PSYCHIATRIC SURVIVORS AND NARRATIVES OF ACTIVISM

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ABSTRACT

Despite there being a substantial history of survivors challenging psychiatry, there has been little attention paid to the lives of these individuals. The literature has primarily focussed upon 'recovery' and the development of typologies of emotional distress. Whilst the focus upon people's individual experience is to be welcomed, the literature has tended to background the causes to which survivors have committed part of their lives. The aim of this study was to explore the 'journeys' of survivors into activism to challenge psychiatry. The project drew upon a social constructionist epistemology and narrative theory. Nine interviews were conducted with survivors with a history of involvement in activism. A dialogic/performative analysis was used to explore issues of identity construction amongst the participants.

The analysis is presented as 'case studies' in order to try to capture the complexity of each person's narrative. The discussion section then brings each of these narratives together. It is argued that the participants' narratives shared common characteristics and reflected the narratives of the collective of which participants were a part, the wider survivor movement as well as dominant societal narratives. However, the way in which participants drew upon these narratives differed both within and across the accounts. Variations were apparent regarding the ways in which participants' narratives contested psychiatry. A personal and moral construction of activism featured heavily, with participants positioning themselves as both individuals with experience of the psychiatric system and as citizens.

This project highlights the need for understandings which take into account the complexity of people's lives, and their wider collective and social context. Recommendations include raising awareness about survivor groups/networks without co-opting their practices. Furthermore, this study attests to the need to take up issues of power and inequality, and their impact on people's lives, in research and clinical practice.

CHAPTER 1: INTRODUCTION TO THE PROJECT

Stories are argued to always be told from a particular position (Riessman, 1993). Viewing this research project itself as such a story, I start by describing my own journey and motivations for exploring the lives of those who are challenging the psychiatric establishment. Although one story amongst many, I begin with my own personal experience of being given psychiatric labels as a teenager. This was a profoundly negative experience on many levels and thankfully my family helped me to avoid entry into the psychiatric system itself. Whilst training to be a clinical psychologist at the University of East London (UEL), I have been exposed to a range of academic critiques of psychiatry which resonated with me deeply, helped me to give meaning to some of my own experiences and aroused a sense of injustice towards such practices.

However, this left me wondering how such a seemingly entrenched system could be tackled. Influenced particularly by Michel Foucault, I became interested in how the 'oppressed' themselves could 'resist' the power of the psychiatric system. In retrospect, I am aware of how such stories were largely absent from our teaching. By chance, I heard about a newly set up anti-psychiatry campaign group. I attended their first meeting and this opened up a new world for me. I was struck by the stories of awful life experiences followed by inhumane 'treatment' at the hands of psychiatry. However, such individuals were not the 'passive victims' of psychiatry but organised, angry and fighting back. At this meeting, one of the members introduced me to first-person narratives, such as Joanna Greenberg's (1964) *I Never Promised You a Rose Garden*. I wanted to find out more and, as such, began attending survivor-led conferences, such as those run by the Hearing Voices Network.

Reading first-person narratives and hearing people speak at these conferences influenced me both personally and professionally. It reconnected me to my own experiences but also challenged my assumptions, gave me an experience of a different kind of relationship with people experiencing distress and took me outside of academic theorising. I met more and more people who were actively challenging psychiatry and all in different ways. Given below are many such

examples, which are broadly referred to in this project as 'activism'. This study felt like an opportunity to speak to such individuals in more depth and find out about how they reached where they are now – this was the departure point for this project.

Epistemological Position

I will be drawing on a social constructionist epistemology and on narrative theory in this project. Although aspects of this approach are elaborated upon later in this section and the Methodology, some initial remarks are made to set the scene. Importantly, narrative theory argues that human beings are 'storied selves' (Andrews, 2007, p. 42). Yuval-Davis (2006, p. 201) proposes that '[i]dentities are narratives, stories people tell themselves and others about who they are (and who they are not).'[1] Indeed, Freeman and Brockmeier (2001, p. 97) go so far as to argue that 'there is no way to speak about what a life means, what a life *is,* apart from narrative.'

In line with a social constructionist epistemology, narrative theory critiques essentialist conceptualisations of identity (Burr, 2003) and, instead, views identity as 'multiple, fragmentary, and unfinished' (Langellier, 2001, p. 176). In addition, narrative is intrinsically related to context. This is articulated well by Riessman (2008, p. 105) who says that '[s]tories don't fall from the sky (or emerge from the innermost 'self'); they are composed and received in contexts.'

It is also important to note that narrative theory draws, often implicitly, upon positioning theory (Davies & Harré, 1990; van Langenhove & Harré, 1999). In this theory, the concept of 'positioning' is distinguished from the 'more static concept of role' (van Langenhove & Harré, 1999, p. 14) in that 'subject positions…offer discursive locations from which to speak and act rather than prescribing a particular part to be acted out' (Willig, 2008, p. 116). These positions are viewed as relational (Harré & van Langenhove, 1999) in that individuals position

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[1] I will also be using 'narrative' and 'story' interchangeably as other narrative researchers have done (e.g. Riessman, 2008).

themselves and/or are positioned by others through the language used (Davies & Harré, 1990). In turn, this has consequences for 'ways-of-seeing' and 'ways-of-being' as well as subjectivity (Willig, 2008, p. 113). In this regard, the 'self' is a viewed as being a negotiated discursive product (Davies & Harré, 1990).

Indeed, Andrews (2007, p. 9) makes the relationship between narrative, positioning and politics explicit when she describes how narratives of identity are always political 'even when they are personal, as they reflect the positionality of the speaker'. Stories (and positions adopted) are, therefore, always 'strategic, functional, and purposeful' (Reissman, 2008, p. 8), although it is crucial to note that this does not imply that the narrator always makes deliberate choices in this regard (Freeman, 2002). Thus, narrative plays an important social role and, indeed, is central to the politics of belonging; namely, 'who belongs and who does not' (Andrews, 2007, p. 9).

Language Use

In light of the social constructionist epistemology adopted, it is important to be clear about the language used in this research, given its role in the construction of meaning and experience (Burr, 2003).

Firstly, the term 'survivor' will be primarily used instead of 'patient', 'service user', 'client' or 'consumer'. I have chosen 'survivor' because this is the term most often adopted now within the literature by those who are challenging psychiatry (e.g. Campbell, 2008; Wallcraft, Read, & Sweeney, 2003). In addition, the other labels are argued to infer potentially negative connotations (Mental Health Foundation, 2013). However, in respect of self-definition (Campbell, 2008), the terminology of the participants will be adopted in the Analysis chapter. Nonetheless, it is recognised that none of these terms 'capture a rounded picture of the individual…in a wider social context' (Campbell, 2008, p. 197).

Secondly, the activities that people are involved in to challenge psychiatry are referred to as 'activism', which is defined here as 'the active participation, in various ways, of people advocating a particular set of issues' (Urrieta, 2005, p.

189). This broad definition was deliberately chosen to leave open the means by which people may be attempting to challenge psychiatry. Importantly, the term 'activist' will not be drawn upon. Firstly, in accord with the social constructionist epistemology, this is to avoid simplistic essentialist constructions of people's identities. Secondly, although the term 'activist' is in growing circulation within the survivor literature in the UK (e.g. Campbell, 2008; Wallcraft, 2009), it is not assumed that all individuals will identify with this term and, as such, adopting it might foreclose the ways in which people might understand themselves in relation to their activities.

Thirdly, in light of the topic of this research, 'psychiatric system' will be used instead of 'mental health system' and, also, 'distress' will be adopted instead of 'mental distress', 'mental disorder' or 'mental illness', given that the latter terms include assumptions about the 'location' of distress (i.e. the 'mind') and have pathologising connotations (Cromby, 2013; Mental Health Foundation, 2013). In addition, it is important to note that 'psychiatry' refers to the paradigm, or 'narrative', of psychiatry, which is expanded upon below, rather than to individual psychiatrists who work within this paradigm.

Lastly, I will also use the first-person to emphasise my active role in the storying of this research at all stages (c.f. Holloway & Wheeler, 2010).

