seem to relate to past experiences and heavily dependent on the context. Whilst participants didn't employ self-censorship absolutely it also became clear that members often employ tactics when they do talk about their mental health which could be seen as contemporary examples of 'covering', such as humour, as Patricia (member, int., Creative Mindz) explains:

> *I do find myself trying, like explaining to people that I have mental health problem and I went through a phase where I made light of it…not sort of belittling the fact that people have mental health problems, but I just made it sort of erm, just made light of it so people weren't worried about me.*

Conversations with participants indicated that often they didn't like to tell people outside of the organisation that they attended an organisation for support which is associated with mental health. Felicity (member, int., Creative Mindz) initially came to volunteer at the organisation but was advised to become a member instead, highlights this point:

If I say to someone I am coming here, it depends on the people if I am going to continue saying what it is about, and or, I don't say it's a charity for mentally ill.

However, Linda (member, int., Bright Futures) said:

I would rather tell people I go to XXXX or here and then they can make up their own mind as to what's wrong.

Whilst members may reach different conclusions, as in the examples of Felicity and Linda, they are decisions which are negotiated and members seem to think quite carefully about how they manage that information. Thus, there is evidence of 'hidden labour' (Scully, 2010) which does not occur when staff members attribute 'self-stigma'. Members demonstrated selectivity with regard to who they shared their experiences with and what they chose to disclose about their experiences of mental distress. Much of the members' reported behaviour closely relates to the self-stigma literature. Self-management techniques, such as secrecy/concealing information are referred to by Link et al. (1989) as "coping orientations." Secrecy, selective disclosure and 'cost benefit' analyses are frequently reported as ways in which individuals cope with social and self-stigma (Holmes and River, 1999). Individuals may develop a disposition to see the world in a certain way resulting in a strong sense of 'felt stigma' and a predisposition to secrecy and concealment (Scambler and Hopkins, 1986). Scholars such as Ritsher et al. (2003:47) refer to the notion of "internalized stigma" which goes beyond the effects of direct discrimination and is more about internal perceptions, beliefs and emotions of the stigmatised person (Ritsher and Phelan, 2004). Corrigan (1998) concurs and believes 'internalised stigma' relates to devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to yourself. That said, the literature still considers there to be some distinction between 'self' and 'public' stigma and discrimination. Conversely, the empirical material indicates that self-stigma and discriminatory experiences are so closely linked by those who experience it that to conceptually create a dichotomy, particularly in the way staff members do, is potentially misleading. This becomes clearer as I explore how members 'avoid' situations.

In 5.1 I explored how staff members considered avoiding situations or certain opportunities as manifestations of self-stigma. In this vein, literature also suggests that such avoidance is described as a "coping orientation" (Link et al., 1989) and demonstrable of the "persistent predicament" of stigma and the occurrence of "indirect discrimination" as a result of the internalisation of stereotypes (Link and Phelan, 2001). Member participants certainly recognised avoidance of certain situations, particularly in an employment context, as a form of self-stigma and/or felt that if they could talk about their

experiences more openly in this context without the fear of negative repercussions then they would feel better. For example, member participants in FG2 at Bright Futures agreed, via the composite character, that avoiding situations where they would be compelled to talk about experiences of mental distress was common:

Jon: *So I've just written there, erm, hasn't talked to his boss about his illness and what they could do to help him back to work because he's scared of what they'll think about him…*

Gary: *Could sort of expand a bit more on that one, like his work colleagues, if they've made jokes about him, you know kind of not necessarily meaning it to be nasty but because, you know, he's still coming to terms with it and he's sort of took it that way, so what's classed as a bit of like banter between workplace friends, but it's not, it's kind of bullying…*

There is a suggestion in the example above that people who have experienced mental distress may avoid situations because of past experiences, such as bullying. Thus again, 'enacted stigma' strongly influences any notion of 'felt stigma'. Others recognised that situation avoidance wasn't necessarily born of the direct reaction or negative experience but the internalisation of a more general feeling, as my conversation with Daniel (staff, Creative Mindz) indicates:

> *Daniel said he used to be project manager and he thought he would lose a lot of friends when he developed mental health problems because many of them were doctors, lawyers etc. and he didn't feel he could hang out with them anymore…Daniel said that often stigma isn't there and we think it's there- because he used to be a project manager and had friends who were solicitors and had good jobs, he felt when he was ill and on benefits, that he couldn't hang out with them, but they never displayed that attitude towards him… D tried to explain that he must have got that impression from somewhere, so whilst his family and friends never gave that impression, D said this clearly came from external influences and external feelings which he had internalised*. (Creative Mindz, FN4).

Daniel recognised that his feelings about his friends with 'better' jobs not wanting to spend time with him wasn't a result of anything his friends did, it came from himself, but he explains this as internalisation of external feelings which are already out there in society. Whether there had been any direct discrimination such as bullying (although in subsequent conversations Daniel described how he was bullied at work) or just a 'feeling' from society,

it seemed member participants explained why they avoided situations because of experiences or perceived responses. For example, many member participants said they avoided situations because of what people may think and their thoughts were often accompanied by a sense of shame. Maria (member, int., Bright Futures) said:

> *Well, I mean I remember when my manager was trying to get in touch with us when I was on the sick, and I didn't want to go into work I wouldn't speak to them on the phone and I didn't want to go in for the meetings because I didn't want, I think, I didn't want everybody seeing us, the way I was.*

Avoiding people or situations seems to be a way members manage situations based on actual experiences or perceived responses. In other situations, members identified that they stopped doing things because of negative experiences related to experiences of mental distress. For example, Patricia (member, int., Creative Mindz) avoided going on holiday for a while because it was when she was on holiday she first 'took ill' and so now she only travels with a trusted friend or sister:

> *When I first became ill in '89, and I had to be flown home and that sort of made me think, oh my god, it put me off…but I have been, I've been to India, Sri Lanka and all over the world but I'd only go with people like my sister or a good friend who I've got, who is, has got good insight into mental health issues and erm, she said well we'll just deal with it if you do become ill…*

This sort of behaviour described by Patricia could be interpreted as a sensible form of self-management as a result of a frightening experience. However, the comments by members such as Maria, Jon and former member Daniel, suggest stigma impacts on their psycho-emotional well-being; how they go about their lives and how they feel about themselves. What these examples demonstrate is the considerable 'cost' of these coping strategies and self-management techniques which may be better understood in the context of discrimination or disablism. For example, thinking about the psycho-emotional aspect of stigma and discrimination led me to thinking about the work of Carol Thomas (2007:73) who extended the social model of disability to encapsulate this type of private social oppression:

> Disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.

Reeve (2014) talks about how "direct psycho emotional disablism" occurs as a result of interactions, often without malice, which serve to invalidate disabled people as people (Hughes, 1999) by undermining their self-confidence and self-esteem because of the negative messages they receive about their self-worth. Following Thomas (2007) and Reeve (2014), whilst members may not experience structural barriers or barriers which overtly prevent them from talking about themselves openly or being present in certain social situations, the "psycho-emotional disablism" operating on a private level as self-stigma seems to create a barrier to 'being' for some of the members. Furthermore, "internalised oppression" (Mason, 1992) as a form of psycho-emotional disablism may also arise often as a result of the relationship a disabled person has with themselves. The negative relationship (which may fall within the remit of what 'self-stigma' is conceptualised as) seems to come about in this context as a result of invalidating interactions and public perceptions of what a person who has experienced, or experiencing, mental distress is thought to be. Thus, it seems many of the members I spoke would concur with Mason (1992:27):

> We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives.

For example, Susan (previous member of Creative Mindz and now staff, int.) felt she holds herself back or attributes not doing things to both her 'mental health problems' and because of traumatic experiences:

S: *I've got into my head that I can't do things and I always think I'm really stupid…*

V: Like what kind of things?

S: Just anything in general, I always think other people can do it better than me and I always think like, I generally don't like going out on nights out because all my friends are prettier than me and it stops me doing things and I think, I sometimes think it's because I'm incapable and I've got mental health problems and then I put that on myself, instead of thinking, you know what, you can do that… I think also the problem with mental health, because I've had a lot of trauma and a lot of shit after shit after shit that I constantly think, that's not going to go right for me because good things like that don't happen to me, and I think something's going to spoil that and then if things go well for a few weeks I start to feel panicked and

think, shit this has never happened before, like something, the next day something is going to go wrong because things like that don't happen to me and you get into that mindset that yeah it'll be all right for a few weeks and then it's going to be shit again and yes it probably will but that's just the nature of things…

Many of the comments above, particularly Susan's, highlights the difficulty, and perhaps impossibility, of separating feelings or characteristics of mental distress (which some may describe as symptoms of an 'illness' such as depression, bipolar, schizophrenia etc. or disorder, e.g. personality disorder), from self-stigma manifested as 'avoiding situations'. Scholars such as Shakespeare (2006:36) and Watson (2002; 2003) point out how, in some cases, it is nigh on impossible to distinguish between social and impairment engendered psycho-emotional problems. Furthermore, the comments in this section highlight the interlinked nature of the relationship between attitudes/thoughts and actions or behaviours (as introduced in 5.1) with reference to the stigma discourse. Rather than trying to separate out the components to decide what might be an effect of mental distress or 'illness' and what self-stigma is, I am concentrating on the social responses which members consider and use to negotiate self-management techniques, such as not going out, avoiding certain situations and not disclosing details of their mental health to employers. I am interested in how social responses, along with projected or expected responses play a role but I also became interested in how members' own behaviour may contribute to the 'stigma' which staff would perhaps consider a form of 'self-stigma'. I illustrate this further using Jon's (member, int., Bright Futures) comments:

Really, it wasn't really a matter of being treat[ed] differently, it was me, the way I reacted to people I think and when you've got like mental health problems you react differently to people, in terms of your appearance and how you project yourself and how you communicate with people, so, you do notice people looking at you, as though, wait a minute, there's something amiss with this person. When I was most isolated, erm, and I wasn't involved with this organisation, it was like, I didn't feel there was anybody said anything negative towards me or anything like that, but, I think, the way I projected myself probably made people feel a little bit uneasy about, erm, my appearance and the way I communicated… I was badly dressed, and unkempt, sometimes I was, my communication was a bit odd, if I would go into a café it would be like, you know, I'd say unusual things or something like that. There was just a period where I wasn't really, I don't think I was really very integrated with people, so if I would go to the library or a café, you know and sit down, you know, I wouldn't feel there was anybody around me who could

communicate with me because I wasn't communicating with them really, so it was like, this distance, the fact that I went to all these places and I was really distant, and people could see that you know. But, I mean you don't generally talk, if you go into a library or a café you don't generally talk to staff anyway, so I couldn't tell what their opinion of me was like, but certainly, I would have said I got a few looks and a few like, who is this guy, what's he doing and things like that.

Jon says he wasn't very integrated with people, but the social model of disability approach would perhaps consider this as people not being integrated with Jon. Jon seems to see *his* own behaviour, *his* isolation and *his* 'problems' as the cause of other people's reactions and any resulting stigma. However, Jon's experience of mental distress which he explains as the reason he was treated differently cannot be separated from the social responses and how he thinks others see him, which in turn affects the opportunities he chooses to take. Jon felt that as a result his behaviour, such as the way he dressed and saying "unusual things" in cafés, he was treated differently which he was aware of because of the social responses or getting a "few looks". Jon's particular example emphasised how, as French (1993:17) found, that there are certain sorts of impairments which are difficult, if not impossible to solve by social manipulation, and that these "impairment effects…have direct and restricting impacts on people's social lives" (Thomas, 2004:42). However, it remains that it is the social responses from others which create, for Jon, the possibilities (or impossibilities) of situations he can cope with and opportunities he can take up. Jon goes on to explain how he believes it's his 'illness', not stigma, which prevents him from doing things such as voluntary work:

I've considered working voluntarily in charity shops, but I would say my illness has stopped me from doing that because you know, I'd have problems, probably have problems communicating with customers and feeling pressured working behind the till. I think, the idea of working behind the till is one of the biggest problems because, er, doing something that required thought, you know, not just using a till in a pressured situation, but whilst communicating with customers...

Jon has not pursued voluntary work in a charity shop not because he does not want to, but because he feels that his 'illness' means he wouldn't be able to communicate adequately and operate the till. Jon seems aware of the social norms of customer service, believes he is unable to meet them and so does not take up that opportunity. I didn't speak to any staff members specifically about Jon's situation and so I don't know if they would think Jon would be an example of 'self-stigma' on the basis he has an 'excuse' for not taking up an

opportunity. Staff may have interpreted this, as they have in similar situations, as a 'confidence issue', yet as we have seen in the example of Jon, and others above, it is the social responses (via experiences or perceptions) which trigger many of the feelings of what participants refer to as stigma and impacts on these behaviours of self-management. It seems that to behave in a way that isn't seen as 'self-stigmatising' requires behaviour which 'fits in' with societal norms. Thus, attributing self-stigma to members' behaviour may be effectively misrecognising their modes of self-management, and a disablist or sanist practice.

There is a body of work which suggests that individuals often avoid mental health services to avoid stigmatising themselves (Thoits, 1985; Corrigan, 2004; Pietrus, 2013; Clement et al., 2014). Previous research (e.g. Adewuya et al., 2010; Chronister et al., 2013) also suggests social support such, as that provided at Bright Futures and Creative Mindz, is negatively linked to "internalized stigma", or 'self-stigma' in the way the members describe it. Findings explored in Chapter 4 indicate that members' feelings of 'self-stigma' may indeed be ameliorated as a result of their attendance and interactions at the organisations where members report improvements in their confidence and self-esteem. Notwithstanding the discussion in this chapter so far there was little to suggest that members felt that the attitudes of the staff were negative in any way or that they were aware 'self-stigma' was attributed to them in the ways I described in 5.1. Thus, it is difficult to go further and explain how exactly members are affected by staff and what the unintended consequences of staff members' attribution of self-stigma might be; this would need further work and research which takes a longitudinal approach. What the findings in this subsection can be said to demonstrate empirically is how 'stigma power' may operate through the stigmatised person (Link and Phelan, 2014), yet how that power operates is nuanced and complicated. The dynamics of that power differential and its role in understanding the phenomena of 'self-stigma' is something which will now be explored.

5.3 Unravelling understandings of 'self-stigma'

In *Stigma: Notes on the Management of Spoiled Identity* (1963), Goffman regularly refers to a group of people known as 'The Wise':

> persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it… (1963:41)

Many of the positive dynamics and relationships between staff and members at Creative Mindz and Bright Futures covered in Chapter 4 could support the argument that staff members are affiliated to 'the wise' and that staff do not stigmatise members. However, as the findings in this chapter suggest and Bates and Stickley (2013:570) point out:

> Goffman seems to assume that professionals have a superior level of insight and sympathy into the plight of the stigmatized group, and therefore are above a point where they themselves would succumb to stigmatizing behaviour.

Goffman fails to pay full attention to the power differentials between the stigmatised and 'the wise' as a potential source of stigma and the political climate which may impact their attitude. The findings in this chapter suggest that the disjuncture between how staff and members understand and describe self-stigma is not simply a matter of semantics or definition. The two groups of people (staff and members) conceive of self-stigma quite differently and it is important to emphasise here that the difference in interpretation matters because of the power differential. Staff members have, relatively speaking and in the context of the support environments, the power to label members as 'self-stigmatising'. Thus, it is necessary to contemplate the implications of that difference in interpretation for both understandings of 'self-stigma' and mental health support delivery.

Staff comprehend that what they determine as 'self-stigma' may be born of members' negative experiences, often of actual discrimination or abuse, stereotypes in the media, or perceived discrimination, or even as a result of welfare reform. However, some staff often relate self-stigma to 'holding yourself back', mental health problems becoming an 'excuse', or self-defeating ruminations on politics etc. Staff classify 'holding yourself back' or 'excuses' as 'self-stigma' and thus set members apart in this way. This attribution of 'self-stigma' tends to ignore, or at least simplify, and perhaps professionalise, the struggle and conflict which members experience.

Attributions of self-stigma are important in the support context because staff members are the 'more powerful' group and therefore have the power to stigmatise or label (Link and Phelan, 2001). The raised status of staff in the support environment means that they may validate or allow certain narratives to be possible. For example, we have seen how the process of staff sharing their stories of mental distress can be used as a device to bring together staff and members in 4.4 and 4.5 but the selective disclosure of information evidences a degree of 'distancing'. When staff members with experience use themselves or others hold them up as an 'example' against certain members who don't follow a similar script to staff members or don't satisfactorily subscribe to the support

narrative perpetuated by the organisation, there seems to be a setting apart of those members as different via the label of 'self-stigma'. Attributing self-stigma to those people who staff consider not to be responding positively to the support on offer in the support environment and/or are perhaps seen as 'passive', has the potential to feed into the stigma cycle and may be potentially stigmatising, discriminatory and/or excluding. When it comes to overcoming 'self-stigma', staff do display sensitivity and are somewhat understanding of external influences. Despite this understanding, staff tend to continue to believe some members not to be 'trying' or that they are 'making up excuses', simply because they don't 'fit in' with what's on offer in the support environment. It must be said, that from my own experiences and engagement with the case study organisations, none of the staff were malicious or overtly discriminatory in their attitude, and there was a genuine belief that the support they were providing could overcome 'self-stigma' in most cases. However, it seems that if you don't 'try' or 'comply' in a prescribed way, members run the risk of being indicted for being 'self-stigmatising' and 'set apart' further. There isn't the data to suggest that attributing self-stigma to members is stigma in itself; I argue that it is a form of 'setting apart', a component of Link and Phelan's (2001) model of stigma and it is *potentially* stigmatising, contributes to the 'politics of stigma', and could impact on how support is delivered.

The empirical material in 5.2 highlights how the notion of 'self-stigma' is complicated and nuanced for members. However, just as Link et al. (2004) found that anger and irritation are likely emotions experienced by stigmatisers, it seems staff members attribute 'self-stigma' to members who staff find frustrating to work with and support. This approach locates the 'stigma problem' within the individual and, by setting them apart in this way, may reinforce feelings of stigma rather than mitigate them. It could therefore make it more difficult for members to break from the stigma cycle.

Similar to attitudes common amongst the general public towards people who experience mental distress (Corrigan, 2000) self-stigma is frequently seen by staff as a 'choice' or an 'excuse' members use and that ultimately, members are responsible for controlling/managing responses to discrimination. This suggests the idea that a reason for the attribution of 'self-stigma' may relate to our culture of individualised approaches to support and a lack of a social model of mental distress, combined with neoliberal political rhetoric. For example, many of the behaviours to which staff members attribute self-stigma are diametrically opposed to what national policy says people who are 'recovering' ought to be experiencing:

> greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live… (Dept. of Health, 2011a:6)

Link and Phelan's (2014:30) thoughts on "stigma power" recognise how macro factors such as social and health policy, drive stigma processes and that power (re)creates social structures. The way staff members attribute self-stigma seems to empirically reflect the operation, to some degree, of "stigma power" which is described as "hidden, misrecognised processes serve the interests of the stigmatizers and are part of a social system that gets them what they want" (Link and Phelan, 2014:24). However, the evidence does not suggest that this is what staff *want* (directly or indirectly) or that it is intentional; far from it, it seems to be a by-product of the support relationship in this particular socio-political context. Link and Phelan (2013:534) talk about stigma being "a source of power that helps the stigmatizer control the stigmatized person and thereby keep them down, in or away." However, thinking about it from the staff perspective, there are a limited number of tools staff members have available to them to 'overcome' what they describe as 'self-stigma'. If using rapport building, presenting opportunities, and generally verbally encouraging and supporting members doesn't seem to 'work', rather than attribute this to the method of support (which would risk funding, affect 'outcomes' and undermine staff members' sense of self-efficiency and skill), it is attributed to the member. External/socio-political factors are acknowledged, but once staff members have employed their arsenal of support mechanisms there is little more they can do within their remit. Moreover, it is perhaps professionally untenable for staff to accept it is the support mechanisms which fail some members; such acceptance is not in line with contemporary mental health policy and welfare reform. It seems easier for staff to place the responsibility for not engaging satisfactorily with the members, call it 'self-stigma', and readily apply it to the members who staff members find most 'frustrating'. Conversely, it would be stigmatising for staff to not attribute any agency to members or recognise their capacity for agency or choice, yet the notion of 'self-stigma' seems to pigeonhole the individual. Part of this pigeonholing seems to come about because staff members seem more concerned about working towards reducing difference rather than working positively with difference. This notion of 'fitting in' is key to attributions of self-stigma; the more members 'fit in' with the ethos of the organisation, and fit in with social norms more generally, the less likely staff will attribute 'self-stigma' to their behaviours and attitudes. Thus, those who are 'different' often become self-stigmatising in the eyes of staff. Perhaps staff members could recognise

agency in a way that allows for 'possibilities' but not in such a way which puts pressure on the member to work hard at being 'normal' to be 'accepted'? It is possible that peer support as described in 4.3 goes some way in mitigating any negative effects arising from this behaviour of staff.