Literature Search Strategy

A literature review was conducted over a period of 20 months. The full details of this are given in Appendix 1. In summary, an electronic search of key terms was conducted (e.g. 'survivor', 'activism', 'narrative' and 'social movements'), which reflected the interests of this project. The databases searched included Ingenta, PsychINFO, Pubmed, Web of Science and Google Scholar. In addition, references and citations within relevant articles were followed up, as were articles and books recommended by my peers and supervisor.

CHAPTER 2: OVERVIEW OF THE DOMINANT NARRATIVE OF PSYCHIATRY & HISTORY OF CHALLENGE BY SURVIVORS

The Dominant Narrative of Psychiatry

The medical model is the dominant paradigm of 'mental distress' in the Western mental health field (Kerr, Dent-Brown, & Parry, 2007). This paradigm is argued to explain people's experiences of distress 'in terms of illnesses, chemical imbalances and broken brains' (Adame & Knudson, 2007, p. 157). This 'disease' model is common parlance within the NHS; for instance, the Care Quality Commission (CQC) (2013, p. 2) reports that '[n]early a quarter…of the total burden of disease in the UK is attributable to mental disorder'. Many have suggested that diagnosis is pathologising and reductionist and leads to a view of people as 'powerless victims' and their distress ('symptoms') as 'irrational' and without meaning (Bassman, 1997, p. 238; Blackman, 2012). Furthermore, the paradigm of psychiatry is said to disconnect people's experiences of distress from their actual lives and social context, limiting the construction of alternative meanings (Adame & Hornstein, 2006; Adame & Knudson, 2007). Furthermore, psychiatric diagnoses is argued to contribute to people experiencing 'devalued identities' in society and social injustice, impacting on people's ability to participate economically, socially and politically in society (Harper & Speed, 2012).

Discrimination against individuals with psychiatric diagnoses is even enshrined in the *European Convention on Human Rights* (1950) that makes possible the removal of liberty of those with 'unsound mind' where there has not been a criminal offence (Bindman, Maingay, & Szmukler, 2003). Negative perceptions of those given psychiatric labels are further promulgated by the tabloid press and in government policy, such as through advocating a link between 'mental illness' and dangerousness (Beresford & Croft, 2010), even though such a connection is not supported by the evidence-base (Taylor & Gunn, 1999). Indeed, coercion in the psychiatric system appears to be on the rise. Following the amendments to the *Mental Health Act* (1983) in 2007 (*Mental Health Act,* 2007*)*, the CQC (2013, p. 3) reported a 5% increase in the number of involuntary psychiatric admissions,

a 10% increase in the use of Community Treatment Orders and expressed concern that 'cultures may persist where control and containment are prioritised over the treatment and support of individuals.' Indeed, psychiatry is argued to expect people to be 'silent recipients of treatment' (Dillon & May, 2002, p. 25), with medication continuing to be widely advocated (c.f. NICE, 2009).

The validity of the psychiatric model has been challenged from different theoretical perspectives; for instance, Boyle (2002) argues there is a lack of evidence to support the idea of psychiatric diagnoses as 'brain diseases' and Moncrieff (2008) provides counter-arguments to the idea of the specificity of psychiatric medication. In addition, contrary to the medical model, first-person accounts and individual narratives highlight how distress can be understood in terms of 'social, political, spiritual and economic factors' (Adame & Knudson, 2007, p. 162). Indeed, the links between distress and social inequality are also supported in the literature (e.g. Brown & Harris, 1978; Wilkinson & Pickett, 2010). However, such ideas are argued to be down-played by psychiatry and pharmaceutical companies (Boyle, 2002; Fisher, 2003). The construction of distress as a health rather than social issue also has political effects; for instance, it removes the responsibility of the Government to make expensive social interventions (c.f. Boyle, 2006). As a result, Adame and Hornstein (2006, p. 334) comment on how the 'perspective of ex-patients is usually left out of the history books and the psychiatric literature'. Indeed, in this light, Bassman (1997, p. 238) describes how individuals began to explore ways to 'change their status from powerless victims to agents of change'.

Overview of Survivor Challenge to Psychiatry

A summary of how survivors have challenged psychiatry, rather than a detailed history, will be given here (see Campbell, 2008; Cromby, 2013; Rogers & Pilgrim, 1991). Key issues and debates emerging within the history of this struggle will be reviewed to help contextualise the influences that may affect those currently challenging psychiatry. The focus will be on survivors in the UK as this is the interest of this research, although it is recognised that developments in the UK

and other countries are not mutually exclusive and have significantly influenced each other historically (Crossley, 2006).

Historical Context of Challenge to Psychiatry

Challenge to psychiatry is not a recent endeavour and, indeed, it has been argued that 'contention surrounding psychiatry is as old as psychiatry itself' (Crossley, 2006, p. 69). For instance, in the UK, protests have been organised by survivors since 1620 (e.g. 'Petition of the Poor Distracted People in the House of Bedlam') (Wallcraft et al., 2003). In addition, a collective of 'lunatics' formed called the 'Alleged Lunatics' Friend Society' in the mid 1800s to challenge 'wrongful confinement' and conditions in the 'madhouses' (Cromby, 2013; Crossley, 2006, p. 50).

Even these early examples highlight for me the way in which challenges to psychiatry have often been a collective phenomenon (Crossley, 2006). The beginnings of the modern day collective contest are widely debated (Survivors History Group, 2011), but an important moment in history was the forming of the first 'union' or 'federation' of survivors in the UK in 1971, called the Mental Patients Union (MPU) (Crossley, 2006). This emerged out of a strike and occupation by professionals and 'patients' at the Paddington Day Hospital (PDU) over its proposed closure (Crossley, 2006).

The MPU is said to have been the first modern explicitly politicised group within the UK (Cromby, 2013). They made 24 demands of which 14 remain outstanding, including the 'abolition of irreversible psychiatric treatments' such as ECT (Harper, 2010; Roberts, 2013). Following the setting up of the MPU, other groups were created in its wake, such as Community Organization for Psychiatric Emergencies (COPE) in 1973, the Campaign Against Psychiatric Oppression in 1985 (CAPO), as well as Nottingham Advocacy Group and Survivors Speak Out (Cromby, 2013).

Although not framed as such at the time, the language used in relation to the fight for rights by other social movements and campaigns is now applied to the

collective work of survivors (Cromby, 2013; Crossley, 2006). For instance, Dillon (2011, p. 156) says 'fighting for the rights of people deemed mad…is the last great civil rights movement'. Wallcraft et al. (2003, p. 3) give a definition of this movement and describe it as:

> 'A term used to describe the existence of numerous individuals who speak out for their own rights and those of others, and local groups and national organisations set up to provide mutual support or to promote the rights of current and former mental health service users to have a voice.'

There are different terms used to describe this collective struggle, such as the 'ex-patients movement' (Chamberlin, 1990), the 'British mental health users movement' (Rogers & Pilgrim, 1991), the 'survivor movement' (Harper & Speed, 2012) and many others. The 'survivor movement' will be adopted here in line with the terminology used in the rest of this project.

The Growth of Challenge to Psychiatry in the UK

Since the setting up of the MPU over forty years ago, there has been a very large increase in the number of individuals and groups associated with the survivor movement (Crossley, 2006). For instance, in their survey, Wallcraft et al. (2003) found at least 318 groups who associated themselves with the survivor movement as defined above. Whilst this development has been widely welcomed within the survivor movement, it has also contributed to concern about, as well as changes in, the way the survivor movement is organised (Crossley, 2006).

Firstly, Campbell (2008, p. 206) describes how the survivor movement had historically focussed on local issues but comments on how there are so many national networking groups, whose work considerably overlaps, that there is a risk of 'fragmentation'. Secondly, due to this growth, Crossley (2006) argues that a pressure has been created for newer organisations to find their niches. For instance, whereas the MPU was set up to represent 'patients' in general, it is argued that there has been a 'differentiation' and 'specialisation' of challenge to psychiatry, focussing on specific issues or forms of human experience (Crossley,

2006; Warner, 2009). For instance, Women at the Margins foregrounds gender and is aimed at issues faced by women diagnosed with 'borderline personality disorder' (Warner, 2009, p. 68; Women at the Margins, 2004), whereas the Hearing Voices Network (HVN) aims to challenge dominant discourses around 'schizophrenia' and/or 'psychosis' (Romme & Escher, 1993).

The Socio-Political Context of Challenge to Psychiatry

Crossley (2006, p. 206) comments on how the 'style, tactics [and] aspirations' of survivors in relation to contesting psychiatry have changed over time, which he understands within the socio-political context of the period. This reaffirms the point made at the start of the Introduction about the importance of context for understanding the lives of survivors engaged in activism.

Crossley (2006, p. 206) describes how the MPU was formed at the end of the 1960s and, in this context, was framed in Marxist terms. For instance, they were a 'union' and viewed their politics within class struggle and as revolution (Crossley, 2006). In contrast, groups in the 1980s, such as Survivors Speak Out, formed at a time when 'Marxism…was falling out of fashion' and '[l]anguage and subjectivity were now hailed as the key terrain of struggle' (Crossley, 2006, p. 206). In turn, Crossley (2006, p. 207) argues that this informed the more 'tentative and pragmatic' approach taken at the time with a 'focus upon listening and speaking, making testimony and putting one's experience into words.' Interestingly, Crossley (2006, p. 207) reports how one of his interviewees, who was active during this period, described a need to 'present a very rational face to the outside world' at the time due to the ongoing stigma regarding 'mental illness'. Crossley (2006, p. 207) suggests that Mad Pride (c.f. Curtis, Dellar, Leslie, & Watson, 2000) challenged this viewpoint, rejecting the idea of 'mad people' as 'the same' as everybody else 'underneath'. Indeed, Mad Pride describe themselves as a group which 'promotes raves and rock concerts…celebrates madness…[and] asserts the rights of 'mad' people without pleading for them' (Curtis et al., 2000, p. 7-8). As before, this form of protest did not occur within a vacuum and Crossley (2006) locates Mad Pride within the broader anti-corporate

movement. In addition, Warner (2009, p. 69) argues that Mad Pride represents a return to a 'politics of autonomy…with a distinctively deconstructive feel'.

In relation to the expansion of groups mentioned earlier, Crossley (2006, p. 199) suggests a key influence was the neoliberal politics of the recent era, consumerism and the change in government thinking, which led to a redefinition of 'patient as consumer'. Thus, it is argued that whereas survivors had been backgrounded in the past, they were now 'welcomed into the mainstream', often under the rubric of 'service user involvement' (Campbell, 2008, p. 196), and were seen to possess a marketable form of 'knowledge' and 'expertise' (Crossley, 2006, p. 203). Indeed, the NHS Plan (Department of Health, 2000) and the National Service Framework (Department of Health, 1999) highlighted roles for 'users' as trainers and consultants, and encouraged their involvement in management and service development (Davies, Holden, & Sutton, 2001).

However, there is debate within the survivor movement about whether these changes represent a positive development or a threat to the survivor movement (Crossley, 2006). In particular, there is concern that these changes are 'tokenistic' (Campbell, 2008) and an attempt to 'recuperate dissent' rather than to 'revolutionise' practice (Warner, 2009, p. 68). Notably, in relation to the current project, Crossley (2006, p. 204) also comments upon how these new opportunities drew some 'potential activists away from the activist route'.

Issues and Debates amongst Survivors Challenging Psychiatry

Different Views amongst Survivors

Although a brief background to the survivor movement is given above, it is important to recognise that survivors position themselves differently in relation to psychiatry (Campbell, 2008). Indeed, although implicit, an unstated assumption up until this point has been that all those within the survivor movement are actively challenging psychiatric practice in some way. However, this is not the case and, in reality, the survivor movement represents a broad range of views (Campbell, 2008). For example, in their survey, Wallcraft et al. (2003) found

varying opinions about the acceptability of the biomedical model, forced treatment and attitudes towards pharmaceutical company funding. Similarly, Rogers and Pilgrim in their interviews with ten groups from the 'British Mental Health Users Movement' (MHUM) in 1991 found that the 'ideology of the movement clearly varied' (p. 141). Some groups were very opposed to psychiatry (e.g. CAPO) whereas others were more supportive (e.g. VOICES[2]) (Rogers & Pilgrim, 1991). Rogers and Pilgrim (1991) found these differences to be particularly reflected in the language used by the different groups, such as whether or not illness labels and biomedical terminology was adopted (e.g. 'schizophrenia' and 'sufferer'). Nonetheless, despite these differences, Rogers and Pilgrim (1991, p. 141) also suggest that 'the issue of dignity and users having a voice connect the different factions'.

In the light of this, it might therefore be unsurprising that survivors also hold different views about where change should occur; for instance, whether this should be around raising awareness and improving access to 'treatment', challenging psychiatric practice, campaigning for 'patient rights' and/or concentrating on civil rights (Campbell, 2008). On this latter point, Campbell (2008, p. 197) argues that there has been too much of a focus on 'patient rights' instead of 'civil rights' and, as a result, 'activists…appear to think of themselves as service users first and citizens second'. Alternatively, some groups campaign on wider social issues. For instance, at the time of writing, the Mental Health Resistance Network is campaigning on the impact of the welfare cuts on those people with 'mental health' issues. However, what is most clear from the literature review is that assumptions about the existence of only a 'single voice' of the survivor movement should be avoided (Sweeney, 2009, p. 23).

Identification with the Survivor Movement & Divisions Between Survivors

It is important to note that not all survivors identify with being part of the survivor movement. Indeed, Wallcraft et al. (2003) found that a large number of individuals, particularly black survivors, did not identify as such. For instance,

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[2] VOICES was the patients' group within the National Schizophrenia Fellowship (Rogers & Pilgrim, 1991).

some respondents felt that the movement was 'too intellectual' for them, did not accept people who were continuing to use mental health services or felt that its interests lay too much with professionals (Wallcraft et al., 2003). From the literature review, no other material could be found which spoke to these experiences.

In addition, there have been attempts to distinguish between the different ideologies of survivors. For example, in the United States, Adame and Leitner draw a distinction between 'consumers' and 'ex-patients/survivors' saying that '[c]onsumers usually accept the discourse and premise of the medical model and do not challenge the existence of the mental health system as a whole, as survivors/ex-patients tend to' (2008, p. 148). Similarly, Speed (2011) puts forwards separate 'patient', 'consumer' and 'survivor' discourses. However, in respect of these differences, such as between 'service user' and survivors, Campbell (2008, p. 197) argues that such distinctions are over-simplistic and 'may not indicate profound ideological differences'.

Relationship with Professionals

A further significant issue raised in the literature is the nature of the relationship between survivors and non-survivors, such as professionals[3] (Crossley, 2006; Warner, 2009). This clearly echoes debates within the feminist movement, such as whether 'separatist' or 'collectivist' strategies should be adopted (Warner, 2009). Indeed, in Rogers and Pilgrim's (1991) study mentioned above, they found a range of opinions about working alongside psychiatry, veering between positive attitudes (e.g. VOICES) to very negative views (e.g. CAPO). Of note, where professionals do work alongside survivors, the term 'ally' is often used (c.f. Adame & Leitner, 2008).

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[3] It is recognised that a dichotomy is created here between 'survivors' and 'professionals' which reflects the literature base. Of course, an individual could identify with both groups, which is beginning to gain greater attention (e.g. Adame, 2011).

CHAPTER 3: RESEARCH ON SURVIVORS CHALLENGING PSYCHIATRY

<u>Psychological Literature Exploring The Experiences of Survivors Involved in Activism</u>

Given the history of the survivor movement, it is therefore surprising that there has been 'scarcely anything at all' within the literature which focusses upon individuals who are challenging psychiatry (Crossley, 2006, p. 1).