In terms of how members consider themselves to 'self-stigmatise' or identify 'self-stigma', conversations with members suggest that the most common ways self-stigma manifests itself is via feeling you should censor what you say i.e. not telling people or managing what you say about your mental health if you are in a position to do so, and/or avoiding certain situations. Self-stigma in the way members, and even the way some staff members identify and negotiate it, may more appropriately be considered a form of self-management and responses to past experiences of discrimination or expected discrimination. As Johnstone (2000:209) explains:

> Instead of being enabled to locate a significant portion of their problems where they belong, in externally imposed conditions and expectations, they adopt and impose those same conditions on themselves, and the messages they receive about being inadequate, defective, abnormal and inferior are translated into actually *experiencing themselves* as inadequate, defective, abnormal and inferior.

Whilst behaviour described by members is understandable, it doesn't challenge the "deeply embedded cultural conceptions and stereotypes" (Link and Phelan, 2013:537). How members refer to self-stigma provides an insight into the ways "stigma power" operates through the "stigmatised person" (Phelan et al., 2008), as we see ways in which members keep themselves "down", "in" or "away" (Link and Phelan, 2014). 'Self-stigma' is not something people do individually and in isolation of their social environment, and so may be more appropriately considered as a form of governmentality, self-surveillance, or self-management. These self-management techniques can often be misrecognised by staff members who attribute 'self-stigma'. Thinking about self-stigma via the examples of avoidance lends support to the idea that 'self-stigma' is an oxymoronic concept because what some of the existing literature, staff and members define as 'self-stigma' is predominantly resultant from negative experiences or the attitudes of others.

Corrigan and Watson (2002a) point out the paradoxical nature of 'self-stigma' but the premise of their argument is different to the one I am suggesting; they talk about how reactions to stigma vary from a loss in self-esteem (self-stigma) whereas others are energised by prejudice and express anger. According to Corrigan and Watson (2002a:36) "low self-esteem versus righteous anger describes a fundamental paradox in self-stigma"

and develop a situational model that explains that paradox i.e. it depends on the context of a person's experience to how they react. However, I suggest that the notion of 'self-stigma' is a paradox because it is born of the prejudice or the perceived prejudice of others, not the self; the self simply interprets stigma inherent elsewhere. Whilst it may very well not be staff members' intention to contribute to a stigma cycle, when taking into account the empirical material and the existing literature on stigma, labelling behaviours as self-stigmatising does not challenge the notion or existence of stigmatised identities. Thus, we see how such "misrecognition serves the interests of the powerful because it allows their interests to be achieved surreptitiously" (Link and Phelan, 2014:25). In the case of the support environments, attributing self-stigma could be said to serve staff members by absolving them of responsibility when the support doesn't seem to be effective in the ways that they think it ought to be.

The notion of 'self-stigma' removes us from any understandings of a social model of madness and distress. It could be suggested that this individualised way of labelling information management or avoidance of situations as '*self*-stigma' or attributable to the 'illness' itself, moves in the opposite direction of social models of disability, madness and distress. Attributions of self-stigma appear to place responsibility on individuals who have experienced mental distress to help themselves more, and focuses on their ability to 'fit in', which seems unfair on the member if it is born of negative experiences or attitudes. That said, I could empathetically comprehend how frustrating it was for staff to only have a number of tools and resources available to professionally help and support members within the remit of support provision. Perhaps we should object to self-stigma as a sanist practise on the grounds that it places responsibility for overcoming it and/or 'fitting in' on the person concerned and has the potential to distort systemic and individual discrimination. Encouraging staff to understand what is so easily termed 'self-stigma' as misrecognised responses to discrimination and reflecting on these processes may help in the short term. In the long term, these findings may contribute to the literature critiquing notions of recovery, support, and contemporary mental health policy.

Staff members at the two organisations appeared to work on a similar basis and attribute self-stigma to similar behaviours. There was no discernible difference between how self-stigma was attributed by staff members in Bright Futures and Creative Mindz. However, my empirical observations indicated that there tended to be a little more resistance (Thoits, 2011) to stigmatised identities and self-stigma at Creative Mindz. I felt 'difference' was embraced a little more and considered as an asset for creativity and art; however, as this study wasn't exploring this particular area I have little evidence to justify any strong claims.

Generally speaking mental health professionals are often considered lower in status than other health professionals (Hinshaw and Stier, 2008) and can be prone to burnout, which in turn has the capacity to influence their attitudes (Kopera et al., 2014:10). Although further work would be required to establish this, part of the 'frustration' some staff members experience may be related to the little power and resources the organisations have themselves to support members. In the first instance, staff themselves may benefit from support and space to deal with and vent that frustration.

Power differentials are integral to understanding stigma and support. Staff members' opinions and thoughts about members matter because of the relative micro-power they may exercise via their status as 'staff' in the interactions which take place in the microcosm of the support environment. Whilst there is a power differential between staff and members, it is micro-power, and the coercive power of staff at Bright Futures and Creative Mindz is ostensibly less than that of mental health professionals such as psychiatrists, psychologists, mental health nurses etc. and less than the power of statutory welfare services such as social workers. The findings in both Chapter 4 and this chapter demonstrate that the sort of relationship between staff and members, with less obvious power dynamics, has the potential to help break the stigma cycle and provide meaningful support but that that support can also subtly reinforce elements of the stigma cycle. Furthermore, staff members might very well experience a degree of micro-power in the roles that they perform but the type of work they do, particularly drawing on their own experiences and interpersonal skills, can also leave them feeling vulnerable. This is something I will explore in the next chapter.

5.4 Concluding comments

It is clear that 'self-stigma' is described and understood by members and staff differently. Exploring 'self-stigma' from a member perspective led me to understand that what members describe as 'self-stigma' always occurs as a result of actual experiences or perceived reactions of others based upon experience. As a result, members 'govern' themselves by employing methods of information management/self-censorship and/or avoiding certain situations. I have suggested that the empirical material supports the idea that staff members' attributions of self-stigma may be better conceptualised as staff misrecognising members' reactions to stigma and/or discrimination. Furthermore, it is conceptually inaccurate, sanist, and paradoxical for 'self-stigma' to be considered synonymous with self-management techniques formed as a result of negative or discriminatory experiences because such classification locates the 'problem' within the

individual. Both staff and member perspectives on self-stigma sees members contributing to their social condition, yet staff seem to see members' contribution to their own situation as blameful in some way, or at least assume more personal responsibility or agency on behalf of a member, whilst members do not. Thus, members are not self-stigmatising but self-manage in a way which is sometimes misrecognised or misconstrued by staff as self-stigma. Whilst passing and covering might be understandable, it places demands on members and perhaps support environments could think more about the ways members contribute to their social condition without blame. For example, setting the attribution of self-stigma in the context of discrimination, as I have done in this chapter, not only highlights the cost of self-management techniques for those of us who experience mental distress, but can also provide an alternative perspective on how we think about self-stigma.

These findings, particularly those relating to staff attributions of self-stigma often seemed incongruent with what I observed in practice and the empirical material I explored in Chapter 4. Staff members clearly don't *want* to attribute 'self-stigma'; it seems to be a way of regulating behaviour and coping with both the demands of the job and the socio-political climate in which they work. In the next chapter I consider, in more detail, how staff members negotiate their position via their role in the context of the organisations and the relative 'distance' between themselves and members.

CHAPTER 6:

The support context and stigma: the proximity of people in performing support

I began Chapter 4 by considering the significance of stigma and discrimination in the lives of members. The findings suggested that stigma and discrimination were commonly experienced by members in contexts such as work, other support services, and with family and friends, but not in the context of the case study organisations. In the remainder of Chapter 4, I explored interactions and relationships construed by members and staff as non-stigmatising. I examined the components of these interactions with reference to sociological concepts of stigma to explore why such interactions may be construed as non-stigmatising. In Chapter 5, I considered in greater depth how staff and members interpret certain behaviours and attitudes in the support environment, with particular reference to interactions which take place between staff and members. I explored the notion of attributing 'self-stigma' as a potentially stigmatising 'side effect' of how staff at the case study organisations work. However, I also highlighted how socio-political concerns were a contributing factor to such attribution, along with the limits of what support, as conducted in/by the case study organisations, is able to provide. During discussion in the previous two chapters, the context of the organisation was not absent. It is, after all, the context of the organisations that enables these interactions to take place, whether those interactions are construed as non-stigmatising, or could be said to result in attributions of self-stigma. That said, the focus of the previous two chapters were relationships, interactions, and socio-political concerns. Thus, the findings and discussion in this chapter bring the support context and what contributes to a supportive environment, which permeated the previous two chapters, into the foreground.

This chapter begins by considering the approaches of staff to information sharing, humour, and 'being informal' in their interactions with members, with particular attention to the organisational context in which the interactions and the performance of support is taking place. As 'distance' between staff and members has been identified in previous chapters as being important when thinking about stigma, I consider how the 'support devices' staff employ impact this notion of 'distance'. I consider how staff members contemplate their role at the organisation, and explore how staff negotiating their role contributes to creating an organisational context which may be construed as non-stigmatising by members. Moving on, I explore further how staff see themselves in the

context of the organisation in terms of their 'professional role' prescribed by the organisation and/or interpreted by individual staff members. In doing so, I contemplate how, as a result of that 'professional role', boundaries are often drawn around relationships which develop in the support context, and I deliberate how these boundaries play into the notion of 'distancing' staff from members. I also consider the different sorts of 'work' which staff carry out in order to maintain their role, relationship boundaries, and the environments at the organisations. Section 6.3 considers members' positive response to support performed by staff with reference to the organisational context and staff performing a professional role. Members often speak comparatively positively about the case study organisations which brings into play a critique of the socio-political individualisation of care and support provided elsewhere. Finally I consider the empirical material in relation to the performance of support in terms of what contributes to making an environment supportive with reference to the stigma discourse, and what 'work' is required of the actors in the support environment to make such an environment supportive and non-stigmatising.

6.1 Supportive interactions and reducing distance: using personal information, informality, and humour, in the context of support environments

In Chapter 4 I considered some of the hallmarks of a supportive relationship from an interactionist perspective. The types of interactions deemed supportive and not stigmatising seem to involve those which reduce the distance that members are set apart from each other and from staff members. One of the ways I identified that this reduction in distance occurred in Chapter 4 was via some staff sharing stories about their own experiences of mental distress. Another reoccurring theme arising from the empirical material, and the focus of this section, involves staff members negotiating information about themselves, and information about members, along with the use of humour, to perform a supportive role within the organisations. Exploring how staff share personal information and use humour as 'support devices' sheds further light on how the context of the organisations allow for the interactions which are interpreted by members, as we saw in Chapter 4, as supportive. In doing so I reflect on the ways staff and members are with each other and I identify these 'ways of being' as significant contributing factors to what is considered supportive in the context of the organisations. This section begins by considering two empirical examples; one taken from Creative Mindz where staff member

Kirsty appears to use significant personal information in her role supporting members, and the other from Bright Futures where staff member, Neil, chooses not to talk about himself so much. Although there is a difference in approach in sharing personal information, it seems that both staff members use the information they know about the members, along with what could be described as humour, to perform a supportive role and reduce the distance between themselves and the members.

I spent six weeks attending and participating in the weekly writing group run by sessional staff member, Kirsty, at Creative Mindz. Around five members usually attended any one session and for the period of time I attended there was a core membership of around seven regulars. Kirsty approached the sessions very informally which was evident in the way she talked to members and the topics of general conversation:

> *We sat around the table wondering if anyone else was going to turn up. Kirsty (staff) says she has stomach cramp, Sid (member) says he is not well, someone asks him what the matter is and he says brain haemorrhage and everyone laughs. Sid explains it's like a headache and says he's seeing the doctor tomorrow. Kirsty said she is on her period and she sometimes gets a really bad one and she just wants to be on her own. Kirsty added that her teenage son is 'doing her head in' at the moment. Greta (member) said it was a release and a relief when she got the menopause. Kirsty said she quite likes the build-up and then the release of having a period. Greta said she was making it sound like an orgasm. Everyone laughed again and Gavin (member) said something about the male menopause… During the session and the exercise Kirsty said she was going to give us prompts for our writing. Sid went off on a tangent about the table we were sat around which he described as becoming a key feature in the studio. Kirsty cut him off and said she isn't interested, and everyone, including Sid laughed, she then invited Sid to explain. Sid explained an incident at the member's meeting last week- he made some comment about women enjoying washing dishes which didn't go down well with the female members. Sid asked Greta how she thought it went down, he said he meant it as a joke but he had been worrying about it all weekend. Greta said he was overthinking it and should let it go, and Kirsty said he needed to stop worrying. Kirsty said if people haven't got a sense of humour it's their problem, she says she's going to stop him there, and that she was going to do one to one editing, but she 'couldn't be arsed' and this made everyone laugh again.* (Creative Mindz, FN17)

Kirsty discussed personal details; she talked about her stomach cramps and her relationship with her son. The members present at the group engaged with the conversation, particularly Sid who was also feeling unwell. Kirsty's manner of cutting Sid off when he went off on a tangent was humorous and playful, and overall it seemed Kirsty's approach encouraged Sid to talk more about himself and feel more at ease about his own insecurities and anxiety relating to an incident in the studio a week before which he felt anxious about. There is also an element of peer support (see 4.3) as Greta contributed to allaying Sid's anxiety. Apart from Kirsty providing prompts for writing exercises, the atmosphere was very much like friends chatting and everyone appeared at ease. In the session a week later, Kirsty observes and reflects on the week before, which I also recorded in my fieldnotes:

> *Kirsty said it's amazing how relaxed she's got with the group but she feels like she can 'be herself'. She noticed Sid wasn't there and said she worries about him or that he might think or worry about things she says to him, she said she feels like ringing him up. Other members say that Sid knows Kirsty is only joking.* (Creative Mindz, FN19).

Although Kirsty may well have been 'being herself' and relaxed in the first excerpt, this later account indicated to me that Kirsty is reflective of her approach, her role, and support style because she wondered whether she is being 'too relaxed'. Kirsty seems to negotiate her position in the support role by sharing information about her personal life which she is comfortable sharing, and appears to be treating members like friends to try and make them feel at ease. Kirsty was aware of Sid and his feelings of anxiety and perhaps she trivialised parts of the conversation with him and used humour in the way she did because she knew he tended to dwell on things. Kirsty seemed to adapt her style to Sid and that adaption and her approach to interacting with him is based on the knowledge she has of him. Sid missed the following week's session because he was unwell and returned the next week. Kirsty asked if he was okay about the comments she had made and said she had been worried, Sid made light of her concern and said she shouldn't "worry so much", a conversation culminating in laughter. This example also raises another important point regarding what staff members choose to challenge in the context of the organisation and indicates what staff members regard as important to/for the support relationship. The focus here seems to be on ensuring Sid is supported in relation to his anxiety and does not provide a challenge to the potential sexism Sid demonstrated which appeared to be a contributing source of his anxiety.

Moving on to the example from Bright Futures, I attended the weekly photography group for five weeks and, in comparison with the writing group, experienced a completely

different approach to support; very little was disclosed by Neil, the instructor, about his personal life as I observed in this example after the group had been talking about their weekend:

> *Sarah (member) was telling the group about the weekend she had had, she had been away to the seaside and stayed in a big house with all of her relatives and spent Saturday drinking in the sun and having a BBQ- she said didn't go to bed until after 1am. Sarah seemed in good spirits after such a good weekend. I notice that Neil doesn't really disclose much about his weekend and when I think about it, he doesn't really say much about his life at all. Last week he talked a bit about coming from Wales, but I got the impression he keeps himself out of his work because I notice he changes the subject. Having said that I don't think that matters, it seems the members are comfortable with him and he has a really nice manner when he's guiding them in their work.* (Bright Futures, FN8)

Each week I observed Neil (staff) and he rarely said anything about himself but he always tried to ensure the members were okay, practised patience, and offered a lot of technical support. For example:

> *Neil came in. I note that he takes the time to speak to everyone and shakes their hand, he notices Finn (member) is new (although I didn't know this at the time) and Neil introduces himself and they have a brief conversation in the corner of the room… Jimmy (member) opened up the file with his photographs on the laptop and a beautiful photograph of some ducks sailing away was projected onto the wall. Neil says he thinks they're sailing away from Jimmy, 'metaphorically, physically, spiritually…' we all laugh. Jimmy said 'no' and that they were sailing away from the freak next to him (referring to Neil), Neil says 'I'm glad he didn't see him' and there was more laughter. Neil then said he was only joking and looked at the photograph again. Jimmy switched to his next photograph of some purple flowers and Neil said 'there is another excellent shot on the screen'. Jimmy said he thought it was 'alright'. Neil said 'it isn't even all right, it's superb.' Jimmy says 'thank you very much' and that he has 'a good teacher'*. (Bright Futures, FN18)

I got the impression Neil took his role seriously and tried to make members feel comfortable, supported, and included. For example, the friendly yet quiet ways he performed his role such as the formality of introducing himself to the new member and shaking each member's hand.

Neil had known Jimmy for a number of months and knew Jimmy has a propensity to make pun-like jokes and so I sensed Neil felt it was safe to crack a joke. This seemed to be Neil's way of negotiating his role in supporting Jimmy and that the joke almost served as an acknowledgment that Neil did know Jimmy, particularly as he followed it up with a compliment, which Jimmy returned, suggesting mutual respect. Similar to the example from the writing group, the element of informality with the joke seemed to be based on Neil's knowledge of Jimmy. Furthermore, the feedback he provided Jimmy also served to reassert his role as instructor.

Neil and Kirsty demonstrated two very different styles of, or approaches to, support. The differences are perhaps slightly reflective of the different approaches of each organisation to how staff members consider their personal lives in relation to their professional roles; Creative Mindz being slightly more informal, although no less 'professional', than Bright Futures. Both staff members use humour based on their knowledge of the members they are supporting and both manage the information they disclose about themselves to different degrees. Both approaches seemed to initiate interactions which could be deemed supportive, but I suggest they only seem supportive because Neil and Kirsty knew the members well and they negotiated the interactions based on the information they had about the members via their previous experience and individual relationships with those particular members. It seems it was the management of information that made the interaction 'smooth'; the interaction didn't seem to create distance and the humour helped close any gap which may have opened in other contexts. For example, it would be unlikely a psychiatrist or psychologist would behave in the same way but this is largely due to a difference in context and a different supporting role. Comparisons to other support relationships are considered in more depth in 6.3.

In Chapter 4 I explored how staff members often use information about themselves, particularly details of their own experiences of mental distress, as a support device to create rapport with, and support, members. I also explored how an element of distancing was involved as to not share 'too much'. Staff talking about themselves, whether that is about menstrual pain, family members, or about their own experiences of mental distress, seems a way in which staff members connect with members. That said, similar to the findings in 4.4 and 4.5, all staff members I spoke to said, in different ways, that they held back from talking about certain aspects of their personal life. There seemed to be invisible lines or boundaries for every staff participant I interviewed. For example, as Peter (staff, int., Creative Mindz) explained:

I suppose I try not to give too much personal information away and not get too heavily involved in the emotional aspects of what people are dealing with in their everyday life…

Nicola (staff, int., Creative Mindz) had similar thoughts:

I think like I wouldn't talk about my personal life, so like I'd quite happily be like, 'yeah, I'm going on holiday with my boyfriend blah blah blah', but there's definitely things that I hold back like, I wouldn't really go any further than that… I don't want there to be a crossover of things, because I don't thinks that's right, there needs to be a certain…I think they <members> need to know we're here to help, but kind of like, I don't know, like it sounds horrible to say we're not your friend, because like I'm totally there to be their friend and I want to help but like, you're my friend here like, like not in my private life, I'd never, like if we've had an event, I'd totally go for a drink with the members but I'd never go for a drink [outside of work]…

Nicola distinguishes a difference between the context of the organisation and her personal life and draws a line for herself, despite the fact the contexts overlap. It seems that this overlapping of contexts 'sets up' the way support is delivered. For example, Nicola considers being a friend to members, but only in the context of the support environment. In this respect there are some parallels with the relationships explored in 4.3 where members support one another, i.e. their relationships remain in context.