The only psychological research found in the literature review which does so are two papers by Alexandra Adame and Roger Knudson in the United States (Adame & Knudson, 2007, 2008). Both articles appear to use as their data the same four interviews with individuals involved in 'political activism'. Their research explores these participants' narratives of 'recovery' and their ideas of what it means to lead a 'good life' (c.f. McLeod & Lynch, 2000). Each of the participants in their study emphasised the important role that their involvement in the survivor movement played in helping them to 'reengage with the world' after coming out of the psychiatric system (Adame & Knudson, 2008, p. 152), and described how the psychiatric system had made it difficult for them to form connections with other survivors (Adame & Knudson, 2008). Their participants, it is argued, considered that living a 'good life' involved 'reconnect[ing] personal struggles with socio-political and existential ones' (Adame & Knudson, 2008, p. 145). Based on these accounts, Adame and Knudson (2007, pp. 172) suggest the existence of an alternative narrative of recovery which is 'less to do with personal growth and transformation and more with social activism and advocacy work' and a 're-connection of the personal and the political'. The authors propose that such a narrative challenges the medicalised meaning that psychiatry gives to 'recovery' – namely, as an 'absence of symptoms' (Adame & Knudson, 2007, p. 160).

Arguably, this work ties into a larger body of literature that has problematised and deconstructed the concept of 'recovery' (e.g. Harper & Speed, 2012; Pilgrim, 2008) which is now a central part of UK Government policy and 'mental health services' (Harper & Speed, 2012). In particular, Harper and Speed (2012) have

drawn attention to how 'recovery' has been used in UK policy in an individualising way, typical of neoliberal politics, and maintains a reliance on deficit-based models and backgrounds the structural factors impacting on people's lives (Harper & Speed, 2012).

As in Adame and Knudson's (2007, 2008) research, some survivors have attempted to re-appropriate 'recovery' by arguing for a meaning of 'recovery' which is more to do with 'liberation rather than cure' (Coleman, 1999; Harper & Speed, 2012, p. 11; Pilgrim, 2008). For instance, Jacqui Dillon (2011, p. 157) also advocates a politicised version of recovery, as do some others within the Hearing Voices Network (e.g. Coleman, 1999). Drawing on arguments from the feminist movement and Herman's (1997, p. 207) concept of the 'survivor mission', Dillon (2011, p. 157) proposes that '[i]mproving all of our personal experiences means that we must collectively address oppressive political structures. This for me is why the personal is political'.

However, in my reading of the literature, such debates over the preferred meaning of 'recovery' are problematic and could inadvertently distance some individuals with experience of the psychiatric system from joining more collective efforts. For instance, whilst Adame and Knudson (2008) claim not to 'advocate one specific path of healing' (p. 148), they appear to generalise from their sample to say that an important part of 'recovery' for 'ex-patients and survivors…means turning [anger] outward to address the social institutions that led them to believe that they were sick, insane, and defective' (p. 159). Similarly, Dillon (2011, p. 150, my italics) states that '*real* recovery is only possible outside of traditional psychiatry'. Whilst this is clearly contesting psychiatric orthodoxy, where does this leave those survivors who describe their 'recovery' as occurring within the system? Does this mean that they have not *really* 'recovered'? The potential for 'ghettoising' 'recovery' and for identity divisions again appears to echo the feminist movement (Warner, 2009).

In Harper and Speed's (2012, p. 21) critique of the construct of 'recovery', they advocate the usefulness of focussing upon survivors' 'biographical narratives'. However, they highlight the risk of downplaying the power of survivors' narratives

by inserting these narratives into 'professionally derived conceptual frameworks', such as 'recovery' (Harper and Speed, 2012, p. 21). On this note, in my reading, the literature on 'recovery' also backgrounds the causes to which people have committed at least part of their lives. A case in point would be Thornhill, Clare and May's (2004, p. 181) research where they delineate three genres of 'narratives of recovery from psychosis'. In this study, they comment on how most of their participants 'were involved in user groups which often take a critical stance on psychiatric treatment' (Thornhill et al., 2004, p. 195) but neither the journeys into such involvement nor the impact of this involvement upon people's narratives of 'recovery' are explored, say. This appears to be a significant omission in the literature and in need of further research.

However, following the arguments developed by Harper and Speed (2012), it was decided not to premise the current project on the construct of 'recovery'. In particular, Harper and Speed (2012, p. 21) suggest that '[n]either biographical journey narratives nor optimism necessarily entail the other conceptual and policy baggage' of 'recovery'. Drawing on Trivedi (2010) and Wallcraft and Michaelson (2001), Harper and Speed (2012, p. 22) advocate 'more sophisticated understandings of experience…framed in people's own words, using the language that survivors themselves use' and that 'these narratives need to be understood in a collective and political and economic context'. This suggestion is taken up in the current project which is discussed further in chapter 4 of this Introduction.

First Person Accounts of Survivors Involved in Activism

Another body of literature from which it might be useful to draw, in order to understand the lives of survivors involved in activism, are first-person narratives. As mentioned earlier, first-person narratives have been largely ignored within the literature (Adame & Hornstein, 2006). However, Gail Hornstein (2005) has produced a large bibliography of such narratives and has conducted research specifically looking at these (e.g. Adame & Hornstein, 2006).

Of particular relevance to the current project, Adame and Hornstein's (2006) study included books by authors who went on to challenge the psychiatric system, such as Clifford Beers' *A Mind that Found Itself* (1908), Mary Jane Ward's *The Snake Pit* (1946) and Anton Boisen's *Out of the Depths* (1960). Using narrative analysis, Adame and Hornstein (2006, p. 143) developed a 'typology of first-person narratives of emotional distress'. The aim of this research was to compare these 'emotional distress' narratives with 'illness' narratives. For instance, they cite Frank (2012) who described three types of 'illness' narrative - 'restitution', 'chaos' and 'quest'.

In Adame and Hornstein's (2006) study, accounts given by the survivors, in the books mentioned above, fell under their category of a 'psychiatric oppression' narrative, in which the writers 'seek to protest psychiatric abuse, raise social awareness…or challenge psychiatric authority.' They highlight how the authors present their accounts in different ways; for instance, Clifford Beers explicitly contests the psychiatric system, whereas Mary Jane Ward draws on a fictional storytelling style to bring to life the experience on a psychiatric ward. Although useful for giving an 'inside view' of the experience of distress and highlighting how people narrate their accounts (Adame & Hornstein, 2006, p. 151), there are two important limitations of such typologies.

Firstly, whilst acknowledging their usefulness, Frank (2012, p. 49) also comments on how a 'typology is dangerous because its categories propose terms in which people can feel constrained to identify themselves'. Along similar lines, typologies, like any umbrella description, run the risk of being reductionist and obscuring the significant variations in people's lives (c.f. Farley, 1986). To illustrate this point, consider these two brief summaries of more recent first-person survivor narratives by Pete Shaughnessy (2000) and Jan Wallcraft (2009).

In the Mad Pride anthology, Pete Shaughnessy (2000, p. 15), a founding member of Mad Pride, describes his 'road into "madness"', saying that '[l]ooking back at the sea of exploitation and violence at the time…I took the only logical way out: to go into my "madness"'. In the run-up to the Maudsley's 750th 'celebration' in

1997, Shaughnessy (2000, p. 21) helped to organise Reclaim Bedlam saying that it was 'commemoration versus celebration' and 'for the first time…we were taking the user movement out of the ghetto of smoky hospital rooms and into the mainstream'.

Jan Wallcraft (2009, p. 132) talks about how as a teenager she 'began to see political and sociological explanations for my unhappiness', but after a 'breakdown and mind-numbing ECT I felt the only community to which I belonged was that of outsiders' (Wallcraft, 2009, p. 134). She describes finding her way into 'survivor research and activism'. Wallcraft (2009) took on a post at MIND and was later recruited to, and commissioned by, the Government's Mental Health Task Force. Wallcraft (2009, p. 137) states that '[m]y purpose was political: I wanted people to have the information to argue for their choice of treatment'.

Both these individuals are referred to as 'survivor activists' (Chambers, Glenister, Kelly, & Parkes, 2005; Wallcraft, 2009) but it is notable how different their journeys, into activities to challenge psychiatry, appear to be for each of them. Whilst typologies can certainly be useful, such details can too easily be lost.

Secondly, the layers of context within which the individual's narratives are embedded can also be neglected in typologies. A good example would be Adame and Hornstein's (2006) research, mentioned above, as this does not place the authors' accounts within their historic time period nor their respective socio-political contexts (c.f. Whooley, 2006). Indeed, from a social constructionist point of view, Whooley (2006, p. 299) argues that the 'meaning and political relevance of a narrative cannot be understood without investigation into the context in which it is produced'. In addition, understanding people's experiences in terms of typologies may also encourage an overly simplistic reading of people's lives and neglect the 'struggle over meanings' within people's narratives (Langellier, 2001, p. 151). This 'struggle over meaning' is argued to be central to understanding how people position themselves in the world and, thereby, their construction of identity (c.f. Andrews, 2007; Langellier, 2001). Interestingly, drawing on a social constructionist epistemology, Hydén (1995) critiques the way in which 'recovery' has been conceptualised within a realistic epistemology within the literature.

Instead, Hydén (1995, p. 73) argues that accounts of 'recovery' can be better viewed as stories 'shaped by and created out of her own life situation and the interview situation in which she is engaged'.

A notable exception to this pattern is Crossley and Crossley's (2001) research on how the 'voice' of the survivor has changed over time. To do this, the authors study two anthologies written by survivors who are 'speaking out' about psychiatry. The first is *The Plea for the Silent* (TPFTS) (McIntosh Johnson & Dodds, 1957) and the other is *Speaking Our Minds* (SOM) (Read & Reynolds, 1996). In this research, Crossley and Crossley (2001, p. 1477) adopt a 'narrative-style analysis' and social constructionist epistemology. They make a number of interesting observations, a few of examples of which will be given here. Firstly, they note how 'appeals to credibility' have changed a great deal (p. 1479). In TPFTS, this was done on behalf of 'patients' by professionals who drew upon their qualifications and status to claim legitimacy for the patients' accounts (p. 1480). However, in SOM, the authors of this anthology are argued to do so by identifying themselves with oppressed groups or politicised categories, such as a 'mental health system survivor' or 'disabled lesbian' (p. 1480). Secondly, the accounts in TPFTS were said to be almost entirely descriptive and 'particularised' experience (p. 1482). However, in contrast, the accounts in SOM were more theorised and '[n]o longer…purely individual experiences of the solitary ego. They are the experiences of a group; collective and shared experiences' (Crossley & Crossley, 2001, p. 1484). Thirdly, they comment on how a 'whole "new" language of "self": a therapeutic language of "healing" and "recovery"' is present in SOM (p. 1486). They contrast this with TPFTS 'where people simply "pleaded" for someone to talk to' (p. 1486).

Crossley and Crossley (2001) make sense of these changes in 'voice' by grounding their understanding in the historical and socio-political context. Crossley and Crossley (2001) note the political influences upon the rise of the survivor movement, such as consumerism and neoliberalism. Interestingly, on the point about the new language of 'self' in SOM, they relate this to the growth of psychotherapy and the 'self-help industry' (p. 1488). These changes, it is suggested, have helped the survivor movement to develop its 'own self-help

projects and, more generally, for developing credible and authoritative alternatives to the "medical model"' (p. 1488).

Wider Literature on Activism, Collective Action and Social Movements

The literature review also revealed a considerable area of research on activism, collective action and social movements within political psychology, social psychology and sociology. This will not be covered in depth here but some of the main themes will be considered which may help to inform the current project. In her review of the literature within political psychology, Andrews (1991, p. 19) argues that political activists are 'portrayed as sometimes pathological, usually irrational, and always deviant.' More recently, Blackwood and Louis (2012, p. 72) make a similar point, saying that 'activists' tend to be represented as either 'nobly altruistic or mad'. Attempts have been made to counter this position in the social psychology literature, with particular attention given to a social identity perspective (e.g. Blackwood & Louis, 2012; Drury & Reicher, 2005; Reicher, 2004). In particular, this literature has sought to explore 'who will participate, under what circumstances, and why' (Blackwood & Louis, 2012, p. 73) as well as the impacts of involvement in collective action, say (Drury & Reicher, 2000). For instance, Drury and Reicher (2000, p. 579) explored the psychological outcomes of involvement in activism (e.g. mass strikes, occupations), which included a more 'radicalized self concept.'

Although this approach has given some possible ways of understanding involvement in activism, the social identity perspective is problematic from a social constructionist point of view. Indeed, much of this research has proceeded by adopting a realist epistemology and using quantitative methodologies (c.f. Plummer, 2001). For instance, Liss, O'Connor, Morosky and Crawford (2001) use quantitative measures of 'feminist ideology' and beliefs in the importance of collective action to predict 'feminist social identity'. This literature also often views people as possessing multiple social identities but, as Spelman (1988, p. 158) argues, '[s]elves are not made up of separable units of identity strung together to constitute a whole person'. By adopting such an epistemological stance and methodology, it is proposed that there is a risk of 'premature theoretical closure

and a tottering towards sure, safe absolutism, denying the role of active human beings and their lived experiences' (Plummer, 2001 p. 5). Thus, as discussed in the Methodology chapter, a social constructionist epistemology may be better suited to explore the complexity of people's lives who are engaged in activism.

Although in its infancy, narrative approaches are being applied to the study of collective struggles (e.g. Davis, 2002). Narrative is argued to be 'central to group identity' (Fine, 2002, p. 239) and, indeed, social movements have been conceptualised as 'bundles of narratives' (Fine, 2002, p. 229). Poletta (1998, 2002) notes the role of storytelling in the 1960s student sit-ins and argues that collective narratives can mobilise participation from others, strengthen commitment amongst members, as well as sustain struggles during setbacks by giving meaning to these experiences (Poletta, 1998, 2002). In addition, Fine (2002, p. 244) also proposes that narrative can 'cement individuals into group life emotionally, intellectually, and behaviorally'. Indeed, Whooley (2006, p. 297) proposes that the narrative approach is 'particularly attuned to political ramifications of narratives for marginalised individuals'. Thus, it appears that the narrative approach might be useful for bridging the gap between the individual, the group and the wider context (Davis, 2002).

CHAPTER 4: THE CURRENT PROJECT

From the literature review above, it appears that there has been relatively little attention paid to the lives of survivors specifically engaged in activism to challenge the psychiatric system, despite the significant history of such activities.

The review highlighted how research with survivors has focussed primarily on their experiences of distress under the rubric of 'recovery'. It has been argued that whilst the focus on individual narrative appears a useful way forwards, the literature on 'recovery' has decontextualised people's experiences and has backgrounded the causes to which people have committed part of their lives. Similarly, it has been argued that the development of typologies, and the literature on activism from a social identity perspective, is limited and tends to disconnect people from their historical and socio-political contexts. In this regard,

literature adopting a social constructionist and narrative methodology has been highlighted as a potentially useful alternative way in which to explore and contextualise the lives of survivors involved in activism.

In particular, the aim of this project was to explore the 'journeys' of survivors into activism, and their experiences of involvement in activism, with an analytic focus upon narrative identity construction. Indeed, arguably, issues of identity are especially relevant in relation to the survivor movement. For instance, Bassman (1997, p. 238) refers to a central feature of the survivor movement as the move from 'powerless victims to agents of change' and Dillon and May (2002, p. 25) refer to 'recovery' as a 'decolonising process, a reclaiming of experience'. Speed (2011, p. 124) also talks about how the move from 'patient' to 'survivor' 'subject positions' (or 'identities' within a narrative analytic framework) are 'examples of how discourses are constructed, contested and change'. Indeed, drawing on a social constructionist epistemology and narrative theory, the premise of the current project is that such shifts can be viewed as a change in the construction of identity in the context of the dominant psychiatric narrative. From a social constructionist point of view, discussed further in the Methodology, identity construction is vital because of the possibilities it enables and constrains in terms of what can be said and the action which can be taken by a person (c.f. Burr, 2003). Although some of the studies mentioned earlier (e.g. Adame & Knudson, 2007) touch on this subject, there has been no research specifically looking at how survivors story their journeys into, and involvement in, activism nor the kind of identity claims people make in the process. Such a study could therefore potentially add considerably to the literature base in relation to survivors, the survivor movement and activism more broadly.