The empirical material in this section illustrates that the 'ways' staff and members are with each other, e.g. using personal information, the knowledge they have about members, informality, and humour, contributes to the context which is deemed supportive and allows for the interactions which seem to reduce the distance that members are set apart as different and thus, creates a potentially non-stigmatising environment. Humour and information management about yourself and others, intricately woven in the support context, provides for interactions and an environment members appear to find supportive. However, these findings also begin to illustrate what is a priority, between challenge and support, in these particular contexts. For example, choosing humour to support someone experiencing anxiety may overshadow challenging a members' behaviour which may be construed as sexist. Furthermore, there are tensions in the context of support which staff comment upon which indicated by the negotiation of how you should talk about yourself as a member of staff in the support context, along with notions of what is appropriate. This will be considered in depth in the following section which considers how staff members, often by virtue of their role in the organisation or organisational rules, draw boundaries

around what information they will disclose and the relationships which develop in the support context.

6.2 Creating distance and drawing boundaries around relationships in the context of support provision

The example involving Neil from Bright Futures in the previous section indicates that sharing personal information isn't a prerequisite for providing support in the context of the case study organisations. However, evidence from this study suggests that when personal information is shared in the support context it can be used to reduce distance between staff and members in the context of the organisations, and can help to provide a non-stigmatising environment. However, it also appeared that by virtue of staff members' professional role in the support relationship, lines around what information is shared were drawn by organisations and/or staff members. The reasons staff gave for this were often attributed to the fact that staff members were performing a professional role and the amount of personal information shared had to be 'appropriate' to the context and managed with regard to that. We have seen in Chapter 5 some of the potentially negative effects of interactions and interpretations of certain behaviours in the support environments of Creative Mind and Bright Futures via the attribution of self-stigma. As explored in Chapter 5, broadly speaking, this attribution matters because of the power differential between staff and members. This section considers further how both organisations and staff making decisions on what personal information they share, and where and how they choose to draw their boundaries around their relationships with members, could potentially be reflective of the distance between staff and members. I explore the notion that when staff members make a decision on what to share and how to interpret their 'professional role' in the context of the organisations, they are negotiating the proximity of members from themselves which potentially impacts on support environments such as Bright Futures and Creative Mindz. I also consider how organisational rules shape the context of support and explore how flexible approaches to 'rules', along with the overlap of personal and professional contexts, demand significant emotional effort from staff in their negotiations. However, I also highlight how sensitively applying organisational rules also demands emotional effort from staff and these interactions further shape the support context and can contribute to less stigmatising interactions.

I begin by thinking about the organisational rules which shape the support context. In both organisations sexual relationships between members and staff were prohibited, as was the exchange of money. Bright Futures had more prescribed organisational rules than Creative Mindz such as specifying that there should be no relationships with members outside of the support context, that members and staff should conduct themselves as if they are in a workplace environment, and that any staff disclosure of personal experiences should be to benefit the member, not as therapy for the staff member. Creative Mindz did not have the same prescribed rules and, as the following examples illustrate, it seemed to be up to the individual member of staff to decide what was and was not appropriate in terms of information sharing and relationships inside and outside of the support context. Conversely, organisational rules at Bright Futures provided more prescriptive lines within which staff relationships with members were drawn and it was these rules they chose to discuss in more depth when I asked them about how their roles at the organisations impacts on their personal lives.

At Creative Mindz most staff brought up a number of 'tricky' scenarios relating to members and staff being friends on Facebook. For example, Daniel (staff, int., Creative Mindz) went from volunteer to paid staff member and describes how he thought there ought to be some professional boundary or separation from himself and the members when he became a paid staff member. When I asked specifically as to why he felt like that, he didn't give any reason apart from saying "*I felt I should*". Daniel negotiated his transition from volunteer to member by no longer accepting members as friends on Facebook and decided to place existing members he had previously accepted as friends on Facebook on a restricted list so they could only see his basic information:

> *I do explain to people 'it's not that I don't want to befriend you, it's just that it's not professional'…I say 'it's not that I don't consider you a friend, it's just that, we do have to keep sort of a boundary'…*

Unlike the situation at Bright Futures where it was prohibited to be Facebook friends with members, there was no organisational policy at Creative Mindz about allowing or prohibiting staff befriending members on Facebook. However, in the absence of organisational rules Daniel refers to his own mode of boundary setting and conceptualises his own understanding of what is 'professional'. I went on to ask Daniel whether he thought that his decision not to accept members as new friends on Facebook and putting existing 'member friends' on a restricted list was useful, and he explained:

I think, it doesn't really have a use, other than, if for whatever reason that person had a relapse or didn't like the way you treated them, they could make things very complicated for you, that's the nature of mental health…

Daniel explains how he keeps himself "*slightly detached*" and does this by managing the information he discloses about himself. This indicates that information management is a way staff can create distance from members in the support environment. Furthermore, Daniel's rationale for doing so is that any personal information members have could be used against him because "*that's the nature of mental health*." The statement may be construed as stigmatising in itself i.e. implying the stereotype of the 'unpredictable nature' of people who experience distress but Daniel's comments also indicate a dilemma. Whilst he believes any personal information he discloses may give members power they might abuse, we have seen how exchange of personal information is a gesture of trust which helps reduce power differentials and build transformative non-stigmatising relationships. That said, Daniel also indicates that disclosure can leave him feeling vulnerable in his professional role; it seems this sort of information management is complex.

Nicola (Staff, int., Creative Mindz) explains a predicament which emphasises the culture of risk in the public and third sectors, highlighting the vulnerability of workers employed in organisations like Bright Futures and Creative Mindz who rely upon their 'selves' as a resource for the support they perform:

I had a bit of an awkward whatever, last week, and I don't know whether it's going to like occur, but like XXXX <member> was like, 'what's your full name?' I was like 'Nicola XXXX', she was like 'I'll add you on Facebook' and I was like, 'fuck', cos like I did a course on like boundaries for my other job and I'm totally like, XXXX <member> tried to add me and I just ignored it…I think, especially, it's a bit different for me because I'm trying to go into support work and so like, I can't ever be seen to be having that relationship.. Also that kind of like opens up a world that is my life, and like, I don't know, like even little things like we moved house in September and there's pictures of us when we've just moved house and like, that's my life, this is different…

Nicola was very concerned about maintaining a professional boundary, separating her personal and work lives, and presenting herself professionally for her future career in support work. Both Daniel and Nicola's comments reveal that the notion of 'boundaries' is significantly impacted, and potentially breached, by the information members have about staff e.g. access to personal details, photographs, and life events such as moving house.

However, not all staff members were keen to establish such a definite 'Facebook boundary' like Nicola and Daniel. Jake (staff, int., Creative Mindz) recognised that Creative Mindz had a presence on Facebook which was a useful communication tool. When I asked Jake about Facebook friends he explained a more subtle personal policy:

> *Well I've got about four, maybe five people, who aren't staff who are on the friendship thing which is really tricky because there are people who request who I'm not in any shape or form going to accept, because it can cause all sorts of potential issues…Erm, yeah it's a tricky one and I think I'm quite upfront, I mean XXXX, XXXX <members> both of them having, on the autistic spectrum, I feel that they don't have the capacity to understand some of the subtleties that communication on Facebook can be, you know, people's humour and things, it's a minefield and I could go down the line of having a strict policy for all staff but then you know, XXXX <member and now volunteer>, a good example, she isn't officially a staff member yet and we're trying to employ her, so…there's lots of blurred boundary lines and I think we all communicate together a lot about those issues…so we sort of iron out any potential issues…*

V: By?

J: Making judgment calls, based on sort of well-informed open discussions as a team…

V: And would you go back to that person and say why you haven't accepted them as a friend or whatever…

J: Yeah XXXX <member> for example, I said I didn't think it was appropriate and you know she said 'well you're friends with such and such', I go 'well yeah, but to be completely honest, I had different friendship links with them and at the time it seemed like the right thing, but I don't think it is appropriate, I work with you in the studio all week and if there's anything we need to communicate that's where we will communicate….'

V: And how did she react?

J: She was okay, she has a bit of an issue, same with XXXX <another member>, but I have to draw a line in the sand for myself sometimes and deal with the shit.

Jake explains how he approaches and negotiates the 'Facebook boundary' in a shrewd yet sensitive way, on a case by case basis, and he explains candidly to members when he

doesn't accept them as a friend on Facebook. There is perhaps an implication that as a staff member, in a relative position of power to the members, he has a responsibility to manage boundaries between the contexts of personal and professional life. However, in some ways he embraces the blurring of boundaries and doesn't think a strict organisational policy would be particularly beneficial to the way staff and members communicate. Jake's comments highlight how he has to "*draw a line in the sand for himself*", indicating that staff drawing their own boundaries around relationships in the support context could be considered to be most useful to staff than the members. This is not to say that organisation or professional boundaries are not useful to both staff and members but it should also be noted that it seems it is the staff, in this context, doing the deciding about what they disclose and whether they befriend or engage with members on Facebook, which suggests that any power, in the crudest sense, lies with the staff. However, the situation is complex and it is perhaps not the 'type' of boundary that ought to be the focus here, but the exploration of the management or negotiation of that boundary. It could be argued that the room for negotiation around being Facebook friends with members may result in unfairness in terms of some members being accepted as friends and others not. Conversely, a less flexible approach would mean that staff members are unable to negotiate appropriately on a case by case basis. When staff members do decide to employ their own notion of boundaries and not befriend members on Facebook this could be said to be a form of 'setting apart' or 'distancing'. However, such setting apart could also be said to protect members from abuses of power from staff; it is the staff in this case which are managing these boundaries in a way that would not have occurred at Bright Futures. What is the difference between distance required for a support relationship to be 'effective' for members and setting apart members as 'different'? The former being supportive and non-stigmatising, and the latter which potentially contributes to stigma. This is something I consider further below and in the next subsection. At this point it should also be noted that members also had a choice about whether or not to accept any friend requests that are put to them. Thus, the power isn't all one-sided. However, there was no evidence to suggest that staff members were proactively asking to be friends with members on Facebook.

Some blurring of professional roles and personal lives in the context of the organisations seems to be almost integral to the 'doing' of support in organisations such as Creative Mindz and Bright Futures. Particularly for building meaningful relationships based on a level of trust which can become significant to members for reducing some of the negative effects of stigma and discrimination. Personal information appears to be the currency in which staff members deal to gain the trust of members in order to help and

support them in the way that they do and build a relationship with members and which members and staff seem to find valuable and supportive. Moreover, being transparent with members about why staff can't be friends with members on Facebook in certain situations can be useful for both members and staff in managing expectations. Furthermore, as the tool of the trade at these organisations is often the 'self', many of the comments suggest that staff themselves can feel vulnerable if members know a lot about them. Discussion with staff suggested that they spend a lot of time thinking about how best to manage information about themselves which seems to go unnoticed by members and perhaps other professionals. It also seems that information management about personal details, professional boundaries, reducing distance (as we saw in Chapters 4 and 6.1) along with 'setting apart' or 'distancing' is all part of what makes up the intricacies of these particular support contexts; a theme which is revisited throughout this chapter.

Exploring professional roles and their crossover with personal lives with Bright Futures staff in the context of the organisation did not raise the same issues as they did at Creative Mindz. This seemed to be because more prescriptive organisational rules (as mentioned above) and the organisation itself was instrumental in creating distance in a way it did not at Creative Mindz where those rules were absent. When I talked about boundaries and drawing lines around relationships with staff at Bright Futures, they tended to talk about transgressions of organisational rules which were easily identified by Bright Futures staff. Thus, staff members I spoke to at Bright Futures were more inclined to talk about situations which involved organisational boundaries rather than staff having to draw their own personal boundaries as they did in the examples at Creative Mindz. I have selected two examples of instances where staff considered members to have overstepped boundaries set by the organisation.

The first example relates to a member who made an inappropriate comment to a member of staff about her breasts, as Faye (staff, int., Bright Futures) explained:

> *I had one member who said that when I laugh my breasts jiggled…and I had a very big chat about boundaries and he still didn't see me point…and then he said that I didn't have a sense of humour. So, there are some people who really play on it…he complained to, I think it was XXXX <(male)colleague>, yeah he didn't see what was going wrong, so XXXX <colleague> had a chat with him about it and said, 'well you know, women get a bit, erm'…I don't know what his exact words were, but 'you know what women are like', that kind of thing and 'she's got a point', and 'it's not really the done thing at work so you can't say those things', but he kept bringing it up all the time, like, when I said those things I didn't really mean anything by it, I*

thought well, 'yes you did' <laughs> and I learned from that, that you watch where your tops are [cut]…

Whilst the alleged approach of Faye's colleague in dealing with the matter was appallingly sexist, the example above illustrates that the member crossed a line many of us would recognise at work or in everyday life as a form of sexual harassment or inappropriate behaviour. As an organisational rule at Bright Futures was that staff and members ought to behave as if they are in a workplace environment, it was important to enforce that rule to protect Faye and, ultimately, other members and staff. As Faye states, she 'watches where her tops are cut' and so it is not just members who adjust (or are expected to adjust) their behaviour when boundaries are overstepped; this example also demonstrates how staff members also adjust their behaviour. However, this wasn't a boundary relating to information management like many of the others we have seen, or about setting apart members as different because of their status as members; I expect many people would find the member's behaviour inappropriate in most contexts. Although I didn't witness similar or comparable behaviour at Creative Mindz, my experience of spending time there suggested to me that such behaviour would be deemed inappropriate and the member would be spoken to about his behaviour.

The second example concerns a member who 'fell in love' with a staff member as described by Deborah (staff, int., Bright Futures):

Just last week, one of the female members of staff got a text from somebody who she's link worker with, expressing undying love for her, with that one and there's that bit of, we need to address it, but we need to do it in a way that we don't attack his confidence by it, also so that it's then not uncomfortable for the member of staff. Before I knew about it, it'd come to, well we'll just change his link worker, and the new link worker will ask him to come in…no, we owe him that bit of, the person he sent the message to contacting him to explain that 'because you've expressed this, to protect you and to protect me, I can't work directly with you anymore, but we don't want to stop using the service and I want to introduce you to your new link worker', it makes it sort of…you're being truthful with somebody without trying to make them feel bad about themselves and just explain it…We've had undying love, so if I can't see, it's usually XXXX <laughs>, 'if I can't see XXXX then I won't, that's it, I'm not using the service' and it's sort of like, 'that's your choice' with that bit, what we're saying to you is, to protect you and the member of staff, that isn't, you can't help how you feel about her…sometimes it's not so much

expressing undying love it's just erm, a member is in investing too much, expecting too much, of a member of staff, sort of like, if you ring up it has to be that member of staff they will speak to, erm, all the time and you've got to sort of weigh that up as to how helpful is that to the person, because we're not in with you for the long term and somebody is becoming very over dependent on that member of staff. So I do strongly believe that instead of trying to just organise things that you need to be up front with the person about what you're doing and why you're doing it because if that is a behaviour that they've got elsewhere in life, that they're investing too much into one person and then suddenly that person disappears and doesn't want to have anything to do with them anymore, then it just feeds into their constant belief that people reject me…rather than, but this isn't something that's normal in society, that actually all of us keep boundaries, and this is what you do with your very close friend, not maybe the shopkeeper or a member of staff, and we do, we have worked with people who just haven't understood the social norms and have been really isolated and when somebody pays them some attention, they misinterpret it and you can understand how that's happened and where it's come from, but you still need to treat people like adults, but doing it in a way that doesn't make them feel bad about themselves.

Deborah described how a member overstepped the boundary with his link worker but also explained how this was negotiated with care, sensitivity, and by being "up front" with the member; all important elements of a supportive role and the creation of supportive environment. Furthermore, Deborah's comments indicate how organisational rules in the support environment exist for the benefit of both members and staff, and suggest how one of the functions of boundaries or organisational rules within the support environment is to reinforce social norms in a way that members can feel good about themselves. For example, clear organisational rules help staff to explain what is and is not acceptable in a workplace environment and perhaps the support context, in this respect, is a way of preparing members for other contexts, as Deborah describes. Moreover, it could be considered that whilst the organisational rules created some distance, Deborah spends time negotiating the rules in a way which doesn't emphasise difference on the grounds of their experiences of mental distress. In Chapter 5 I formed a critique around staff attributing self-stigma to members who didn't conform to, or 'fit in' with the support environment, particularly when staff members had exhausted all of their 'tools' and/or 'support devices'. In doing so I suggested that this attribution should be considered in the context of discrimination or sanist practice. The notion of 'fitting in' is key to attributions

of self-stigma; generally speaking, as we saw in Chapter 5, the more members 'fit in' with the ethos of the organisation, and more generally social norms, the less likely they will be labelled 'self-stigmatising' by staff. It is the labelling that is potentially stigmatising or at least contributes to a cycle of stigma in the form of setting apart. The examples in this chapter don't involve labelling members when they 'break the rules' or 'transgress boundaries' and it seems the staff members' reflexive negotiation of boundaries and organisational rules is evidence of staff performing their role without the attribution of labels, and is thus less likely to contribute to stigma.

In both examples from Bright Futures staff, a certain distance is created or enforced between staff and members, usually as the result of organisational boundaries and/or rules along with members' behaviour which breaches those rules. It has to be said that from my own knowledge of Creative Mindz, should a member make sexual remarks to, or 'fall in love' with, a member of staff I think it would have been dealt with in a similar way. The examples from Bright Futures illustrate how it is easier for staff to distinguish between what is and what is not acceptable if rules are explicit and these organisational rules shape the support context. If Creative Mindz had had a policy which prohibited being Facebook friends with members, the negotiation and staff considerations of the proximity of members in the social media context wouldn't have taken place. Thus, more explicit rules protect staff and also provide a vehicle to considerately and compassionately remind members of what is appropriate behaviour in the workplace; preparing them sensitively and 'coaching' them to avoid behaviour that would be sanctioned in 'normal social life'. However, it could also be said that an explicit setting of the rules that members must follow, by the more powerful staff/organisations, also 'reminds' members of their place. Conversely, a 'case by case' negotiation conducted interpersonally between a particular member and staff member, within the support context and as part of supportive relationships, can perhaps contribute to supportive and non-stigmatising interactions. It seems that simply because 'rules' make things 'easier' or 'clearer' it doesn't necessarily follow that such rules are therefore 'better'. The examples in this subsection point to the notion that the ambiguity of the support space which has the potential to minimise the 'distance' between staff and members, within the limits identified in the examples, can perhaps contribute to what we may understand as non-stigmatising support, or interactions which have the effect of reducing the negative effects of stigma.

There were other ways that staff created and reduced distance in the support environment of both organisations. Some describe the distance between themselves and members as being quite a physical thing, as Daniel (staff, int., Creative Mindz) explained:

I also avoid making physical contact even if somebody is very upset, as much as I would like to give them a hug or just hold their hand and just say, 'come on you know, everything won't seem as bad tomorrow', erm, I won't. I just think it's wrong.