Thus, the research question was, 'How do survivors story their journey into, and their involvement in, activism to challenge psychiatry?'

As well as addressing an area in particular need of research, this study also has potential relevance to the profession of clinical psychology. The Division of Clinical Psychology (2010, p. 3) advocate that clinical psychologists form 'partnership arrangements with local service user and carer organisations'. In

addition, Newnes (2004, p. 372) also argues that '[p]sychology and psychotherapy should align themselves with the oppressed and speak out about injustice'. Although there are different opinions about professional involvement amongst survivors as described earlier, there does seem to be scope for 'mutually enriching dialogues between these groups without co-opting alternative discourses into mainstream practice' (Adame & Leitner, 2008, p. 146). By developing a greater understanding of the lives of those involved in challenging psychiatry and by using each survivor's own language, this research can hopefully help achieve this aim and be used to raise awareness amongst clinical psychologists about available alternatives to mainstream services.

This research could benefit survivors as well. Firstly, it could also help raise awareness amongst survivors, who are unfamiliar with the survivor movement, of the different survivor groups and networks. Secondly, by focussing on the lives of survivors engaged in activism, it could provide a new perspective on the 'stories and systems which enable a reclaiming of experience' (Dillon & May, 2002, p. 26).

CHAPTER 5: METHODOLOGY

In this section I will outline the rationale for adopting a qualitative approach, discuss my epistemological position further and justify the use of a narrative approach. I then provide details of the procedure and the criteria chosen for evaluating this project.

A Qualitative Approach

The choice of methodology was made on the basis of both the practices of survivors as well as the aims of this research project. Campbell (2008, p. 198) comments on how 'legends of oppression met and overcome are important parts of the service user/survivor culture'. In addition, Harper and Speed (2012, p. 18-19) talk about how the survivor movement developed 'a focus on the survivor's individual experience as a counter to the totalizing, pathologising discourse of medicine.'

Thus, a qualitative methodology seemed most in keeping with the ethos of the survivor movement as it would enable a focus upon people's subjective experiences, the development of 'thick descriptions' and the contextualisation of people's lives (c.f. Geertz, 1973). In addition, a qualitative methodology is also argued to be well suited to examining under-researched topics (c.f. Strauss & Corbin, 1990).

This approach contrasts with the quantitative research in the field of activism mentioned in the Introduction, which has sought to develop predictors, causal explanations and/or generalisable theories (c.f. Blackwood & Louis, 2012). As well as subsuming individual differences and decontextualising people's experiences (Andrews, 1991; Plummer, 2001), Gergen (1973, p. 314) points out how 'activists' have 'reacted bitterly to explanations of their behaviour' and goes on to say '[t]hus, we may strive to invalidate theories that ensnare us in their impersonal way'. This was an important consideration both in terms of the epistemology and the analytic method chosen.

Further Details on Epistemological Position

As stated in the Introduction, a social constructionist perspective was adopted, which, it will be argued, fits well with the aims of this project. The significant distinction between social constructionism and positivism is said to be a 'difference between the representational and the constitutive views of language' (McNamee, 1993, p. 4 as cited in Emerson & Frosh, 2004, p. 5). In this way, positivism assumes that descriptions of the world '*represent* what is actually there' (Emerson & Frosh, 2004, p. 5) and thus makes claims about 'reality' and 'truth' (Burr, 2003). However, social constructionism rejects such propositions and, instead, 'invites us to be critical of the idea that our observations of the world unproblematically yield its nature to us' (Burr, 2003, p. 2).

In particular, central to the notion of social constructionism is the idea that knowledge and meaning is constructed through language (Burr, 2003) which is intertwined with power relationships (Emerson & Frosh, 2004). Of special relevance to the current project is the way in which social constructionism

challenges essentialist views of identity. Namely, social constructionism argues that '[t]here are no essences inside things or people that make them what they are' (Burr, 2003, p. 4). Thus, from a social constructionist perspective, identity is not seen as a 'thing' an individual 'has' which can be 'discovered' but as a co-construction (Burr, 2003). Burr (2003, p. 4) notes how essentialism can 'trap' people within pathologised identities, which is arguably particularly the case for those given diagnoses of a 'mental illness'.

Another feature of social constructionism is the way in which it invites us to view our knowledge as historically and culturally specific (Burr, 2003). This highlights again the need to understand the lives of the participants in this project within their historical and socio-political context. Indeed, this was an important reason why a description of the history and current climate of activism was given in the Introduction in order to help locate (and therefore give meaning to) the lives of those involved in this project.

Furthermore, in her review of social constructionism, Burr (2003, p. 3) notes how 'knowledge and social action go together…each different construction also brings with it, or invites, a different kind of action from human beings'. Arguably, this is again particularly relevant to the exploration of the lives of those involved in activism. For instance, 'mental illness' has long been argued to be an especially powerful construction (Szasz, 1960) and, as mentioned in the Introduction, it brings with it a web of power relationships, enabling the removal of someone's liberty and of the legal responsibility for the person's actions (Dillon & May, 2002). Indeed, in line with the research question of this project, a central aim of this study was to examine what other constructions might be available and what actions these invite (c.f. Dillon & May, 2002). As such, a social constructionist epistemology appeared particularly well suited to this task.

Why Narrative Analysis?

As mentioned in the Introduction, a narrative analytic framework was chosen through which to view the participants' lives. This method fits well with a social constructionist position; for instance, Riessman (1993, p. 2) comments on how

'[i]ndividuals construct past events and actions in personal narratives to claim identities and construct lives'. In fact, as discussed in the Introduction, narrative and identity construction are argued to be synonymous with one another (Freeman & Brockmeier, 2001). In addition, narrative analysis seeks to locate people's stories within their context and gives particular attention to the 'political' dimension of people's stories (Emerson & Frosh, 2004). Indeed, Emerson and Frosh (2004, p. 8) argue that narrative analysis is 'capable of critically contributing to the interplay between personal and social change'. Arguably, this is of particular relevance to exploring the lives of people with experience of 'distress' who are engaged in activism.

A further reason why narrative analysis was chosen over other methodologies is the way in which it honours 'individual agency' (Riessman, 1993, p. 12). Emerson and Frosh (2004, p. 10) recommend narrative analysis 'as an approach respectful of the agency of persons negotiating "possible lives", particularly in the context of breaches of dominant discourses or canonical narratives'. Again, this seems especially relevant for those with experience of psychiatry. Thus, for this reason, Riessman (1993, p. 4) comments on how 'narratives must be preserved, not fractured' 'because they are essential meaning-making structures' which is contrasted with approaches in which 'cases are pooled to make general statements' (Riessman, 2008, p. 12).

Riessman (2008, p. 183) reflects upon how narrative analysis refers to 'a diverse set of methods, a "family" of interpretative approaches to spoken, written, and visual texts'". However, a common feature is the way '[n]arrative analysis takes as its object of investigation the story itself' (Riessman, 1993, p. 2). One approach to narrative analysis is the dialogic/performative approach, which shifts interest from '"what" is spoken and "how"' to '"who" an utterance may be directed to, "when," and "why," that is, for what purposes?' (Riessman, 2008, p. 105). Within this approach, identity is viewed as a 'struggle over meanings' (Langellier, 2001, p. 151) and, as Riessman (2008, p. 106) puts it, 'identities are constructed in "shows" that persuade'. Thus, identity is seen as a public achievement rather than, say, a journey within which to find the 'true self' (c.f. White, 2007). Importantly, in line with a social constructionist epistemology, the

dialogic/performative approach highlights how the 'story is being told to particular people; it may have taken a different form if someone else were the listener' (Riessman, 1993, p. 11). Thus, this was a reason for starting the Introduction with a description of my own position and for reflecting in the Discussion on my role in the co-construction of the narratives.

Study Design

Sampling Strategy

A purposive sampling strategy was adopted with the aim of recruiting up to a maximum of 10 people. Indeed, small sample sizes are typical in narrative research (c.f. Riessman, 2008). This sample size reflected my wish to gather rich accounts whilst also having enough accounts to hear a variety of narratives regarding journeys into activism.