Lucy (staff, int., Bright Futures) described Bright Futures as having fewer boundaries than other services because staff members don't wear uniforms:

because it's so informal and I think, I don't wear a uniform anyway at work, but not wearing uniform and everything like that just makes it a nicer, like more approachable…

These two examples demonstrate how distance between staff and members is embodied within the practise of the organisation and the staff members. Whilst this embodied aspect was important, other staff members such as Faye (staff, int., Bright Futures) recognised that there were people she supported that she did quite like but she couldn't be friends with them because of the fact she was supporting a person professionally:

you've gotta keep in the back of your mind that you don't want to hang on to this person, and you've got to remember that sometimes, some of them, I really like them, and I know you know, and in different circumstances could possibly have been friends with them and sometimes I feel a bit sad that they're moving on, but you've got to let all that go and you've just got to enjoy what you've got at the time, that relationship that you've got with them, and that feeling of, that I get which is, I've done a good job, you know some self-esteem, self-worth…

Organisational rules prohibited any sort of overlap between Faye's personal life and her relationships with members at the organisation; it almost seems like the decision is taken out of her hands and so she doesn't dwell on it. However, staff members from Creative Mindz like Jake (staff, int., Creative Mindz), where there weren't the same organisational rules, tended to consider and negotiate the overlap of their professional role and personal lives on a case by case basis and it was up to the discretion of staff to decide:

There has to be services which will have those professional boundaries correctly, for the right reasons, in place, for them to be very rigid…a social worker, CPN, any clinician that is guided by sort of clinical practices, I mean I haven't been trained as a social worker, I might know a lot of the stuff that social workers know through just having experienced a lot of details and discussions, and reading up and stuff, but I haven't been trained in it, so I'm not governed by those rules and I think the

social aspect is a really tricky one because, I mean, we probably all have friends or family, relatives with some kind of mental health issue, at some point in time, sometimes it's not evident to us because we don't understand mental health issues, you know, working here, the amount of times where, through my friendship group, particularly my friendship group actually, there's quite a lot with mental health issues who can turn up here and there's someone I have socially been drinking with and then suddenly they're here…which is you know a potential issue, but then should I suddenly go I can't have a drink with that person? I suppose it's tricky, it's assessing the individual, you know the mental health issue, you know if someone has got depression, I mean, actually what they need is their friend more perhaps. If it's where they perhaps have episodes of psychosis, being aware that when they're unwell that they could be potentially volatile or act in a way that would be, you know, potentially implicate myself in something, so I suppose it's about assessing what the mental health issues are, because mental health takes up everything, we all have mental health, so at what stage does it become like a brick wall between myself and them…

This interesting quote highlights how the context of personal life and support provision can overlap. In making a decision of where professional and personal boundaries lie, Jake takes into account the circumstances of the situation and there isn't a one size fits all approach which, as Jake mentions, other professions are more inclined to have. Jake negotiates situations on a case by case basis which is centred on his knowledge of the member, the information that member may have about you as staff member, and the particular diagnosis a person may have. This management of information and negotiation seems to result in whether, and how far, a member should be, at the most 'set apart' or at least 'distanced'. Furthermore, Jake's comment emphasises the complexity of relationships formed in the support contexts provided by organisations like Creative Mindz without strict organisational rules and professional codes of practice.

We have seen how there are some 'obvious' organisational rules or boundaries to protect both members and staff, such as no sexual relationships with members and no exchange of money. In Bright Futures, more prescriptive organisational rules meant that boundaries and the lines drawn around relationships in the support context were often discussed in relation to organisational rules. Conversely, the dilemmas arising for staff at Creative Mindz were quite different and negotiated by the individual staff member when it came to drawing boundaries around relationships with members within and beyond the support context. However, in both case study organisations there wasn't a strict

professional code (often linked to professions such as psychotherapy, mental health nursing, or statutory services such as social work), and as the nature of the support work itself is very interaction-based, staff members tend to use themselves and their personal lives as a resource to find ways to support members. Staff using their own lives and experiences in this way seems to create work or labour for staff members which perhaps other professions don't have to contend with in the same way, simply because they don't 'use' themselves and their personal lives so much in the context of their profession. As a result of the 'type' of support relationships formed at these organisations there is potential for considerable crossover of work or professional contexts, and personal lives of staff. It could be argued that this overlapping of contexts is necessary for such support to be effective or to be performed in a non-stigmatising way. This is something the next section explores; how members respond to issues of 'distance' and their proximity to staff, along with *how* support is performed in the context of the organisation.

6.3 Members' response to 'distance', socio-political contexts, and the performance of support

Discussion in this chapter so far has predominantly focused on staff perspectives in terms of the support context and ways in which it could be considered members are distanced, and how distance is reduced, along with how lines are drawn around staff-member relationships by both staff and the organisation. The initial focus has been on staff because they are in the 'more powerful' position to negotiate that distance and potentially 'set apart' members. However, as the previous two chapters have proved, this is not a one way process and this section looks at how members experience distance from staff in the support context. In doing so I consider how support is performed in the context of the organisations and how that performance is impacted, as referred to in Chapter 5, by wider socio-political concerns.

When I explored, with members, the issue of organisational rules and boundaries or distance between themselves and staff, very few members said they felt there was much distance between themselves and staff at the organisations because of the types of interactions and relationships which developed (see Chapter 4). If members did discuss staff members' professional role and their proximate distance from staff as a result of this, most members seemed to feel that the way staff negotiated their role was beneficial to members and they regularly compared their experiences of staff at the case study organisations with those of other professionals, such as psychiatrists. From discussion it became clear that the relationships members developed with staff in the context of

Creative Mindz and Bright Futures differed greatly to other contexts. Members' comments regarding relationships with psychiatric professionals and/or social services suggested that there was a degree of distance in these relationships, and that distance was obvious; this seems to be in contrast to the relationships at the case study organisations. For example, Yvonne (Member, int., Bright Futures) made a distinction between staff at Bright Futures and psychiatric professionals, a comparison which was common amongst members and staff (see 4.1, 4.2 and 6.1). Yvonne felt that the staff members at Bright Futures were more like friends and that her relationships with Bright Futures staff were positive:

> *Here I don't feel like investigated and observed, it's like my choice and she's, the people working here, they, they are still not like psychiatrists or psychologist but like a best friend …*

Carl (member, int., Bright Futures) disclosed he had had an intimate relationship with a named nurse whilst on a psychiatric ward and as a result felt distance and boundaries between staff and members in the support context were generally a good thing:

> *Here it is more casual, I think, well you wouldn't go out for a coffee with your psychiatrist, but here they have coffee groups and that, and it is more casual but I think the client patient relationship still has to stand…I do know of relationships between client and care provider that are actually very very successful and promotive relationships and I don't think there's anything wrong with that but you've got to be very careful before that kind of thing happens…and if you are considering getting into a relationship with a professional or client then you should be open about it and assessed before it happened, open with other people and get supervised during the beginnings of the relationship, I don't think there's anything wrong with doing it, just be very very careful and be monitored because you can't help who you fall in love with…*

Carl's comments call for openness and transparency should personal relationships develop to guard against abuse of power. Felicity (member, int., Creative Mindz) reported that members preferred some notion of boundaries between themselves and staff. Felicity began her time at Creative Mindz as a volunteer but it was suggested, due to her continuing experiences of mental distress, that she became a member. This created confusion for Felicity about what boundaries there should be relating to the information she acquired from staff about other members:

Sometimes they [staff] tell me sort of things I shouldn't know, they shouldn't say maybe, things like between a member and staff, so this is like a drawn line on the water, that you don't know if you're part of these ones or those ones, sometimes it's like to me, it's hard and a difficult one to know, shall I listen or not, shall I go and say we are having issues in here or not.

The source of Felicity's confusion seems to relate to information management; what she ought to know and what she shouldn't know. As a result of being party to some sensitive conversations and not others about other members, her role as member overlapped with her initial role as volunteer. However, it could be argued Felicity was a 'special case' boundary crosser because she originally came to Creative Mindz as a volunteer and thus, it would be misleading to generalise from her to all members. It is interesting to note that the idea a member could become a volunteer and/or a member of staff is a distinctive element of these organisational contexts, and it is something that would be very unlikely to occur in other professions such as psychiatry. It is possible that this is another characteristic of the organisations which contributes to their stigma reduction potential. Nevertheless, what both Felicity and Carl's comments illustrate is that whilst we have seen how staff members negotiating some distance from members in certain situations in the support context (6.2), that distance and those boundaries are also useful for members, particularly in term of providing clarity.

I didn't speak to any member who reported a profoundly negative experience relating to how staff members provide support or how staff members negotiate boundaries between themselves and members, and/or create or reduce distance. Instead, and most importantly to members and as Yvonne did (above), they tended to compare support at the organisations to other services and praised the organisations I worked with for their approach. In doing so Stevie (member, int. Creative Mindz) pointed out the wider problems with professional boundaries in other contexts, and as they relate to the personalisation agenda and professionalised care:

I prefer it here because I'm somebody who likes to be more sociable, and the modern style of individualised personal packages of care, where there's you and your carer, and because of the rules that apply to carers, they're not allowed to take you to meet their mates down the pub at the weekend, or their family and like say, 'oh you're interested in whatever, my brother and you would get on like a house on fire let's go to me dad's barbeque at the weekend you'll meet him', and they're cut off from the chances of being connected to meet others…and also, in

cafes, you can't just go and speak to just anybody in a café…and in pubs, when people are a bit vulnerable you get a lot of drunkenness, it's not always the best thing…

Stevie's comments are in line with how some scholars have understood the implications of personalisation and closing day services. For example, Roulstone and Morgan (2009) argue day service recipients risk moving from a position of enforced collectivism to an enforced individualism, a characteristic of neoliberal constructions of economic life. Stevie suggests that the sort of support she describes, diametrically opposed to the setup of Creative Mindz, is lonely and individualistic which has the result of dividing her from society rather than making her feel integrated or part of a community. Stevie continued:

What I don't like about befrienders, and whether it is a paid carer paid by an organisation, a caring organisation, to come and look after you because you are vulnerable, you have, you can't manage on your own, you have to have somebody looking after you or someone to do you shopping for you…or if it's a case of a causal volunteer just for a couple of hours a week, two or three hours a week not doing any looking after you, just going out for a coffee with you, going to a market, or cinema, there are prohibitive rules and regulations, I can understand in carer situation, but in a casual volunteer befriender, they're not allowed to be your friends. They're not allowed to have an association with you outside the appointed time and place of the job. They're not allowed to take you to visit their friends, and in both cases, paid carer or casual volunteer befriender, you have to buy their drinks, their meals, their tickets, they get a free ride on your back and some people, with some of the more vulnerable people, they can be taken advantage of…and with the personal budget scheme, annual personal budget, it's turning this whole thing into a capitalist trader, it becomes a trade, a commodity, a paid for commodity and it's, you're a service customer, not a service user…

Stevie indicates how individualised methods of support propagated by the personalisation agenda may make people feel more vulnerable in the support scenario. What Stevie's comments also demonstrate, along with the evidence in 4.3 and other material covered in this chapter, is a significant need for group and building based services which provide a context where staff and members can come together with one another, and other members too, to experience supportive interactions. Stevie also touches on an issue around terminology of 'service customer' and 'service user' and how they relate to the commodification of services. It is interesting to note that those who attend Bright Futures

and Creative Mindz are referred to as 'members' not service users, survivors, clients, or patients, etc. Thus, the concept of membership does not overtly subscribe to a medical or 'service' discourse (although it is certainly imbued with medical and service discourse); the term member conveys solidarity and belonging. This was something I reflected upon whilst reviewing my empirical material and perhaps subliminally impacts on how members are considered by staff, on how members see themselves and staff, and their relationship to staff and one another in the support environment. Following Forrester-Jones and Barnes (2008), it seems that the type of support provided by Creative Mindz and Bright Futures may help members manage a less stigmatising identity than that of 'being sick'; the term 'member' conveys so much more. Furthermore the term member implies membership of a community and/or an element of collectivism, as opposed to the service user/consumer discourse which is individualistic.

In Chapter 5 I considered how some of the socio-political concerns, mentioned by Stevie (above), impacted upon support relationships, interactions, and negotiations in the support context with reference to the attribution of self-stigma. Part of the role of staff members in the organisation, which seemed to be unwritten, was 'shielding' members from many of the funding concerns that impact the organisations. Staff members often avoided disclosing information about funding problems to avoid causing members any worry; it is as if 'shielding' and 'protecting' members from these socio-political realities was taken on as part of their role and this contributes to the support environment to ensure interactions were as supportive as they could be. For example, staff at Bright Futures suggested that there was often a struggle to obtain the money staff required for training and that funders moving the goalposts can be a source of stress which they don't talk to the members about. As Faye (staff, int., Bright Futures) explained:

> *I think I know that we're wanting to do certain training that we've not been able to do because XXXX <manager> has fought and fought to get funding for us, and there's some training coming up that we've waited for, for about eighteen months for, and I think that will enable us to do our jobs much better but it's hard when you have to wait…also I think we had an idea which way it was going and then funding changes and you know, it's hard but you have to move with that, your referrals come from different places, we have to move with funding but we have to try to move keeping what people want.*

In a slightly different vein, at Creative Mindz, there was an opportunity to apply for funding for specific courses for members to complete and gain a qualification. The ethos of

Creative Mindz is that members progress in their own time and so when the prospect of this funding became available for time-limited courses it made members feel uncomfortable:

> *Peter (staff) suggested the idea of accreditation of some courses from the WEA. Daniel (staff) explained this by saying that some funders are saying that the courses they're funding have to lead to something. Jess (member) asks if accreditation is another word for qualification. Daniel assured Jess that she didn't have to do it, especially if it would put members off. Jess said it depends on the written work she would need to do because she doesn't like that and mentioned another course she did where she found the written element difficult and said she thinks it is good to go at your own pace, that's what she likes about the studio, so would like the accreditation if you could go at your own pace, it was practical and with no written work…Stevie suggested that the accreditation might be used by the government and add towards the pressure on getting a job…and that the accreditation may be used as an indicator of being fit for work and she wouldn't want to fall into that trap.* (Creative Mindz, FN3)

Discussion about accreditation clearly made the members at the meeting feel uneasy and staff members took this on board, trying to find a way to get funding for the accredited course without unsettling the members:

> *After the meeting Peter came in, Daniel asked if I wanted a drink, and I asked for a glass of water which he got for me. There was Peter, Greg and Daniel (all staff) and I around the table and Daniel reported back the concerns over accreditation, Peter said it wasn't about changing the place, it is just the way that funding is going. Greg reiterated the way he felt about not being a teacher and Peter said that in the past the facilitators had just filled the forms in recognising they weren't supposed to and so he wondered if there was a way around it to ensure members didn't feel pressured.* (Creative Mindz, FN3)

The latter isn't necessarily 'shielding' members but accommodating or taking into account members' feelings when it comes to delivering a service in the face of socio-political realities relating to available funding. Although the examples from each organisation are different, in both cases there is a degree of unseen work that staff members perform, the first example involved staff having to process and hide their own frustrations, and the

second example involved staff adjusting what was delivered. Neither is written into any role/job description. However, such work seems to contribute to what makes the environment supportive and allow for interactions which are considered by members to be supportive.

Whilst a number of members welcomed the notion of boundaries or distance from staff in the interests of professionalism as a way to guard against abuse of power, most didn't seem to consider it. Furthermore, the ways staff members are viewed by members at the organisations was in stark contrast to their feelings towards other support services. This suggested, although this could not be confirmed, that the support provided by Bright Futures and Creative Mindz was much more valuable to members socially than other services. That is not to say other services are not valuable in other ways or don't support people, but it should be noted that modes of support and environments created by dedicated staff and organisations such as Creative Mindz and Bright Futures are integral to many people who experience madness and distress in the contemporary socio-political climate. The way staff 'do support' i.e. the interactions and negotiations which take place between staff and members, in tandem with socio-political and organisational contexts, will be considered again in next section with further reference to key elements of the stigma discourse.

6.4 'Doing' supportive and non-stigmatising support in the context of the organisations

According to Goffman (1968:19) a stigmatised person doesn't receive acceptance and "those who have dealings with him fail to accord him the same respect and regard with which the un-contaminated aspects of his social identity have led him to anticipate receiving." Chapter 5 indicates that the environments of Creative Mindz and Bright Futures are not free from what could be termed the 'politics of stigma' or at least a power differential which may allow components of stigma to unfold. However, from the evidence in this chapter and Chapter 4, it seems the scope for stigmatising interactions is reduced because members are, to borrow from Goffman, 'accepted' in the organisational context of the case study organisations. This 'acceptance' seems to be down to both the reduction in distance between staff and members via the identified support devices, and as a result of the considerable work that is done by the actors in that environment, particularly the staff members, to ensure this happens within the context of the organisations. The findings in both this Chapter and Chapter 4 indicate that there is something about the organisational contexts of Creative Mindz and Bright Futures which 'allow' for the sorts of interactions

which members describe as positive and non-stigmatising and which contribute to a supportive environment. These interactions, or 'ways of being', were regularly interpreted by members and staff as being favourable in comparison to members' relationships with professionals in the fields of psychiatry, social welfare, social work, psychology, nursing, housing support etc. The empirical material suggests that a contributing factor to why these interactions are considered to be much more supportive and less stigmatising relate to the reciprocity of sharing stories and the organisational context which allows for humour and interactions which may be regarded as relatively informal, and often where the personal lives and professional roles of staff overlap. The findings indicate that it is commonplace in the organisations I worked with for staff members to use themselves and their personal experiences as a way to develop supportive relationships with members in the context of the organisations. It is these interactions, an approach the organisations allow for, that create the context and the environment where members are not 'distanced' from staff and don't feel 'set apart' as different.

Staff having space and time to build individual relationships with members are ingredients of what members describe as positive and non-stigmatising support relationships. When staff members get to know the members they support they are able to use humour and trivialise certain problems in a way which is both positive and personal, and seems to be an effective way to support members. As Webb (2006:212) argues "the value of the caring relationship lies in the contribution it makes to a kind of inter-personal democracy that is critical for human flourishing." Shakespeare (2006:146) also highlights the importance of reciprocity in social relationships. Moreover, Beresford et al. (2011:55) also comment on how trusting relationships between practitioners and 'service users' are integral to good supportive relationships and that those relationships help staff build up practical knowledge of those they support. Following Bleach and Ryan (1995) it seems that it is interpersonal qualities that members value which influence and engender trust; including warmth, acceptance and honesty (Maluccio, 1981). On a practical level, time and space are integral to building those supportive relationships, and having staff who are prepared to negotiate information about themselves and the members they support, create opportunities for relationships to form between members and members and staff, which contribute towards flourishing relationships in the organisational context. Having the space for these interactions to occur lends support to the case for retaining and developing building based services as opposed to their elimination which has been an outcome of contemporary neoliberal 'care in the community' initiatives.

Whilst staff members often use themselves, their personal lives, and personal experiences as a resource to support members, they do draw lines around the relationships

they form and what details they are prepared to disclose about their own life. Staff sharing details about themselves, whether information relates to details about their personal lives or personal experience of mental distress, is an important 'support device'. Strict boundaries and rules about everyday interactions and disclosure would be a barrier to the sort of work that staff members at organisations like Bright Futures and Creative Mindz regularly perform. Thus, there is a degree of inevitability that there will be some crossover of social, private and work lives for this sort of support to be effective. It seemed to me that professional, organisational, and personal roles converge in the 'doing' or practice of support. The focus on practice is important here because:

> Practice is understood as something that people do in "real" or everyday life. The doings of everyday life are seen as constituting a foundation for social order and institutions. What people do every day to get their work done, in this view, itself constitutes an explanation of social life... (Miettinen et al., 2009:1313)

It seemed that boundaries, relationships and decisions relating to information sharing were under constant negotiation *as part of* the practice of the staff at the organisations. I suggest that these negotiations contribute to the ethos of the organisation and the everyday life of the people involved. Although Bright Futures had more organisational rules than Creative Mindz, the relative 'freedom' of staff members to negotiate boundaries and be as flexible as they could be in what and how support is provided, including the application of organisational rules, seemed to me to be a central feature of the organisations I worked with and a contributing factor to the sanctuary they provide from other professions and structures without this flexibility. That said, it wasn't to say that certain organisational rules and practises weren't clear to the members; rules seemed to be clear and such clarity was welcomed.

Staff members sharing personal experiences is also a mechanism by which staff members engender trust and foster transformative relationships with members. Banks (2004:168) identifies trust as being integral to supportive relationships implying "a kind of personal engagement on the basis of which we believe others will not let us down", and refers to Seglimann (1997, quoted in Smith, 2001:291) that trust arises in the gaps "between and around institutional roles". Thus, it could be said that the contexts of Creative Mindz and Bright Futures are the 'gaps' where this trust and transformative relationships develop. We have seen in Chapter 4, staff sharing details about their lives and experiences can help build non-stigmatising relationships by reducing the social distance between members and staff. However, we have also seen in this chapter how it

can make many staff members feel vulnerable, and how reducing 'distance' takes a degree of unseen effort from staff members. Information management seems to take place with each individual staff member having some reference to notions of 'professional boundaries' or the performance of their professional role, in order to protect themselves. These boundaries also seem useful to members as it makes things clear for them and protects them too. Thus, truncating the scope for personal relationships not only protects staff but also members from exploitation or abuse of power. These findings are supported by existing research which also suggests professionalism, and by implication 'professional boundaries,' are important to service users. Even if emotional attachments are formed, relationships can be professional "while acknowledging that emotional attachments grow when working with service users over a period of time" (Beresford et al., 2011:247). Whilst the organisations I worked with have policies which guide how they work, they have no obvious/established ethical codes, professional regulations or large volumes of policies. Staff at the organisations, because they don't have copious volumes of policies or prescribed ethical guidelines, in day to day interactions seem to have a degree of "professional autonomy" (Banks, 2004:155) within the organisational space. However, whilst staff members have this relative freedom within the organisation, they are restricted by the socio-political constraints of funding etc. and the remit of their role which can also be frustrating as they are often limited in terms of the tools available, particularly when they have to rely on their personal lives and attributes as support devices. Conversely, it is also important to point out that simply because I didn't speak to any member at the organisation who was particularly negative about their experiences at the case study organisations, or witness any exclusion, it is not to say that potential inequalities don't exist. For example, might this be seen in staff having 'favourites' and/or members who may get more support than others (particularly as we saw in Chapter 5, if members are seen to be 'trying harder')? As Warner et al. (2012:321) points out in relation to a community café operating in a similar way, that organisations such as Bright Futures and Creative Mindz can lack "the ethical framework or codes of ethics that might protect some individuals from exclusion."

Power is key to understanding interactions and support, particularly with reference to stigma. Staff at the case study organisations undoubtedly have less 'power' (in the crudest sense) than traditional caring, social or medical professions, and can be in vulnerable and/or precarious situations themselves. Furthermore, staff using their lives as a resource means that the relationships which ensue are very different to the types of relationships members experience elsewhere, particularly in psychiatry, of which all members I spoke to had some experience. Whilst staff members may not have the same

'power' and in particular, 'coercive power' as other professions, they still enact a degree of micro-power which, as I argue in Chapter 5, has the potential to contribute to a pattern of stigma. Moreover, in some of the empirical examples it seemed (and I don't *know* that this was the reason) that to sustain a supportive relationship, staff may not challenge sexist behaviour.

It is also worth considering how and why staff members exercise micro-power in negotiating their role and providing support. For example, perhaps it is a form of self-management performed to make their own jobs 'liveable' in a particular socio-political climate and therapeutic landscape. Human beings are interdependent (de Swaan, 1990:21) and so the way in which staff members negotiate their role and manage information, both disclosure and non-disclosure, is a way of living out that interdependency; being involved in interactions that mean something to the staff, just as the same interactions will be significant for members, but perhaps for different reasons. This idea that staff members negotiate their practice to make their jobs 'liveable' could be considered to be the staff 'working on themselves' and can be explored further in relation to how staff members shield members from some of the socio-political realities facing Bright Futures and Creative Mindz.

Evidence in this chapter and Chapter 5 suggests staff members at the organisations I worked with spend considerable time and effort 'shielding' members from the funding realities, outcomes, and targeted element of some of their work. This creates an effort or labour which goes on behind the scenes which members (and funders) don't see in the same way. Such a predicament indicates a sort of 'double burden' for staff in that they may be occupied by funding concerns yet as a result of the way they perform their professional role, they don't share this with members, and instead have to think more creatively to make the environment as stress free as possible for them. Similarly, whilst disclosure and using the 'self' as a resource is integral to the type of support provided by staff at the case study organisations, members appear to have little knowledge of the negotiations that go on between staff, and in the minds of staff, about what staff are prepared to disclose to members about their own experiences and personal lives. These negotiations could be understood with reference to Hochschild's (1983) notions of 'emotional labour' and 'emotion work.' Hochschild ([1983] 2003:7) describes emotional labour as "the management of feeling to create a publicly observable facial and bodily display…sold for a wage and therefore has *exchange value…"* and describes emotion work as *"*the same acts done in a private context where they have *use value."* The former refers to enforced expression of emotion which staff may not feel and usually found to be applicable to those working in a role involving some degree of customer service. The latter

isn't expected or prescribed by the employment role but it is the individual who does this work and it has often been associated with informal care in the home, and is thus often gendered. However, as Bolton (2000) points out in the context of nursing, there are certain roles where emotion work and labour are blended, and I suggest the organisations are sites where this blending also occurs. For example, we saw that when staff members at Bright Futures apply the organisation's rules they do so with sensitivity to try not to unduly hurt the feelings of members, or when staff at Creative Mindz are trying to work out how best to negotiate who they interact with on Facebook and outside the context of the organisation. Furthermore, although it is not inscribed in the roles of staff members, the empirical examples, particularly those examples centred on shielding members from funding realities, demonstrate how staff seem to be employing emotion work to maintain a 'type' of service for members and to funders. At times, considerable emotional labour and emotion work is employed by staff to maintain consistency for members and prioritise the 'doing' of support. It seems important to acknowledge this unseen effort in social policy, both as emotion work and emotional labour, which staff members employ to shield members and negotiate personal information. In doing so it is essential to highlight the practical importance of staff members receiving suitable support and recognition from one another and the organisation in which they work. Prima facie, excluding members from the stresses and strains of their role was not problematic. However, it is possible that a by-product of working in this way could contribute to the attribution of self-stigma. For example, if staff members invest so much emotional labour and employ a degree of emotion work this may be a reason why they take it 'personally' or look for individualised reasons when certain members don't comply or support methods don't 'work'. However, whilst I can contemplate some correlation, it would be nigh on impossible to establish causation and would demand a research project of its own. Interestingly, members employ a degree of 'hidden labour' (Scully, 2010) around the behaviours staff identify as self-stigmatising as we saw in Chapter 5, yet here a similar concept could be applied to the staff in terms of negotiating the information they share, along with the emotional effort that constitutes and the shielding of members from some of the realities of funding or lack of resources.

Thinking about the organisational context and what contributes to allowing for what members consider to be non-stigmatising interactions. The empirical examples highlight how Creative Mindz and Bright Futures were distinct organisationally but interpersonally there were many similarities. For example, the caring approaches to relationships and interactions, shielding members from funding realities, caring and supportive dynamics, etc. It occurred to me that perhaps the notion of creativity had a part

to play in the difference between the organisations. For example, Creative Mindz had fewer organisational rules and used art as a way to explore issues which weren't diagnostic or therapeutic; this assertion would require further work. Whilst public sector organisations experience what many of their employees consider the imposition of increasingly restrictive policies which constrain, organisations such as Creative Mindz and Bright Futures face their own set of particular challenges around scarce resources and funding concerns. As Banks (2004:134) recognises, whilst there are differences between how the voluntary sector and local authority work, they can also open up, as my evidence suggests, a space to work creatively. Not least in terms of the organisations providing a supportive space which members can't or don't find in public sector services. Within these contexts I considered how much the organisational set up facilitated the fostering of a feeling of 'community' where members report a sense of belonging because of the approach of staff. 'Community' is a complex and 'confusing concept' (Clark, 2007:4), and it is beyond the scope of this study to offer a detailed analysis. However, I use Day's (2006:25) definition:

> 'to speak of community is to speak metaphorically or ideologically' (Urry, 2000:134) about what is it that different sets of people are trying to achieve, in the face of reality that seems to be increasingly fragmented, fluid, and chaotic.

The situated actors in the case study organisations appear to work differently from professions like social work when it comes to their relationships with members, and this is something the members find positive. That's not to say other relationships in other support contexts such as social work or psychiatry with more distance and clearer boundaries between themselves and their 'service users' are not supportive, they often 'work' in the context in which they are performed. However, distance and proximity of members is something which is important in the context of the organisations and for how stigma and discrimination are experienced and their effects mitigated.

Using Day's (2006:25) definition of community and to paraphrase- 'community' acknowledges different sets of people working in the face of fragmented realities. The staff and members are present in the same context but the 'work' that is going on by those two 'sets' of people is different. There is emotion work and emotional labour being 'done' by staff, and hidden labour being 'done' by members. The members' hidden labour appears to get misrecognised as self-stigma (if it is acknowledged at all), and members seem to take for granted the work done by staff because they perform their role 'so well.' To understand this phenomenon further I draw on symbolic interactionism. Herbert Blumer

(1969:180) suggested that the ways in which people relate to things are a function of what they mean to them, the meaning is the result of (or derives from) the interaction with people, and as each person interprets objects, that meaning is manipulated and modified by each person. Thus, members and staff interpret the actions of one another differently yet these different interpretations occur within the context of the organisations and contribute to the support environment, which in turn, allows interactions which are construed as non-stigmatising to occur. Despite different interpretations by staff and members, relationships of the type which develop at the organisations between staff and members do so because members and staff are 'informally interdependent' on one another within the context of the support environment and the socio-political landscape in which Creative Mindz and Bright Futures sits. If staff and members were not informally interdependent there would be increased social distance between the staff and members. Without any formal structure or regulation of medicine, social work, therapy etc., 'informal interdependency' (as opposed to more 'formal interdependency' in the case of some of these more established professions which perhaps require more distance for them to be 'effective'), is the key to making these support relationships work in this particular context. This doesn't eliminate a power differential, which, as we have seen in Chapter 5 is of some significance to understanding the stigma cycle. However, it seems likely that as a result of informal interdependency, hallmarks of which are sharing personal details and staff 'using their selves' to support members, there is not the 'setting apart' of members in a way they might be set apart as different in other social situations or contexts and thus, stigma is reduced or mitigated.

6.5 Concluding comments

In previous chapters I have explored how individual interactions in the support environments of Bright Futures and Creative Mindz create meaning, both positively in Chapter 4 and with more negative implications in Chapter 5. As this chapter highlights, interactions in the organisational setting are reflexively contextual; interactions make up, and reflect, the organisational context. I have emphasised how staff and members are relational subjects in a particular organisational and socio-political context. Understanding these relationships sheds light on how we understand stigma, particularly in terms of what constitutes 'non stigmatising interactions' and some of the social conditions which allow them to occur. Part of what makes the contexts of the case study organisations relatively free from stigmatising interactions, and could be said to mitigate some effects of stigma and discrimination, relate to the 'informal interdependency' of staff and members. This

‘informal interdependency’, the characteristics of which involve support devices such as staff informally negotiating how they construe their professional role, humour, and the sharing of personal information, seems to be what makes support of the kind provided by the case study organisations non-stigmatising. This seems to be because these support devices serve to reduce the distance between staff and members. To engender relationships which are informally interdependent, with the capacity to reduce the scope for stigmatising interactions, staff and members undertake different types of work or labour. That work seems to go unnoticed or is often misrecognised. In the following concluding chapter I will build on my theorising of the role of these organisational contexts and interactions which occur in the support context. In doing so I consider the implications of the findings of this study for people who experience madness and distress, along with organisations and staff providing support, theoretical concepts of stigma and discrimination, and social policy.

CHAPTER 7:

Conclusion

7.1 Introduction and revisiting the research questions

The findings from the study detailed and discussed in chapters 4, 5, and 6 will be briefly summarised in this chapter, with particular focus on the implications of these findings for people who experience madness and distress, organisations and staff providing support, theoretical concepts of stigma and discrimination, and social policy, along with a number of recommendations where appropriate. In particular, the summaries and conclusions in the subsequent subsections of this chapter will be considered in light of the research questions:

1) How are stigma and discrimination identified, defined, and experienced by people who experience or have experienced mental distress and also receive support from third sector organisations?

2) What is the impact of stigma on experiences of support provided by third sector organisations?

3) How do support and the relationships within the support environment impact on stigma and how might this support help reduce/mitigate the impact of stigma and discrimination?

4) What recommendations, if any, can be made for policy makers and practitioners to mitigate the negative effects of stigma and prevent discrimination?

As I have identified in the findings chapters, many of the interactions members experience in the support contexts of the case study organisations are construed by members as non-stigmatising. What makes many of these interactions and ensuing relationships supportive and not stigmatising seems to stem from the lack of overly prescriptive rules and boundaries. Given distance and 'setting apart' are contributory factors of stigma and discrimination, the findings have demonstrated how it is the ambiguity of the relationships and the reflexivity of the agents involved which lessen the social distance between members and staff. Therefore, throughout this concluding chapter, given the importance of ambiguity and reflexivity there is reluctance to prescribe or recommend what practitioners and policy makers *ought* to do. More broadly, this study highlights the contextual and relational aspects of stigma in support services in the third sector, and so any recommendations which ensue ought to be developed in full consultation with the

individuals involved in any particular support context. That is not to say recommendations won't be made, but they will be made tentatively, calling for bespoke practice recommendations and bespoke training for organisations, as opposed to a 'one size fits all' approach. Furthermore, most recommendations made in 7.2 to 7.6 assume that the wider structures and institutions of social welfare, psychiatry, social work, etc. remain in their current forms. There is a wider argument I conclude with in 7.7 which recognises a need to reimagine therapeutic, educational, and training spaces, along with structures of social welfare and psychiatry. This contributes to wider considerations relating to the politics of madness, highlighted by the recent take up of Mad Studies in the UK.

7.2 Summary and implications of findings for people experiencing madness and distress, and in receipt of support

With reference to the first research question, all of the members I interviewed as part of the study described experiences of 'being treated differently' as a direct or indirect result of their experiences of madness and distress. Stigma seemed to be a useful term for members in terms of making sense of, or capturing feelings of, being treated differently in contexts other than those of the case study organisations. The findings indicate that support, such as that provided by the case study organisations, is relatively free from stigmatising interactions. Furthermore, the non-stigmatising interactions members describe as occurring in the support environment seem to go some way in mitigating the effects of stigma and discrimination experienced elsewhere. Thus, and in reference to the third research question, the support environments of the organisations seem to be contexts within which the negative effects of stigma can be mitigated for members, indicating that stigma is not a permanent spoiler of identity, and is context dependent. Furthermore, it seems stigma doesn't obviously impact on the experiences of support provided by third sector organisations (see second research question). However, it is more nuanced than this, as we saw in Chapter 5 where I explored 'self-stigma' (see below).

A compelling component of Link and Phelan's (2001) conceptualisation of stigma is that of 'setting apart' people as different. I found that notions of distance reduction and reducing feelings of difference between actors within the case study organisations seem to be integral to non-stigmatising interactions for members in the support environment. The main contributory factor to non-stigmatising interactions was attributable to the relationships which form in the context of the support environments of Creative Mindz and Bright Futures. Relationships between members (or 'peer support' as it is often referred to

in the literature) seem to reduce feelings of difference, as do relationships between members and staff. Sharing experiences and often emphasising 'sameness' is important to members for reducing feelings of difference and reducing distance in the relationships between members and other members, and staff. This is perhaps because, in Goffman's terms (1963:31-41), there is no discrepancy between "actual" and "virtual" identity as they are each one of their "own"; members have all experienced mental distress and by virtue of membership of the organisation their actual identity is known. However, these relationships have their limits for members. For example, relationships with other members often remain within the support context, and the tensions between some members highlighted in Chapter 4 remind us that members, and more widely people who experience madness and distress, are not an homogenous group. Furthermore there may be judgments and/or stigma based on how distress is managed and/or stigma which is attached to different diagnoses. However, this was not a strong theme which emerged from the analysis process in this study.

Interactions which are construed by members as non-stigmatising seem to be based on care, trust, and the interpersonal characteristics of the actors in the support environment, and contribute to the relationships which develop in the context of the case study organisations. For example, being humorous, chatting relatively informally about day to day events, and sharing stories about their lives. Such relationships aren't obviously time limited and the interactions which take place between the actors in the support environment don't create distance which could be construed as 'setting apart'. In describing the positive experiences and relationships at the case study organisations, many members compare the support they experience in the context of the organisations with that of other services such as psychiatry and/or talking therapies. Many members I spoke to often reported 'feeling different' in the relationships with those professionals with reference to a greater distance between themselves and the professional supporting them. Whilst it doesn't follow that this 'distance' or 'difference' always leads to experiences which members construe as stigmatising, it does highlight the importance of distance and 'being set apart' as integral to feelings of stigma, and the role of organisations such as Bright Futures and Creative Mindz for engendering non-stigmatising interactions involving less 'distance'. Thus, with reference to the third research question, the support provided by the case study organisations can indeed help to mitigate the impact of stigma and discrimination on members. Sharing experiences with other members and staff seems to be a way that members don't feel set apart as different and can thus disrupt the stigma process or prevent it from unfolding despite power differentials between staff and members, the implications of which will be considered in 7.3.

Chapter 5 indicated the importance of 'self-stigma' to both staff and members, yet it was clear that members and staff defined self-stigma very differently. This disjuncture, in seemingly otherwise supportive relationships, emphasised how what was commonly construed as self-stigma by members (self-censorship and avoiding certain situations) is usually born of some actual experience of discrimination. However, members' coping mechanisms seemed to be regularly misrecognised by staff as self-stigma (as a choice, excuse, barriers within members, not 'complying' with support etc.), when those experiences may be more accurately understood as reactions or responses to stigma or discrimination. Furthermore, members managing such negotiations about whether to talk about their experiences of distress or entering a context where a person fears stigma or discrimination as a result of actual experience requires a form of 'hidden labour' (Scully, 2010) on behalf of members, which seems to be, or can be, often misrecognised by staff as avoidance, making excuses etc. The discussion around self-stigma, and in reference to the third research question, evidences that stigma has some impact on experiences of support provided by third sector. Staff members' role in attributing self-stigma is considered again in 7.3, and in 7.5 I consider the importance of understanding self-stigma within the context of discrimination.

In terms of the implications of the findings for members, the relationships formed in the support environment seem to have a positive impact on the lives of members involved in this project. However, the exploration of self-stigma highlights a significant implication; self-stigma can be understood as one group of people (staff) misrecognising the management of stigma by another group of people (members), and members are often 'set apart' as different as a result. Thus, the findings relating to self-stigma highlight this important implication that certain members can be discriminated against via the attribution of self-stigma in third sector support contexts. Recommendations relating to what might be done to tackle this are considered in the next subsection.

7.3 Staff providing support: implications of findings

The way support was performed by staff in the environments of the case study organisations, usually identified via interactions between staff and members, seemed to be construed by members as non-stigmatising. I suggested that this was a result of the support devices staff members employ. For example, staff members sharing their own experiences of mental distress, members interacting relatively informally with staff, staff disclosing information about their own lives, staff getting to know the members and using that information to support them, and using humour. It is this practice and the

employment of these support devices which I found helped to reduce the social distance between staff and members, which in turn seems to impact on how far members are set apart. Furthermore, I found that the meaning attributed to interactions between staff and members, specifically the employment of the support devices I identified, can mitigate feelings of difference and/or the negative impact of stigma experienced in other contexts.

Members regularly compared staff to psychiatry, or psychiatric professionals, in a positive or favourable way; staff at the case study organisations did not have the same coercive powers as those professionals. However, as Chamberlin (1978:95) points out, where there is a service there will always be the server and the served; and always a power differential in that context. The case study organisations welcomed the input of, and feedback from, members, particularly Creative Mindz which held monthly 'member meetings' to talk about issues of service delivery and the direction of projects. However, there didn't seem to be any formal representation of current members on the governing board or as trustees. Thus, in terms of a practical recommendation, this is something the case study organisations may wish to think about to keep a more formal 'check' on power imbalances.