To be included in this project as 'psychiatric survivors', individuals needed to have a self-identified history (either past or present) of involvement with psychiatric services. However, given that people might not identify with this label, this was operationalised as 'people who have had contact with mental health services' in material given to participants. Individuals were also required to be over 18 years-old, so that they could themselves give informed consent, and to speak fluent English as funds were not available for translation costs.

Lastly, the participants needed to have a history of involvement, either present or past, in activism. As mentioned in the Introduction, activism was defined as 'the active participation, in various ways, of people advocating a particular set of issues' (Urrieta, 2005, p. 189). Given the comments in the Introduction about how not everyone may identify with a label of 'activist' and/or define their activities as 'activism', this definition of activism was operationalised as 'involvement in challenging or developing alternatives to the psychiatric system' which was also reflected in the material given to participants. Inclusion in this regard was a matter of self-definition.

Recruitment Strategy

Participants were recruited for this study in different ways. Firstly, individuals known to me or my supervisor, who met the inclusion criteria, were contacted by me, either at events (e.g. conferences, workshops) or by email, to seek their interest in participating. Secondly, an 'advert' (Appendix 2) was circulated by me to different organisations and groups, and by my supervisor (Dave Harper) to a distribution list for which he is the administrator. Thirdly, a snowball sampling strategy was adopted; namely, participants chosen to be interviewed were asked if they knew of anybody else in their network who might be interested in participating. In addition, in the light of people from black and minority ethnic (BME) groups being under-represented in research regarding survivors (Thornhill et al., 2004), such individuals and BME groups were specifically targeted as well.

Participants were selected on an informal basis. People who made contact after the sufficient number of participants had been recruited were thanked for their interest and informed that the recruitment process had finished. The description below therefore relates to those participants who registered an interest before this recruitment phase ended.

All individuals who registered an interest were spoken to either in person or over the telephone about the project. Three people were excluded after this initial screening process. Two people did not have personal experience of psychiatric involvement and the third person described 'aspiring' to be involved in activism but reported no history of any involvement as yet.

Ten people were recruited in total. One person was interviewed but his/her data were not analysed for two reasons. Firstly, despite identifying themselves as meeting the inclusion criteria, it emerged during the interview that this person did not have personal experience of the psychiatric system. In addition, at the time of interview, this person did not wish to be tape recorded and, although they then agreed after discussing the confidentiality arrangements again, this person was clearly reluctant to share details or reflections about their journey to becoming

involved in their activities. Thus, this interview was excluded from analysis and the description below refers to the nine people who were interviewed.

Participant Backgrounds

In order to protect the anonymity of the participants, only limited demographic details are given and details are presented in group terms. Of the individuals included in the analysis, the youngest were in their 30s and the eldest were in their 60s. Eight identified as white British and one was of a mixed background. To help orientate the reader, brief details are included below about the different kinds of activism in which each individual was involved.

Susan has been a member of an anti-psychiatry campaign group since its inception a few years previously. She has helped organise, and has taken part in, a number of demonstrations that the group has undertaken.

Alice is a member of the Hearing Voices Network. She works both nationally and internationally. Alice has talked publicly about alternative understandings of voice hearing and has spoken out in the media against psychiatry.

Geoff has worked in a number of survivor-led services and is currently working in a mental health charity.

Edward has set up different organisations, which offer alternative ways of working with distress. Edward is involved in training, consultancy, campaigning and supports other survivors.

Thomas is a member of a group inspired by a punk/anarchist philosophy and took part in a number of campaigns the group organised.

Sarah was also a member of a group inspired by a punk/anarchist philosophy and has had substantial involvement working in local mental health trusts (e.g. teaching and training), national charities on 'service user' projects and media work.

Joseph works as a qualified allied mental health professional within the NHS and the independent sector. He has campaigned against coercive forms of psychiatry and biological reductionism for a long time and is also involved in developing alternatives to the psychiatric system.

Catherine has a longstanding involvement in the survivor movement and has worked in prominent positions within a number of mental health charities. She has also conducted research regarding distress and the survivor movement.

Emily is a member of the Heaving Voices Network and works in a mental health charity. She has been involved in a number of mental health campaigns.

The Interview Schedule and Procedure

An interview schedule was designed with broad questions and 'probes' relevant to the topic of enquiry, as advised by Riessman (1993) (Appendix 3). These broad questions focussed upon the activities in which people had been involved in, and their journeys into, and involvement in, activism. I began with the opening question 'Can you tell me a little bit about the kinds of things you've been involved in?' However, the fourth participant asked if she could start at 'the beginning' instead and, on reflecting on this afterwards, I thereafter began with the statement 'Some people like to start with what they've been doing whereas others prefer to start at the beginning, whatever would be easiest for you'. Notably, everyone then chose to start at 'the beginning'. All interviews were conducted face-to-face, were tape recorded and ranged between one and two hours.

Following the guidance of Riessman (1993, 2008) and Plummer (2001), I kept the interview as loosely structured as possible, and sought to maintain curiosity and follow 'participants down *their* trails' (Riessman, 2008, p. 24). In addition, the argot of the interviewees was adopted as far as possible (Plummer, 2001) and, in the light of the role that language is argued to play in identity construction, terms were avoided that might appeal to particular identities (e.g. 'activist', 'survivor' etc).

Narrative interviewing techniques were used during the interview, especially the concepts of the 'landscape of action' and the 'landscape of consciousness' which Michael White (2007, p. 77-78) borrows from Jerome Bruner (1986). The 'landscape of action' refers to the content of the story whereas the 'landscape of consciousness' is formed of 'what those involved in the action know, think, or feel, or do not know, think or feel' (Bruner, 1986, p. 14 as cited in White, 2007, p. 78). During the interviews, movement took place between these two 'landscapes' to develop a rich description of people's lives.

Ethical Considerations

Ethical approval for this project was granted from the University of East London Research Ethics Committee (Appendix 4).

Informed Consent and Confidentiality

Information on the project was sent to participants before the interviews took place (Appendix 5 and 6) and they were offered the opportunity to discuss any concerns beforehand. This informed the participants about why the project was taking place, what the interview would involve, confidentiality arrangements, and the benefits and potential disadvantages of taking part. The information and consent form (Appendix 5 and 6) were both read through with participants at the time of the interview and any questions were answered. If the person was happy to proceed, we then completed and signed two copies of the consent form.

In order to protect the anonymity of the participants, they have each been given a pseudonym. Nonetheless, it was recognised that some of the excerpts, or details provided, in the analysis section and elsewhere may lead to some participants being identifiable. As such, the participants were later contacted in order to seek his/her consent for this material to be used. Each person was sent all his/her excerpts from our interview which were included in this thesis and any other information included which might potentially identify them. All the participants responded and any changes requested were made. Thus, consent has been given by all the participants to the excerpts and details included in this thesis.

Participant Well-Being

Participants were given a choice about where they wished to be interviewed; in all circumstances, a third party was informed about the time of the interview and my whereabouts. The interviewees were reminded at the start of the interview that they could halt the interview and/or withdraw from the study at any time. I drew on my clinical skills to observe for any signs of the upset or distress by the interviewee during the course of the interview. In case of distress, the agreed protocol was to offer information about support available (e.g. the Samaritans) and to contact a member of the programme team. All the interviewees were thanked for their participation and were given the space when the interview had finished to reflect upon their experience of the interview.

<u>**Analytic Process**</u>

Transcription

Riessman (2008, p. 21) comments that 'transcription and interpretation are often mistakenly viewed as two distinct stages of a project'. Given that transcription is an important part of the analysis, all interviews were transcribed by me. Riessman (2008, p. 50) also reflects upon how 'transcriptions are by definition incomplete, partial and selective' and how choices regarding transcription should 'reflect theoretical commitments (and practical constraints)'. Thus, in the light of the view adopted in this project about narrative as a co-construction, all the interviews were transcribed verbatim, including my speech (Riessman, 2008). Performative features were included too, such as pauses, emphasis and laughter. Some (but not all) dialogic/performative analyses (e.g. Langellier, 2001) include significantly more detail (e.g. rising/falling intonation), but this was neither practical given the time constraints nor essential to the analysis to be undertaken (Riessman, 2002, 2008).