An exploration of self-stigma demonstrated how 'micro-power' at the case study organisations can operate, emphasising staff members' relatively more powerful position than the members in the context of the support environment, and the relevance of the operation of that micro-power in the stigma discourse. I highlighted the tension between how staff view individual members and socio-political factors indicating how interactions are influenced by discourses of how members should respond to support. This tension may also be linked to the limits of the support environment, and more structural problems such as benefit reform, cuts in services/funding, etc. I identified that it was perhaps frustration, as a result of external influences, which staff experience in their role, and their relative powerlessness in the broader political climate that was a contributory factor to exercising this micro-power and attributing self-stigma to the behaviours and attitudes of certain members. In terms of practical recommendations, building staff awareness of micro-power, exploring with staff how that might work, and using the paradox of self-stigma as a way of highlighting how such attribution can contribute to the stigma cycle could be useful. Furthermore, working with staff members to identify ways of working more positively with difference as opposed to attributing self-stigma would help to guard against sanist practise. This line of thinking contributes to the development of the sociological argument I summarise in 7.5, that self-stigma is better understood in the context of discrimination.

Despite the power differential at play, staff disclosure of experiences of madness and distress is important to members. Exploring self-stigma, how staff talk about

themselves with members, and how staff develop relationships in the support environment led to an understanding that staff members, when using so much of themselves to support members, can feel vulnerable. Staff members often use their personal experiences as a resource for support or as a support device to get members to open up, trust, etc. However, it was clear that there are limits to what support staff will 'use' and it seemed that the internal negotiations which particular participants described have the propensity to introduce an element of distance. This raised the question whether a certain amount of distance, which perhaps could not always be construed as 'setting apart', is necessary to provide support of the kind provided by the case study organisations. If staff did disclose 'everything' then this could be seen as an abuse of power in that they were using their professional position to burden members, when it was the members who ought to be supported. As I mentioned in 7.1 it is potentially problematic to be overly prescriptive in terms of what staff ought to do and it is difficult to make a practical recommendation which would avoid a double bind i.e. if staff share too much they run the risk of criticism and likewise if they don't share enough. Many of the empirical examples in the findings chapters indicate that many staff members do negotiate disclosure with a degree of empathy and so practically it seems important that staff members are regularly encouraged to be reflexive in their practice around disclosure via training and support of their peers and managers.

The findings also highlighted how organisational rules can draw boundaries for staff, around their professional role, so they don't have to negotiate them and their relative distance from members. However, the absence of explicit and formal boundaries and the ambiguity that brings to the support context provides an opportunity for staff to negotiate what information and actions are appropriate for supportive interactions with members. Whilst this was a positive experience for many of the members I spoke with, the work staff members perform in this respect goes relatively unacknowledged. Furthermore, this way of working may potentially lead to exclusions of particular members, e.g. those who are self-stigmatising in the eyes of staff. Moreover, working in the way staff members do means that they often select what is challenged in the organisational space e.g. ensuring someone's 'mental health' is supported at the expense of not challenging what could be construed as sexism. This relates to a wider ethical point relating to implications for practice; this isn't simply about sexism going unchallenged, it may have been any other form of discrimination such as homophobia or racism. The point is that that staff should be challenging discriminatory language or behaviour, it should not be about staff using their discretion in terms of *whether* to challenge discrimination but using their discretion in

terms of *when* to challenge i.e. it may not always be at the point of disclosure but ethically it ought to be challenged at some point.

With particular reference to research question 3, relationships and interactions in the support environment appear to harbour the capacity to be instrumental in positively intervening in a stigma cycle. Staff members at the case study organisations seemed to provide a valuable social role in many members' lives and the value of this ought to be acknowledged; particularly in the face of precarious funding for such services and the contemporary socio-political climate. For example, the way staff members 'shield' members from funding realities indicates a tension between interactions constituting support which staff member employ and want to continue to employ, and the precarious nature of funding and the requirement to report specific outcomes. This negotiation puts pressure on the types of workers at Creative Mindz and Bright Futures which should be acknowledged and addressed by social policy (see 7.6).

There are two further important points to conclude regarding the empirical findings and staff members. Firstly, the work staff do to negotiate their own roles in relation to how they use themselves and their experiences as a resource, and negotiate the organisational rules sensitively, requires a great deal of both 'emotional work' and 'emotional labour' (Hochschild, 1979). Whilst some distance may be required in this process, staff members work to ensure members are, ultimately, not set apart as different. Part of that negotiation and the unseen work staff do is part of the role of these staff members and ought to be acknowledged. Secondly, human beings are interdependent on one another (de Swaan, 1990; Shakespeare, 2006) and this interdependency plays out in interactions between members and staff. Whilst professions such as psychiatry, psychology, social work, etc. are also inevitably interdependent on their 'clients' or service users, by virtue of the professional codes and explicit boundaries drawn by the profession themselves, there is less informality, and so this interdependency is more formal. 'Informal interdependency' between staff and members of the case study organisations requires a certain work, perhaps different from work done in the other professions, from both members and staff. 'Informal interdependency' is a way of conceptualising and acknowledging the relationships, and how support work is performed, at organisations such as Creative Mindz and Bright Futures, and seems key to reducing stigma or mitigating its effects. It is also a way of understanding how the support devices I identified are employed by staff members, where different meanings are made by different actors in the support context to produce supportive and relatively non-stigmatising environments.

7.4 The practicalities of creating supportive contexts and non-stigmatising support environments

Whilst I have been intermittently exploring recommendations in answer to research question 4 throughout this chapter, this subsection considers recommendations in more depth. In doing so, I also focus on research question 3 relating to how the support environment impacts on stigma and how support can reduce the impact of stigma and discrimination.

Practically speaking, organisations such as Bright Futures and Creative Mindz provide opportunities for members to help and support one another informally and allow for informal interactions between staff and members. In terms of practice and implications for support provision for people who experience mental distress, the findings chapters emphasise the importance of, and support the need for, building based support services to allow for these interactions. Furthermore, it is important for many members that the support environment isn't time limited or particularly pressurising in terms of the activities members undertake.

Although micro-power was exercised by staff in the support environments of the case study organisations, the findings suggest that perhaps we shouldn't be working towards eliminating power differentials (which would be impossible in the current structure of the organisations and more generally this is impossible given all relationships have power dynamics within them) but learning more about how they operate in the context of organisations like Bright Futures and Creative Mindz, and work with those power differences. For example, staff members might benefit from a more formalised outlet to talk about how they negotiate their role, including the emotion work and emotional labour involved. This may reduce the potential for individualising problems in the form of self-stigma given that such attributions seem to be born of staff frustration. Furthermore, staff attributions of self-stigma are often based on a staff view of members being 'passive' and not 'wanting to change'. Thus, building staff awareness of micro-power and emphasising that reactions to stigma are not a 'choice' is integral to disrupting the stigma cycle. Responses to discrimination shouldn't be misrecognised as 'self-stigma' and ultimately, individualised. Thus, briefings and staff training for policy makers and practitioners which couch attributions of self-stigma in the context of discrimination are integral to increase understanding of how these attributions fit within a stigma cycle.

Sharing experience seems to be helpful for members if it is done in a meaningful way because it promotes 'sameness'. However, there shouldn't be pressure on people to 'tell their story' or 'fit in'; it should be voluntary and those people who decide to talk about

their experiences should think about guarding against 'sanitised stories' which may put pressure on members to live up to 'examples' of staff. We also need to recognise the limited tools of staff members who are drawing on their experiences to support members; as acknowledged above and in Chapter 6 via the term 'informal interdependency'. This type of support is very different to, but no less significant to members, than the likes of contemporary social work and the relationships which develop in psychiatric care or psychological therapies.

Context is key to stigma and stigmatising interactions, and stigma is not necessarily a "persistent predicament" (Link and Phelan, 2001). We might credit these organisational contexts for cultivating the space within which they work to foster non-stigmatising interactions and reduce the impact of stigmatising experiences. However, as Warner et al. (2012:321) point out, there is "danger of idealizing affective community spaces." Particularly as there may be potential for staff to contribute to cycles of stigma as we saw in Chapter 5, and in some situations there was the potential for what many may consider sexist or other discriminatory behaviour to go unchallenged. That said, the support environments of Creative Mindz and Bright Futures could be considered contexts which go some way in disrupting power relations of more traditional support relationships which members may have experienced elsewhere. For example, the organisations provide a place for informal peer support to occur which reduces feelings of difference; the term member implies something different from service user or patient; the support environment seems to provide a degree of community, despite the fact relationships often remain in the context of the support environment. These support contexts almost serve to shield members from some of the socio-political issues which affect their lives; in doing so I identified the continued need for non-pressurised environments to allow for this type of support which was of great value to members I worked with.

As I have already established, reducing distance is essential for non-stigmatising interactions in the support environments of the case study organisations. It is the support context of these organisations where support devices can be used by staff to reduce distance between themselves and members, and where negotiations of proximity take place. In the absence of organisational rules, staff members employ a degree of 'emotion work' to negotiate their own professional role in terms of distance, particularly with regards to information sharing and drawing boundaries around their relationships with members. It is this ambiguity and absence of prescriptive rules which seems to contribute to the supportive context of the organisations. Whilst more explicit organisational rules demand less of staff members in terms of 'emotion work', applying those rules sensitively also requires similar effort. However, as mentioned above, members also employ a degree

of 'hidden labour'. It seems that the support contexts of the organisations are an environment where the hidden labour of members, and the emotional labour and emotion work of staff, converge in supportive interactions. Although different meaning may be attributed to interactions by staff and members, and some distance is necessary in some situations in order to support members with the devices staff have available to them. It should also be noted that the way in which staff members 'play' with distance creatively within these ambiguous spaces seems to be part of the performance of support and the creation of environments which enables stigma to be challenged and/or its effects ameliorated. Thus, what seems to mitigate the impact/effects of stigma experienced in other contexts is the labour of the staff and members in reflexive relationships with each other. It seems that these semi-institutional spaces (Parr, 200b) or "shadow state" organisations (Wolch, 1990) are important for non-stigmatising interactions and mitigating the effects of stigma. The importance of these organisations, their socio-political location, and their relevance to social policy, will be revisited in 7.6. I will now delineate the contribution of the findings of the study to how we theoretically conceptualise stigma and discrimination.

7.5 Deepening our understanding of concepts of stigma and discrimination

Contemplating theories of stigma, Bonnington and Rose (2015:15), following Archer (2012:4), argue that social life can't be split into micro, meso, and macro pieces because culture and agency are "indispensable" at all of these artificial levels. They also point out that what is 'wrong' with contemporary theories of stigma is that they try to separate them all out. This study also emphasises the impossibility of separating out stigma as a structural or individualised concept. For example, I have shown how stigma is inherently political with the attribution of self-stigma, even if it is played out via relatively informal day to day interactions and interpretations of those interactions.

Conceptually speaking the findings from this study are significant to a number of interrelated aspects of the stigma discourse; the notion or importance of 'power' to conceptual understandings of stigma; the paradoxical and discriminatory nature of attributing 'self-stigma' to people who have experienced stigma and discrimination; a strong interactional/interactive element to Link and Phelan's (2001) component 'setting apart' and negotiating distance; and the importance of context to interactions which are construed as non-stigmatising, including the socio-political context and the context of the organisations in which support is provided.

In Chapter 2 I discussed the importance of 'power' to the stigma discourse, specifically Link and Phelan's (2014) notion of 'stigma power'. The findings indicate that micro-power, exercised via staff attributing the label of 'self-stigma' to certain behaviours and/or attitudes of members, and members referring to their own thoughts or actions as self-stigma, are empirical examples of stigma power 'working'. My findings are predominantly the result of an interactionist analysis and they indicate how, in practice, setting apart can occur. Thus, the findings focused on 'setting apart' and how this occurred via interactions, rather than labels and stereotypes which didn't seem to impact on the members and their support in the case study organisations quite so much.

The idea of self-stigma as a label or a concept is a paradox. Describing people in this way and talking in these terms doesn't seem conceptually or politically useful for mitigating stigma or disrupting a stigma cycle. Attributing self-stigma or using it to describe reactions to discriminatory experiences creates a barrier or distinction, where stigma becomes individualised or a 'choice'. As Corrigan and Fong (2014) suggest, this indicates that overcoming it is up to the person who experienced discrimination in the first place. Such a line of thinking tends to remove us from any social model of madness and distress and I argue that attributing self-stigma is sanist practice. I suggest that we work on collective responses to stigma, recognising experiences and responses to stigma and the hidden labour required of people responding to these experiences; to speak in terms of self-stigma is paradoxical and individualistic. Instead, we can understand self-stigma attribution as being imbued with socio-political factors and frustrations, and the limits of the support context itself. A theoretical contribution this thesis makes to the discourse on distress, stigma and discrimination, is that by exploring the behaviours and attitudes associated with self-stigma it enables sociological understandings of stigma to be linked to discrimination. In doing so we can rethink what we consider self-stigma to be. The findings, particular Chapter 5, emphasise the 'cost' of some of the members' coping strategies and emphasises the importance of understanding stigma in the context of discrimination.

Concepts of stigma are often termed individualistic and attract reasonable criticism as a result (see 2.3 and 2.4). A contemporary response to this is to explore the ways more individualised notions of stigma interact and intersect with political or structural concerns, a focus of Imogen Tyler's current work on a project entitled "Rethinking the Sociology of Stigma" (2015a). An aspect of Tyler's ongoing research aims to theorise stigma as a cultural and political economy, considering stigma as practice of social classification (Tyler, 2015b). Whilst the focus of my study was to examine stigma specifically as it related to 'mental health' support provision and contexts, for which an interactionist approach was essential, this does not detract from emphasising the political economy within which the

organisations operate and the actors interact. Thus, the findings support the call for developing concepts and understandings of stigma which take into account, and continue to develop conceptually, the links between wider political struggles of marginalised groups, the cultural and political economy, and individual experiences.

7.6 Social policy and further practice recommendations

Considering research question 4, this subsection focuses on implications for policy makers and tentatively suggests some recommendations (see 7.1 for discussion on why recommendations ought to be tentative), along with further suggestions for practitioners supporting people who experience mental distress.

Members find the contexts of organisations such as Creative Mindz and Bright Futures supportive and non-stigmatising; other support services may consider learning from the ways in which staff members at these organisations support their members. As Conradson (2003:521) suggests, we should not undervalue the role of these organisations in social policy:

> In a neoliberal polity where welfare transactions are increasingly instrumental and output focused, the significance of such places for marginalized citizens should not be under-estimated.

Objectives of contemporary social policy and mental health strategy (see 2.2.2) are to reduce stigma by improving public attitudes and reducing institutionalised discrimination, and increase public understanding. The support contexts of the case study organisations, despite micro-power and power differentials identified between staff and members, seem to be a place where stigma cycles can be disrupted by negotiating distance in day to day interactions so that members are not 'set apart'. Therefore there ought to be more emphasis on supportive relationships between staff and the people they support with recognition that time, space, and a non-pressurised environment, are often key to achieving contexts which members find relatively free from stigma. Such environments provide opportunities for people with similar experiences to share their 'stories' with those they feel comfortable with, and thus reduce feelings of difference which members often describe as stigmatising.

From a practice and practical angle, in terms of staff sharing their experiences of mental distress, it is difficult to offer definitive recommendations to staff on 'how to tell a story' or 'share information'. This is because it is the ambiguity around staff disclosure (which is not overly prescriptive) that seems to contribute to the supportive and non-

stigmatising aspects of the relationships in the support environment. There were a number of critical and reflective staff members I worked with in this study and identified in Chapter 5 who were able to interact and build relationships with members empathetically. Some staff recognised that the implications of the socio-political climate, such as benefit cuts in the name of austerity, made tackling stigma difficult and thus avoided attributing self-stigma in the way less empathetic and reflective staff members tended to. Working with practitioners and members collaboratively and dialogically, perhaps in a similar format to the focus group work in this study (see 3.7), may help members and staff recognise that when they're talking about 'self-stigma', they're not necessarily talking about the same thing. This could help staff supporting people who experience distress and members of the case study organisations, or service users of other mental health services, problematise the concept of 'self-stigma' for themselves, and think about how they work with that more critically in the support context. This may contribute to tackling more insidious stigma and discrimination at a service delivery level.

On a national level, a significant element of the current mental health strategy and the Time to Change campaign involves public education delivered by people who have direct experience of 'mental illness.' However, most of the participants I spoke to did not feel comfortable 'educating' members of the public and felt that they would/could talk about their experiences in certain contexts, and that this ought to be voluntary. Of course, Time to Change doesn't compel people to 'tell their story', but it does raise the question that if many people who have experience of mental distress don't want to join a public education programme or subscribe to those sorts of stories, what narratives end up in the public domain? And how reflective are those narratives of the range of diverse experiences? Can they really be said to be representative, or do they represent a certain skewed selection of stories? This is particularly important for those who want to speak out against the oppressive nature of psychiatry, mainstream therapeutic approaches, social inequality, and contemporary support services. If mainstream anti-stigma campaigns screen out these stories then the discourse runs the risk of becoming 'sanitised' (Costa et al., 2012). Furthermore, choosing not to talk about your own experiences in this way, or not having the 'right' trajectory or failing to comply with support, shouldn't make a person, or result in a label of, 'self-stigmatising'. Anti-stigma campaigns should recognise the harm of attributing self-stigma, consider self-stigma within the context of discrimination, and be prepared to critique the structures and professions that attribute it, rather than looking to the individual to ameliorate it.

No Health Without Mental Health (Dept. of Health, 2011a) and the related policy documents (see 2.2.2) recognise that legislation is not enough to tackle stigma and

discrimination, and that tackling stigma and discrimination should also involve education and recognition of the links between mental distress and social inequality. Members also recognised that although anti-discrimination legislation was useful, it did not prevent subtle exclusions in day to day interactions which engender feelings of difference. Thus, as Link and Phelan (2001) suggest, it's not only a change in attitudes that is required, but a change in power relations. I have evidenced how this can occur in practice via interactions which disrupt stigma processes by negotiating distance and not 'setting apart' members. As I introduced above, the idea of staff and members (or staff and beneficiaries of any mental health service) working collaboratively to understand what they mean by stigma, and more specifically 'self-stigma', may be a way for people to understand the misrecognition which is occurring in support contexts. Such training or facilitated sessions could also explore power relations in support relationships and encourage staff and members to work through how a change in power relations may occur in support relationships and their organisational context. These approaches may help to contribute to disrupting stigma cycles and may form the basis of initiatives which 'user-led' organisations could develop and deliver.

In terms of the 'shared responsibility' for reducing stigma, organisations such as Bright Futures and Creative Mindz seem to do a lot of work towards this which leads to questions about whether the financial investment in IAPT (Improving Access to Psychological Therapies) may not be shared with other organisations who provide this invaluable social role. That's not to say investment in organisations of Creative Mindz and Bright Futures should be at the expense of services like IAPT, but perhaps it is important to recognise how organisations like the case study organisations involved in this study are an integral complement to individual and more health-oriented services.

Social professions in contemporary times seem to be preoccupied by risk which can result in the erosion of kindness (Neuberger,2005:xii) where warmth, listening, non-judgmental stances are superseded by bureaucratic procedures and risk assessments (Phillips, 2007). Part of the value of staff at the case study organisations is their relative freedom to negotiate their own role to support members where they balance a line between safeguarding or managing 'risk', and providing support. However, the rules at the organisations I worked with were less prescriptive than you may find in other professions such as social work, and those flexible boundaries and negotiation about information sharing seemed to enable staff to support members in a way that didn't emphasise their difference. This sort of 'work' seems to be integral to the work staff members at organisations like Bright Futures and Creative Mindz perform, where informally interdependent relationships with members are fostered. Compassion and care are keys to

this sort of work and this ought to be recognised and valued, along with the considerable emotion work that many staff members employ to make the contexts as free as possible from stigma. However, their work is often hampered by a precarious funding climate and frustrations with other services which can often contribute to making staff members feel vulnerable as a result of how much they use themselves as a resource or support device to support members. This vulnerability tends to go unacknowledged in contemporary policy and rather than prescribing more rules to close down the scope for informality and vulnerability, there should perhaps be more opportunity for them to occur and with adequate support for staff to reduce feelings of frustration.

The findings from this study contribute to a call to focus on tackling acts of sanism and sanist practice in mental health policy. In doing so policy makers need to recognise the value of communities and contexts where communities can share experiences informally (both with peers and staff) and in their own time. Although there is a move towards personalisation, and services which are time limited and targeted, many members expressed the pressure and loneliness which can often result from services being delivered in this way, and ultimately contribute to a stigma cycle.

Given the socio-political context of the organisations it is difficult to suggest policy recommendations which don't involve an overhaul in a number of areas. For example, the way that third sector organisations are funded (i.e. precarious short term charitable funding and/or funding from decreasing pots of public money), on what basis they are funded (i.e. commissioners of services often require target/outcome driven and time limited services to demonstrate 'value for money'), and the institutions surrounding members who attend these organisations such as the social welfare system which is constantly cutting welfare benefits, along with psychiatry and psychological therapies which are often implicated in the stigmatising process. These issues will be revisited in the final subsection below.

7.7 Final thoughts and further work

This final chapter has summarised the findings and their significance with reference to members and staff, organisations providing support, sociological theory on stigma, and social policy. Whilst a number of the implications resulting from the study can be clearly delineated, they also raise a number of questions and avenues to explore in further work. For example, given the differences between the support contexts of Creative Mindz and Bright Futures, what role does the notion of creativity play in support environments and stigma reduction? Given the findings which suggest that context is integral to both stigma and supportive interactions, what role does space/place play in this? Perhaps a longitudinal

study following members and staff at these organisations throughout the period of their attendance would shed further light on the impact of these support environments. Although the topic of organisation governance did not arise as a predominant feature in the fieldwork, an additional focus for study could be to explore governance and consider how, given the importance of power in support relationships, the governance of third sector organisations impacts on these relationships. There is also the potential for a comparative study around support, relationships, and stigma, in other contexts such as psychiatry and/or talking therapies. This would provide an opportunity to consider the concepts of informal and formal interdependency in support services, and their impact on stigma and support provision. In particular, such a study would include exploring the interactional element of 'setting apart' in other contexts and may lead us to consider further whether an element of 'setting apart' is necessary for support to be effective for those who are in receipt of it. A further research question would be to ask; what sorts of practices allow for, and challenge, stigma and discrimination? This may lead us to thinking about how we can create spaces or contexts which challenge stigma and discrimination. It seems important to consider in further depth, using a Mad Studies and/or participatory action research approach (which would also, methodologically speaking, more adequately acknowledge the power differentials in the stigma discourse), how member experiences in organisations such as the case study organisations share a politically marginalised identity and how that can be mobilised to transform how we think about stigma, discrimination, and 'political solutions'.

Re-imagining spaces of support which are free from stigma and discrimination, and re-imagining education and training initiatives for those who provide support are projects which should be considered in relation to the wider political milieu. For example, would stigma and discrimination exist if not for the wider social structures of social welfare, psychiatry, and psychology? If psychiatry was not the prevailing force of authority in 'mental health' work, what possibilities for non-stigmatising environments would/could there be? What about the role of psychology and talking therapies? Particularly in terms of coercion, given the introduction of talking therapies in Job Centres where attendance can be made a condition of claimant's ongoing entitlement to welfare benefits. What is the role of 'coercion', and how does 'coercion' play out in support environments and relationships? This is not the first time some of these questions have been raised, and although I have raised the notion of the 'politics of stigma', questions around the politics of madness is a focus of the Mad Studies movement to which I hope this thesis contributes. The broader point here is that it's not just about working with or in existing support services, it's about reimagining others.

APPENDICES

Appendix I: Consent form for organisations

PhD research study: Exploring lived experiences of a mental health condition

I have understood the aims of the above research. I am willing to support the research and give permission for Victoria to access the members and staff of this organisation.

Signed …….

Name ……..

Position……..

Organisation…….

Date ……..

Please delete as appropriate:

DBS check not required.

DBS check* via Durham University is sufficient.

DBS check* via the organisation is required.

*Please specify which type of DBS check is required.

Appendix II: Invitation to participate and information sheet (members)

PARTICIPATION INFORMATION SHEET

PhD research study: Exploring lived experiences of mental health conditions

Student Researcher	**Research Supervisors**
Victoria Armstrong	Dr Mark Cresswell, Durham University
Durham University	Dr Andrew Orton, Durham University

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take this information and read it carefully. If there is anything that is not clear, or if you would like any further information, please let me know before considering whether to take part or not.

1. **What is the purpose of the study?**

I am a postgraduate research student at Durham University. The study explores the lived experiences of people with a mental health condition who participate in, and attend, community organisations or projects. In order to do this it is important to hear the perspectives and voices of individuals with mental health conditions who participate in community organisations, along with the perspectives of staff who run the organisations and facilitate the activities.

2. **Do I have to take part?**

- It is up to you to decide whether or not to take part.
- If you do decide to take part you will be given this information sheet to keep.
- You will also be asked to sign a consent form.
- If you decide to take part **you are free to withdraw at any time**, without giving a reason.

Your decision will not affect any support you may be receiving.

3. **Why have I been chosen?**

You have been chosen because <organisation name> has agreed to be involved in the project as a case study and you attend and participate in the activities of <organisation name>. <organisation name>'s decision to be involved does not mean that you should feel you have to be involved, that is why we are providing this information to you so you can choose whether you wish to participate.

4. **What will happen if I decide to take part?**

There are a number of ways you can take part and this section describes what will happen if you decide to take part in one or all of the activities outlined below (dates to be confirmed).

Focus groups:

Focus group 1- "experiences of living with a mental health condition" members only (between 4 and 8 people required to take part; focus group will last no more than 1 hour 30 min).

Focus group 2: "mental health: stigma and discrimination" members and staff (between 4 and 8 people required to take part; focus group will last no more than 1 hour 30 min).

Focus group 3: "moving forward" members and staff (between 4 and 8 people required to take part; focus group will last no more than 1 hour 30 min).

Participant observation: I will be present at NAME between DATE AND DATE where I hope to join in with many of the activities and sessions going on. If you have any objections to this please let me or a member of staff know. Please use this opportunity to ask me questions and just generally get to know me! I will, from time to time, make a few notes in my research diary where appropriate. If you would prefer it if I wasn't around at your session or this bothers you, please let me or a member of staff know.

Individual interviews: If you are one of the individuals selected to be interviewed we will arrange a mutually convenient time to set up the interview. The interview will take no longer than one hour, arranged with your consultation in a room at <organisation name>. The interview will provide you with the opportunity to share

your experiences of living with a mental health condition and the challenges you may have faced at the organisation and more widely. With your permission, the interview will be audio-recorded and then transcribed by me, I will also make some notes throughout the interview. You will have the opportunity to ask questions throughout or withdraw from the study if you wish.

If at any point you find discussing your experiences distressing or our discussion prompts any concerns about your mental health you should contact your GP, mental health practitioner or support worker as soon as possible. If you feel the matter is urgent, please contact XXXXX social care team on XXXX between 8am and 6pm Monday to Friday. If the matter is urgent outside of these hours you should contact the emergency duty team on XXXX. If you become distressed during our discussion I will alert an appropriate member of staff at <organisation name>.

5. **What is the next step?**
This information has been provided to you for you to have a look at and to help you decide whether you would like to take part. If you would like any further information, have any questions or would like to express your willingness to take part please contact me on 0XXXXXXXXXX5 or v.e.potts@durham.ac.uk or please feel free to speak to come and speak to me at any time whilst I am at NAME. If you do agree to take part in the interviews and/or focus groups you will be asked to sign a consent form.

6. **Will my taking part in this study be kept confidential?**
All information collected during the course of the research will be kept strictly confidential. All audio recordings will be kept on a secure network and destroyed at the end of the research. Your name or address will not be recorded on the interview transcripts and the transcripts will only be seen by my supervisors once personal details have been removed. Your name and identifiable details will be changed, and I will ensure that your involvement remains anonymous.

7. **Is there any time when disclosure of our conversation might occur?**
What we discuss will be in confidence, however, disclosure may be required if you were to say something that potentially indicated that you or someone else was at risk of significant harm. If you said something of this type, I would indicate this and you could then choose whether or not to continue the discussion. We would also discuss what the next steps would be.

8. **What will happen to the results of the research study?**
The results of the study will be used in my PhD thesis which explores the experiences of living with a mental health condition. I hope that the data I collect will also be useful to NAME and you. In the final focus group in particular I look forward to setting some time aside to discuss what you would like to see happen with the research. Also, it is likely that I will present and publish papers resulting from the thesis, however, anonymity and confidentiality will still be in place.

9. **Who is organising and funding the research?**
As a research student I am organising this research under the supervision of Dr Andrew Orton and Dr Mark Cresswell in the School of Applied Social Sciences Durham University (see details below). I am in receipt of a funded studentship from the ESRC (Economic Social Research Council).

10. Contacts for Further Information
Victoria Armstrong
Tel: 0XXXXXXXXX5
E-mail : v.e.potts@durham.ac.uk

Dr Mark Cresswell: mark.cresswell@durham.ac.uk
Dr Andrew Orton: a.j.orton@durham.ac.uk

Thank you for reading this information sheet and, if it is possible, participating in the study.

Appendix III: Invitation to participate and information sheet (staff)

PARTICIPATION INFORMATION SHEET

PhD research study: Exploring lived experiences of mental health conditions

Student Researcher	**Research Supervisors**
Victoria Armstrong	Dr Mark Cresswell, Durham University
Durham University	Dr Andrew Orton, Durham University

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take this information and read it carefully. If there is anything that is not clear, or if you would like any further information, please let me know before considering whether to take part or not.

1. What is the purpose of the study?

I am a postgraduate research student at Durham University. The study explores the lived experiences of people with a mental health condition who participate in, and attend, community organisations or projects. In order to do this it is important to hear the perspectives and voices of individuals with a mental health condition who participate in community organisations, along with the perspectives of staff who run the organisations and facilitate the activities. Given current changes in policy, cuts in funding and services and the recent welfare reforms it is particularly important to understand the key issues for people with a mental health condition, particularly in a support context. In order to do this it is important to hear the perspectives and voices of individuals with a mental health condition attend organisations such as NAME, along with the perspectives of the staff supporting them.

2. Do I have to take part?

- It is up to you to decide whether or not to take part.
- If you do decide to take part you will be given this information sheet to keep.
- You will also be asked to sign a consent form.
- If you decide to take part **you are free to withdraw at any time**, without giving a reason.

3. Why have I been chosen?

You have been chosen because <organisation name> has agreed to be involved in the project as a case study and you are currently employed by, or volunteer at, <organisation name>. <organisation name>'s decision to be involved does not mean that you should feel you have to be involved, that is why we are providing this information to you so you can choose whether you wish to participate

4. What will happen if I decide to take part?

There are a number of ways you can take part and this section describes what will happen if you decide to take part in one or all of the activities outlined below (dates to be confirmed).

Focus groups:

Focus group 2: "mental health: stigma and discrimination" members and staff (between 4 and 8 people required to take part; focus group will last no more than 1 hour 30 min).

Focus group 3: "moving forward" members and staff (between 4 and 8 people required to take part; focus group will last no more than 1 hour 30 min).

Participant observation: I will be present at NAME between DATE AND DATE where I hope to join in with many of the activities and sessions going on. Please use this opportunity to ask me questions and just generally get to know me! I will, from time to time, make a few notes in my research diary where appropriate. If you would prefer it if I wasn't around at your session or this bothers you, please let me or your line manager know.

Individual interviews: If you are one of the individuals selected to be interviewed we will arrange a mutually convenient time to set up the interview. The interview will take no longer than one hour, arranged with your consultation in a room at ORG NAME. The interview will provide you with the opportunity to share your experiences of supporting people with a mental health condition, the challenges you face and the challenges you

believe those with a mental health condition face along with any recommendations for good practice. With your permission, the interview will be audio-recorded and then transcribed by me, I will also make some notes throughout the interview. You will have the opportunity to ask questions throughout or withdraw from the study if you wish.

5. **What is the next step?**
This information has been provided to you for you to have a look at and to help you decide whether you would like to take part. If you would like any further information, have any questions or would like to express your willingness to take part please contact me on 0XXXXXXXX5 or v.e.potts@durham.ac.uk or please feel free to speak to come and speak to me at any time whilst I am at NAME. If you do agree to take part in the interviews and/or focus groups you will be asked to sign a consent form.

6. **Will my taking part in this study be kept confidential?**
All personal information that is collected about you during the course of the research will be kept strictly confidential. All audio recordings will be kept on a secure network and destroyed at the end of the research. Your name or address will not be recorded on the interview transcripts and the transcripts will only be seen by my supervisors once personal details have been removed. Your name and identifiable details will be changed, and I will ensure that your involvement remains anonymous.

7. **Is there any time when disclosure of our conversation might occur?**
What we discuss will be in confidence, however, disclosure may be required if you were to say something that potentially indicated that you or someone else was at risk of significant harm. If you said something of this type, I would indicate this and you could then choose whether or not to continue the discussion. We would also discuss what the next steps would be.

8. **What will happen to the results of the research study?**
The results of the study will be used in my PhD thesis which explores the lived experiences of a mental health condition. I hope that the data I collect will also be useful to NAME and you. In the final focus group in particular I look forward to setting some time aside to discuss what you would like to see happen with the research. Also, it is likely that I will present and publish papers resulting from the thesis, however, anonymity and confidentiality will still be in place.

9. **Who is organising and funding the research?**
As a research student I am organising this research under the supervision of Dr Andrew Orton and Dr Mark Cresswell in the School of Applied Social Sciences Durham University (see details below). I am in receipt of a funded studentship from the ESRC (Economic Social Research Council).

10. **Contacts for Further Information**

Victoria Armstrong
Tel: 0XXXXXXXXX5
E-mail: v.e.potts@durham.ac.uk

Dr Mark Cresswell: mark.cresswell@durham.ac.uk
Dr Andrew Orton: a.j.orton@durham.ac.uk

Thank you for reading this information sheet and, if it is possible, participating in the study.

Appendix IV: Consent form for individual participants

CONSENT FORM

PhD research study: Exploring lived experiences of mental health conditions

PhD Research Student
Victoria Armstrong, Durham University

Research Supervisors
Dr Mark Cresswell, Durham University
Dr Andrew Orton, Durham University

I have read the information sheet and been given a copy to keep. I have had an opportunity to ask questions and discuss the study, received satisfactory answers to all of my questions and received enough information about the study.

I understand that I am free to withdraw from the study:

- ☞ At any time
- ☞ Without having to give a reason for withdrawing
- ☞ Without affecting any support I receive

I am happy for interview/s and/or focus group/s to be audio-recorded and later transcribed. I agree for the recordings to be stored securely for the duration of the project for the purposes of the study. I also understand that all information will be anonymised (place and identities) both in the thesis and in any publications.

I agree to take part in the study.

NAME IN BLOCK LETTERS . . . . . .

Signed

. . . . . Date . . . . . .

Signature of Researcher

Appendix V: Interview guide (members)

Interview preliminaries, ensure participant has had a chance to read information sheet, ask questions and sign consent form. Explain aim of research is to explore stigma and discrimination in the 'lived experience' of people who have experienced distress and participating in community organisations in the North East of England. Interview should last approximately 1 hour. (These questions not asked verbatim- they are prompts for me).

What sessions/activities do you attend here at the organisation?

How long have you been coming along to the sessions/activities?

How did you find out about the organisation?

What do you enjoy most about coming here?

What do you feel about me using the term "with a mental health condition"? Are you comfortable with me using that term? If not why not and what would you suggest as a suitable alternative?

What challenges do you think those of us with a mental health condition face when they start, or think about starting, to attend an organisation like this one?

Have you experienced any particular challenges in attending this organisation?

When you think about attending this organisation, do you think you have ever been treated differently because of a mental health condition? If so, how?

What do you think the term stigma means? How would you define it?
(Working definition: a mark of disgrace or negativity associated with a particular circumstance or person, e.g. 'the stigma of a mental health condition')

Do you think certain conditions are more stigmatised than others? If so please explain.

Do you think you have ever experienced something like stigma? If so, please explain.

Have experienced anything like stigma whilst attending activities/groups at this organisation?
What do you think discrimination means? How would you define it?

(Working definition: to treat a person or a group of people differently and unfavourably or unfairly because of a particular characteristic such as race, gender, mental health condition etc)
Do you think you have ever experienced something like discrimination?

Do you think you have ever been discriminated against during your time at this organisation?
In what way? Who by?

Do you think that discrimination has anything to do with stigma?

What do you think the difference is between stigma and discrimination?

Can you think of any specific examples when stigma and discrimination has been a significant factor in your life? If so, how were you supported during this time and what happened? If you don't think stigma and discrimination has been a significant factor in your life, why do you think this is?

Do you think stigma and discrimination play a significant part in the lives of those of us with a mental health condition? Why? How?

Do you think stigma and discrimination are more significant depending upon various 'types' of diagnosis and/or behaviour associated with particular mental health conditions? If so please explain and do you have an example of this?

Have your experiences of stigma and/or discrimination varied depending on where you were and what you were doing? So for example you may have experienced stigma at work or visiting your GP, but not here at this organisation? If so, why do you think those experiences varied?
(If participant has experienced stigma and/or discrimination)

Do you think the stigma and discrimination you have experienced has impacted on your experience at this organisation?

Has support at this organisation helped you overcome any experiences of stigma and/or discrimination? If so how?

If you haven't experienced stigma and/or discrimination, more generally, what do you think the organisation does to mitigate or reduce stigma and discrimination?

If a person was stigmatised and/or discriminated against, how do you think it could affect a person's ability to participate in activities at organisations such as this one?

Do you think what we have discussed around stigma, discrimination and being treated differently, affects your ability to attend this organisation? If so how?

How do you your experiences of stigma and discrimination (this can be from outside of the organisation, for example, via friends, in employment, in contact with other professionals- prompts to discuss) affect your ability to participate in this organisation?

What do you think the benefits of attending this organisation are?

If you are or were stigmatised and/or discriminated against, how do you think these benefits would be affected?

How do you think the support provided here helps reduce/mitigate mental health stigma and discrimination?

How effective do you think the organisation is in tackling stigma and discrimination?

Do you think the support environment at this organisation is non-stigmatising and non-discriminatory? If so, how do you think it is made so?

Do you have an opinion on mental health policy and welfare reform (such as benefit reform, work capability assessment)? Do you think this helps to tackle stigma and discrimination or makes it worse?

Do you have any experiences of claiming benefits, the work capability assessment or interaction with other professionals you felt was stigmatising and/or discriminatory which you can share?

More generally, how effective do you think mental health policy is in tackling stigma and discrimination? Please explain.

Do you think the organisation has experienced funding cuts that has made it more difficult to tackle stigma and discrimination and its effects? Please explain.

Do you think this organisation has a role in getting people 'back to work'? If so, how do you feel about this? What are your experiences in 'getting back to work'?

Do you think staff at this organisation (or this organisation more generally) have a role in tackling stigma and discrimination? If so, how do you think they do this? Do you think how they tackle stigma and discrimination could be improved? If so how?

Can you think of a time that the organisation, or a member of staff at the organisation, has tackled stigma and/or discrimination? If so, what happened?

Do you think it is difficult for organisations and professionals to prevent stigmatisation and discrimination? If so why? Or, If not, why?

Do you have any suggestions for organisations on what they could do to avoid stigma and discrimination in the support context?

Appendix VI: Interview guide (staff)

Interview preliminaries, ensure participant has had a chance to read information sheet, ask questions and sign consent form. Explain aim of research is to explore stigma and discrimination in the 'lived experience' of people who have experienced distress and participating in community organisations in the North East of England. Interview should last approximately 1 hour. (These questions not asked verbatim- they are prompts for me).

Can you tell me about your role in the organisation?

How do you, in your role, support people with mental health conditions?

What do you feel about me using the term "with a mental health condition"? Are you comfortable with me using that term? If not why not and what would you suggest as a suitable alternative?

What particular challenges do you think people face when attending, or thinking about attending, this organisation?

How do you support them in overcoming these challenges?

What do you think the term stigma means? How would you define it?

(Working definition: a mark of disgrace or negativity associated with a particular circumstance or person, e.g. 'the stigma of a mental health condition')

Do you think certain conditions are more stigmatised than others? If so please explain.

From your experience within your organisation, how do you think stigma manifests itself in the support context? (For example, do external factors play a part? Have there been instances where the support context has been stigmatising?)

What do you think discrimination means? How would you define it?

(Working definition: to treat a person or a group of people differently and unfavourably or unfairly because of a particular characteristic such as race, gender, mental health condition etc.)

Within your organisation, do you think people with a mental health condition are ever discriminated against?

Do you think people with a mental health condition are discriminated against outside of the organisation? And do you think that impacts on the support context? If so, in what way?

Do you think discrimination has anything to do with stigma?

What do you understand as the difference between stigma and discrimination?

Can you think of specific examples when stigma and discrimination has been a significant factor in the life of someone you support or have supported? How did you or the organisation support that person through it?

Do you think stigma and discrimination play a significant part in the lives of those of us with a mental health condition?

Do you think stigma and discrimination are more significant depending upon various 'types' of diagnosis or behaviour associated with particular mental health conditions? If so please explain and do you have an example of this?

In your opinion, do people's experience of stigma and discrimination vary depending on where they are and what they are doing? For example, at work, dealings with other organisations, claiming benefits, attending this organisation, etc. If so, why do you think those experiences vary? Do you have any examples you can share?

Do you think stigma and discrimination which may occur outside of this organisation impacts on the people supported by this organisation? If so, in what way and do you have any examples?

What do you and/or the organisation do to mitigate stigma and discrimination?

How do you think experiences of stigma and discrimination (this can be from outside of the organisation, for example, via friends, in employment, in contact with other professionals) affect people's ability to participate in this organisation?

Have you got any examples of when this has occurred?

What do you think are the benefits of attending this organisation?

How do you think the support provided here helps to reduce/mitigate mental health stigma and discrimination?

How do you make the support environment non-stigmatising and non-discriminatory?

How effective do you think the organisation is in tackling stigma and discrimination?

More generally, how effective do you think mental health policy is in tackling stigma and discrimination? Please explain.

What role do you think wider welfare reform e.g. benefit reform has in tackling or exacerbating stigma and discrimination? Please explain.

Has the organisation experienced funding cuts that has made it more difficult to tackle stigma and discrimination and its effects? Please explain.

Do you see your role and your organisation as instrumental in getting people 'back to work'? If so, please explain.

What challenges do you think this organisation (and others like it) faces in mitigating the negative effects of stigma and discrimination?

What challenges do you think professionals, such as yourself, face in mitigating the negative effects of stigma and discrimination?

Is it within your remit in your role within the organisation to tackle stigma and discrimination?

If so, how do you do this?

Can you think of a time in your current role where you have tackled stigma and/or discrimination against someone with a mental health conditions? If so, what happened?

Can you think of activities the organisation carries out to tackle, reduce or mitigate stigma and discrimination?

Do you have any recommendations for avoiding stigma and discrimination in a support context?

What more, do you think, could be done within your organisation to tackle stigma and discrimination?

Appendix VII: Focus group guides

FOCUS GROUP GUIDE

Each session will begin by agreeing ground rules regarding respect, reciprocity and freedom to leave at any time and asking everyone if and what they would like to add to the rules which will then be displayed on flipchart paper in the room. I will explain that I am recording the session and ask participants to sign consent forms if they have not already been signed, and provide an opportunity for participants to ask questions about the research. (I expect most questions to be asked during recruitment process in the weeks before.) Make sure everyone gets a chance to contribute and that participants understand there are no right or wrong answers. Dictaphone(s) will be placed on the tables (depending on room set up). Each focus group will contain no more than 8 participants. If necessary, and if members and staff don't happen to know one another, we will carry out a warm up exercise, where we will stand in a circle (if there is room, otherwise we may have to sit) and introduce ourselves, doing a funny action and noise which the rest of the group have to imitate. The idea behind this is to energise people and to break down barriers so we can all be on the 'same level' for the session, i.e. if we're all being silly, no one is being silly. (If people really don't want to do this we can just introduce ourselves and/or people could pair up and just introduce themselves to their partner and then go around the group and partner with another person, introduce themselves etc. until they have met everyone. Even if people already know each other, depending on the atmosphere, I can say this is for my benefit and they can tell one another something about each other they might not already know.) *10 minutes.*

FOCUS GROUP 1: "experiences of living with a mental health condition"

Member participants only; I want participants with lived experience of mental distress to take the lead in creating the character(s) we will use in the remaining focus groups where staff will be involved.

After introductions (above) *10 minutes.* We will gather around a table (or two tables depending on size of group). There will be a large piece of flip-chart paper on which will be drawn the outline of a body and pens. The aim is to create a 'composite' character (or two characters if enough participants; one character created per 3-4 participants) who has lived experience of a mental health condition. Amongst themselves they can name the character, decide on the age and anything else they want e.g. occupation, friends, personal history, how a mental health condition makes them feel etc. and write these characteristics at the top of the paper or around body and/or add pictures or drawings/illustrations to it with minimal prompts from me. They are invited to use their own experiences if they feel comfortable but they are won't be made to share them. 20 *minutes*.

Once this is done I will explain the next exercise (which is really an extension of the first exercise), via discussion in the group and using post it notes each participant can write what the character might do and places they may go in their day to day life, and how the character may feel in these particular scenarios, and they can place these post-its on the paper; each participant will have post it notes to write on to ensure maximum participation in the groups. Post-its will be placed inside the body for what person feels and outside body for what the person does, specific feelings and actions can be linked with a line if

participants wish- *20 minutes*. (I will (perhaps) give more prompts here, for example, where does the character live, how is the character's day to day life affected by a mental health condition, who are their friends, family, what makes them feel happy or things that may make them sad, what do they watch on TV, what do they read, what makes them angry, where do they shop etc. During this time we will also have refreshments.) Towards end of discussion I will ask how the character might feel coming to this organisation.

In turn, I will invite people to feedback one or two of the post-it notes they have placed on the body, which also means people can discuss if they want to. If there are two groups/characters I will go to each group in turn and ask them to explain to wider group. *10 minutes.*

I will then ask, with their permission, if I can go away and 'write up' the character(s) for use in the next focus groups (which they are quite welcome to join) and close the group. *10 minutes*.

*TOTAL*TIME FOR FOCUS GROUP 1: a maximum of 1.5 hours*.

FOCUS GROUP 2: "Exploring mental health: stigma and discrimination"

Members and staff. Again, depending on size of the group depends on whether participants will be sat around one or two tables. I will repeat the same introductions as outlined above and will encourage them to play the same introductory game, this is particularly important to put staff and members on the same plane for the group exercise. *Maximum 10 minutes*.

I will then introduce participants to the character(s) created in the last focus group. If anyone was at first focus group they could contribute to this too if they would like and also, to confirm whether I had 'got it right' in my write up. (I will draw the character(s) again with the post it note info written clearly on or outside the body and this character will be pinned up or on the table.) I will start by asking participants how the character would feel coming to this organisation, they can discuss and put the post it notes anywhere on the character. *Maximum 15 minutes*.

Specific questions already on the flipchart paper will be: How does the character feel coming to the organisation? What doesn't the character like about the organisation? How does being at the organisation help the character? Has the character ever been treated unfairly because of his mental health? Has the character ever stopped himself from doing things because of how others might respond to him having a mental health problem? Has the character ever overcome stigma and discrimination? Has the character ever been treated more positively or received special treatment because of a mental health problem? I will invite participants to talk about why they have said what they have said and open it up to discussion. They are invited to use their own experiences where they feel comfortable. *Maximum 30 minutes* (including refreshments).

Close the group by explaining the final focus groups will be an opportunity to look to the future using the character and also talk about my research more generally and possibilities relating to dissemination etc. *Maximum 10 minutes.*

*TOTAL*TIME FOR FOCUS GROUP 2: a maximum of 1.5 hours.*

FOCUS GROUP 3: "moving forward"

Members and staff. Beginning, the same protocol as previous two focus groups. *Maximum 10 minutes*.

Session about encouraging participants to think about where they would like to see the character(s). For example, I will ask a number of questions for discussion and I will have four pieces of flipchart paper with one question on each. What things does the character want for the future? How might the character want to be supported by the organisation/professionals? What could the character do about mental health stigma and discrimination? (Explaining stigma and discrimination using the themes/ideas I have gathered and from focus group 2.) And what help does the character need to tackle mental health stigma and discrimination? They will discuss and put things on post it notes and come and place their suggestions on the flipchart paper. There will also be a body outline for people to place post it notes on describing qualities of the 'ideal' support worker. Once they have finished will invite participants to explain why they said what they said and open discussion if there is time. *Maximum 25 minutes.*

Finally I will ask what participants want from the work (I will be gathering these opinions throughout anyway and will explain any dominant suggestions already made to me) and how we can work on something together and way of dissemination e.g. going along to speak at their events when the research is completed, helping with a report etc. (I expect this to lead into subsequent meetings/e-mails/conversations depending on the organisation and negotiations about this have already begun.) I will close the group by agreeing any action/further work. *Maximum 15 minutes.*

TOTAL TIME FOR FOCUS GROUP 3: a maximum of 1.5 hours.*

*Note that I don't expect all groups to run to exact time, some parts may take longer than others and don't want to stop good discussion, thus, this is a guide and I will use my own judgement in each particular group. That said, I will ensure groups run to 1.5 hours maximum as described to the participants in the information sheets.

Appendix VIII: Composite character 'Jim' from Bright Futures.FG1

Jim T. Kirk was born in 1986 in York and he is now 27. When he was four years old his twin brother contracted meningitis and died. Jim left York when he was 18 and came to Northumbria University to study drama where he made some new friends who he smoked some cannabis with. He is still close friends with someone he went to university with and this friend often worries about him, because Jim's family still live in York Jim sometimes feels like this friend is his only family. Jim found university a bit of a culture shock, whilst he was excited to be moving away from home he was also scared that he wasn't good enough. Jim hasn't had a girlfriend since he was at university, he says he has low self-esteem and avoids attachment. He feels like the beta-male amongst 'fit lads' who he is often jealous of, he also feels as though he can't figure women out and often resents them. Jim hates his figure and wants to be muscular but he has always been skinny. When he was younger he recalls wanting chest hair and because he didn't have any he tried to glue some on. More recently he has thought that he might be gay but he is not sure what his family would think.

Jim currently rents a flat on his own with his pet cat and feels lonely. He is anxious to get out and about. Jim's cat is a rescue cat and Jim loves him very much although he is scared he might die and he worries because he doesn't know what he would do without him. Jim has been working as a props organiser in a TV studio and he's been there for about for 3 or 4 years. He has yet to do any proper acting but he has found little bits of drama work which has given him confidence because it makes him feels relaxed and able to express himself. He latches onto his creative side and acts in front of the mirror. However, he still feels like he has low self-esteem and that no one sees him like he does. Jim's job is a full time job with long hours, low pay, he often finds it stressful and like he is trapped in a career which has no momentum. He hates the job he is doing at the moment, he hates the people he works with, feels invisible and he is not sure whether he will achieve the job he wants. He often feels like his ambition is running out but he is sometimes hopeful. To relax Jim likes watching soap operas, he also likes computer games and long walks. He also likes going to the theatre and reads Shakespeare, he is not sure whether he is clever enough to read Shakespeare but feels he has to. To cheer himself up he often reads comic books.

About a year ago Jim had a bad manic episode and the crisis team were involved, he had been bullied at work and he fell into quite a depressed state of mind. He left work for a year and the doctor signed him off, but he felt quite useless when he was signed off work, like he was a failure in some way. His parents seemed too far away, his older sister was also still in York and everybody seemed miles away from Jim. However, when he was signed off work there was a weight lifted off his shoulders because he could think about what might be next in life after he had started to get help. There was a feeling of uncertainty as well as relief, and being signed off work gave him more time to think about his dead brother. Jim has a diagnosis of manic depression and often feels like a freak about his illness. When he thinks back, Jim thinks his depression started when he lost his twin brother because he felt like he lost a part of himself and he was never the same again. He has tried to block out his brother's death and thinks he never really faced up to it. Jim often wishes his family lived nearer to him because it makes him feel lonely knowing they are so far away. When Jim was involved with the crisis team they suggested he come to Bright Futures and after discussion the crisis team referred him. At first he was frightened,

scared and unsure of what to expect, he also questioned whether they could help and felt like he might be judged. That said, Jim also felt like it was a bit of a relief and could begin to look to what was next. Jim comes to the bipolar support group and the hearing voices group because he often hears voices and thinks they might be a gift.

Appendix IX: Composite character 'Mickey' from Creative Mindz.FG1

Mickey's full name is Michael but he prefers to be called Mickey. He is a 32 year old man and lives in South Shields. He is from Sunderland but he doesn't like to talk about it. Mickey has a flat but he gets lonely and so he prefers to sleep under a bridge, particularly in the Summer time. This means he is often preoccupied with wondering about where he will sleep and finding somewhere safe to be. When he is under the bridge, he counts sheep.

Mickey is obsessed with Greggs sausage rolls, in fact he eats them all day. Mickey thinks he has a job, but his psychiatrist says it's an imaginary job. He has an imaginary friend too. Mickey likes the Red Hot Chilli Peppers, particularly the song 'Under the Bridge'; he also likes the Smashing Pumpkins and can play the guitar very well. He listens to Mozart, Beethoven and Frank Zappa. Mickey speaks three languages, French, German and English. He is strong minded and generous, although he's not perfect, because nobody is. He is in good health, although he once got poked in the eye by Victoria. Mickey really likes motorbikes and he can't stop wanting them, but when he can't afford bikes he steals them. He's addicted to bikes and lives by the mantra, "born to thrill". He once stole sweets from an old burnt out Woolworths store because he thought it was retro. Mickey's parents are in jail and he says they are there because he drove them to it because of his erratic behaviour. He also claims that he drove his parents to drink. Mickey is quite erratic and covered in tattoos and has been described as a 90s hippy. Sometimes he's happy, sometimes he's not. Some describe him as gregarious, but we're not sure if that's because the word has been confused with Greggs the bakers, where Mickey buys all his sausage rolls. Mickey has a big dream but we don't know what it is yet.

Mickey takes forty sugars in his coffee, plays golf, goes to church on the quiet, and he also demands the fourth commandment which is 'remember the Sabbath day and keep it holy'. Mickey is the type of person who would just say that's he's mad or "I'm mad, mad, mad, freaking mad." At times he wants to give that impression to keep people away from him, but sometimes he wants to be close to people. Mickey can appear to some as being quite screwed up and like many people who are prescribed psychiatric medication, he refuses to take his medication because of the reactions he experiences. He is therefore forcibly injected with his medication. Mickey has been diagnosed with schizophrenia but he isn't sure about this diagnosis, he knows some people say he's a 'schizo'. In his everyday life this makes him quite anxious and incredibly stigmatised, particularly as he is known for stealing motorbikes and sleeping under the bridge. It has also been suggested to him that he has a personality disorder. Mickey only likes to walk around outside when it's dark. Mickey doesn't smoke whilst drink makes him happy but it's got its downsides. He's an underground Tory at heart.

Despite his problems Mickey does have things to feel positive about, he's a good musician and singer and he's kind and generous to the people he knows and likes. He's known as the 'easy rider' and has a good heart; this comes through in his music. It's his music which demonstrates to a lot of people that Mickey is not a simple guy and he's got quite a depth to him, particularly in his heart. He does like to think of other people and he feels more freedom now, because his parents are in prison. Although Mickey is in receipt of benefits, (because he is too dysfunctional to have a job), he is good with money, although he doesn't have a bank account because he doesn't trust banks. Mickey has

been coming to the studio since it opened, he describes himself as being “like part of the woodwork”. When he is at the studio he likes to splatter paint all over the place, he sticks his hands in a bucket of paint and throws it all over, and on previous occasions he has thrown it over the walls and other people’s work. He was subsequently threatened with being banned from the studio and now, although he still likes mess, he draws motorbikes, makes a little bit of money from painting, and uses dried up sausage rolls from Greggs in pictures he paints and the sculptures he makes. The Greggs sculptures are a mixture of pies and sausage rolls, he dunks the sausage rolls into the paint and then paints or makes a sculpture with them; this combines his love of mess and his fetish for sausage rolls. Mickey also uses the music room and has joined music groups, although some of the members there don’t like him. Some members don’t really understand his love of sausage rolls, some members think he is a tosser, others are still trying to work him out, some people think he has a strange fashion sense and some members quite like him because he comes across as warm and quite simplistic. Whilst people are friendly towards him sometimes, he can’t really tell what people think of him. Some people see Mickey as a spoiled brat who made his parent’s lives hell if he didn’t get what he wanted, and when he didn’t get what he wanted he threatened to kill them- with sausage rolls. Deep down Mickey does want to be liked.

Appendix X: Poem written at Creative Mindz creative writing group

A rollercoaster of vomit rises in her throat

Morphing into the familiar worm of heartbreak and anxiety

Burying words in her intestine whilst the syllables climb into her lungs

He's dying

Premature talk of last wishes for staging an end of day's theatre

As tears travel down the familiar tracks of salty terrain

Secreting with them those broken words in booming whispers

He's dying

She doesn't sleep for the deafening yawns of silent hopelessness

Wobbling towards life with the blood of misplaced panic

Like the jelly on a plate at the parties which were always forbidden

He's dying

And the words "he's dying"

Stick for two more days

He's not dying

He's not dying

He's not dying

The truth kicks her as the tendrils of betrayal absorb her insides

Until she feels like a camel starved of water

For he's not dying

He's trying to hollow her out

With each consecutive trick of manipulative menace

Compromising her breathing like formaldehyde

It'll be years before she learns her lesson

Lessons in shadowboxing his memory from her body

Bruised from the inside out and back again

He's not dying, he's lying

She becomes the price she is forced to pay

For the present of a life he still seeks to destroy

And a man who couldn't, wouldn't, care

To her he has to be dead, for she is dying.

Appendix XI: NVIVO codes

NODE	CHILD NODE	Sources	Ref
being able to 'be yourself'		11	12
being treated differently		30	55
co-morbidity and parity of esteem		25	34
confidence and confidence building		23	39
Education		17	24
experiences of medical and psychiatric services		45	122
	negative		25
	neutral		30
	positive		16
following biomedical model		28	54
	not a clinical space about interactions		15
	thoughts on medication		31
hierarchy of MH conditions and stigma		28	44
	mental health as a sliding scale		8
Impact of organisation on the individual		38	134
	negative		5
	neutral		18
	positive		23
	provision of 'structure and purpose'		9
Importance of work		42	119
	after illness and back to work		20
	before illness		21
	being productive in other ways i.e. art		18
lived experience of self reported stigma and		39	71

discrimination			
looking 'normal' or behaving 'abnormally'		14	29
me and the fieldwork- reflexivity		63	259
	how i feel about the research and in the field		45
	me as a member of staff		21
	my lived experience and disclosure		20
	reflexivity (and iterative developments)		15
	researcher or observer effect		16
Media		40	80
	celebrity		13
	TTC		22
patterns of inclusion and exclusion		64	241
	inside organisation		58
	outside organisation		42
positive elements of organisation		69	322
	compassion and care		17
	informal help		41
	Peer support		52
	'qualities' and personal attributes of staff		39
		lived experience of staff	
Recovery		42	108
	info sharing		28
	responsibility		6
referral to organisation and first attendance		33	47

rituals and interactions		38	113
self-reliance and doing things for self		29	55
self-stigma		42	83
social factors and MH		55	129
stigma causes and reduction		41	105
support outside organisation		49	91
technologies (capitals)		56	134
	other technologies (capitals)- creativity		25
	other technologies (capitals)-education		16
terminology of MH condition		22	27
The 'professional relationship'		56	169
	managing risk		19
	professional boundaries		30
	staff disclosure and lived experience		18
	what more staff could do		12
things have got better		8	10
What the organisation DOES		40	73
Wider political climate		59	139
	austerity and cuts to services		15
	back to work		19
	welfare benefits		34

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