Analytic Steps

Unlike other qualitative methodologies, there is 'no standard set of procedures' for conducting narrative analysis (Riessman, 1993, p. 54). Indeed, Emerson and Frosh (2004, p. 11) argue that narrative analysis 'asks specific questions about particular lives'. Thus, in the light of this, my analytic 'lens' and the questions asked of the data were influenced by reading other examples of dialogic/performative analyses (e.g. Andrews, 1991, 2007; Frank, 2012; Langellier, 2001; Mishler, 1999; Riessman, 1993, 2002, 2008), as well as Davis (2002) in relation to narrative and social movements. This literature was adapted to the interests of the current project and the following questions were formulated:

- 'In what kind of a story did the narrator place himself?' (Riessman, 2002, p. 8)
- What 'types of [identity] claims are made and how are they warranted?' (Mishler, 1999, pp. 21-22)
- 'How did [the person] strategically make [these] identity claims through [his/her] narrative performance?' (Riessman, 2002, p. 8). Related to this is politics of belonging - who is included in the 'us' and who is not? (Andrews, 2007, p. 9; Frank, 2012, p. 45)
- 'How [do] these [identity claims] function in [people's] lives?' (Mishler, 1999, p. 22) Namely, from a social constructionist point of view, what do these identity claims enable and limit? (Burr, 2003). In addition, how might these identity claims function to sustain these individuals in their struggles and/or influence others? (Polletta, 1998, 2002)

In addition, as taken up in the Discussion, I also considered my influence in the co-construction of narratives and the influence of the historical and social context (Riessman, 2002, pp. 8-9). Namely:

- 'What was the response of the [listener], how did [the listener] influence the development of the…narrative, and interpretation of it?'
- 'How might [the narrative] be interpreted differently with historicity and social structure in mind?'

It is also important to note that during the process of developing this project, the literature search and the recruitment of participants (e.g. attending workshops and conferences), I came across material produced by people, and heard a number of individuals speak at events, some of whom I subsequently recruited to participate in the project. Whilst this was not a formal part of the data collection, it is likely that my 'pre-understandings' (Martin & Stott, 2010) of participants, formed as a consequence of these experiences, influenced both the interview process and my interpretations of the interview material. In the light of this, I have made explicit some of these pre-interview experiences in the Analysis section and some of the connections between these experiences and my interpretations.

Riessman (2008, p. 3) points out how 'the term "narrative" carries many meanings' and influences what parts of the text are analysed. In view of the social constructionist epistemology of this project, a critical view of narrative was adopted here; namely, it was not viewed as a 'thing' to be 'found' in the text. In line with this (and as other researchers have done), the entire interview transcript was analysed rather than categorised or divided up into units (c.f. Riessman, 1993, 2008).

As is common amongst narrative research (e.g. Andrews, 2007; Langellier, 2001; Riessman, 2002), I give the Analysis section as separate 'case studies'. In line with the comments made earlier, I felt this was the most fitting form of presentation in order to honour people's 'individual agency' (Riessman, 1993, p. 12). As Mishler (1999, p. 18) argues, people 'do not simply follow cultural plots in storying our lives but adapt, resist, and selectively appropriate them.' As such, I wanted to stay as close as possible to people's individual stories and to capture the complexity of each person's narrative in its own right. Indeed, other approaches (e.g. IPA, grounded theory) have been criticised for moving 'too quickly towards cross-sectional themes and seem thinly descriptive' (Harper, 2013, p. 22). In addition, I felt that this 'case study' presentation may allow subjugated stories to be heard (White & Epston, 1990), which might be lost if presented thematically. However, in the Discussion, I bring these stories together and reflect upon similarities and differences between people's narratives.

Lastly, a note on the presentation of the 'case studies'. Importantly, a dialogic/performative analysis does not 'suggest that identities are inauthentic…but only that identities are situated and accomplished with audience in mind' (Riessman, 2008, p. 106). Unfortunately, through its language use, I felt that much of the literature that uses a dialogic/performative analysis could be interpreted in the former way (e.g. Riessman, 2002). Holding in mind the participants and the audience who might read this project, I felt it important to caution against particular terminology. Thus, terms such as 'performance' are used sparsely and, instead, replaced with phrases such as 'had the effect of' or 'enacted'.

Evaluation Criteria

Riessman (1993) argues that the prevailing notions of validity and reliability are reliant upon a realist epistemology and are therefore inappropriate in narrative analysis. She comments upon how one's analysis is not meant to be 'a mirror to a world "out there"' (Riessman, 1993, p. 64) and that 'multiple readings are potential in all narrative research' (Riessman, 2008, p. 49). Thus, it is important to acknowledge that my interpretation of the participants' stories is but one interpretation amongst many possibilities. In the light of this, how is this project to be evaluated? Following Riessman's (1993) guidance, the focus is shifted from the 'truth' of the analysis to the 'trustworthiness' of it instead. Drawing upon Riessman (1993, 2008) and Yardley (2000), I describe how I operationalised 'trustworthiness' for the purposes of this project.

1. Transparency and Coherence: Transparency is argued to reflect the extent to which there is clarity about the data collection and analytic process, whilst coherence relates to the 'fit' between the research question, epistemological position and methodology (Yardley, 2000). I have incorporated these elements into this Methodology section and have also included a 'worked' transcript in the appendix (Appendix 7). Yardley (2000) comments upon how researchers should be open about their influence upon the analytic product. To this end, I have been transparent about my own position at the start of the Introduction and have included a section on 'reflexivity' in the Discussion.

2. Persuasiveness: Riessman (1993, p. 65) refers to this criterion as indicating whether 'the interpretation is reasonable and plausible'. In this regard, quotes from the participants accompany my interpretations in the Analysis section, to allow the reader to assess the meaning of the narrative for themselves.

3. Pragmatic Use: Riessman (2008, p. 193) proposes that an important test of validity is whether 'a piece of narrative research becomes a basis for others' work'. To this end, the academic and clinical relevance of this project was discussed in the Introduction. In addition, in the Discussion, I have reflected upon the research and practice implications of this study.

CHAPTER 6: ANALYSIS

1. <u>Susan</u>

'…I'm just a normal everyday person walking the streets…'

In reply to my question about how she became involved in her activities, Susan began with the above comment. Indeed, this claiming of an identity as a '*normal everyday person*' formed a central feature of Susan's narrative. Susan gave me an account of how she came to be admitted a few years earlier into a psychiatric hospital and of her experience in this hospital, which she said occurred in the context of a significant dispute with a family member. Susan told me that the staff had written down that she was '*paranoid*' about this family member during her admission. However, in her narrative, Susan gave me a step-by-step account and provided meticulous detail about her actions and thinking processes at the time. I wondered if this way of storying her experiences sought to contest the idea that she had been '*paranoid*'. Indeed, Susan claimed an identity as someone who had been thinking '*logically*', which was stated explicitly, and enacted implicitly, through phrases such as '*of course*'.

> *'…I was going into a complete panic so, of course, when the police arrived I didn't know who they were. I thought are they the police or are they dodgy people so I wouldn't open the door but then they smashed the door in…'*

> *'…I actually thought it was a lethal injection or something…so I thought…I was thinking about this logically, if I'm found dead somewhere and I've got pills in my system they'll say she took an overdose or something whereas if I'm injected there's no way I did that so I was kinda trying to leave forensic evidence…'*

Susan's construction of her behaviour as '*leaving forensic evidence*', and her later description of her discharge as being '*rescued*', conjured up an image for me of Susan as someone held 'hostage' in the hospital; namely, an 'innocent' person, held against their will. Indeed, as per the excerpt below, Susan's narrative reminded me of the Rosenhan experiment, which was published in a paper called 'On being sane in insane places' (Rosenhan, 1973).

> *'…I was standing by the door all the time to try and catch anybody that came into the ward…and I would say (.) please can you help me, you know, and they thought well crazy person…'*

Namely, Susan positions herself as 'sane' in her narrative (or a '*normal everyday person*'), the effect of which is to enable Susan to bring into question psychiatry's ability to recognise when someone is not '*crazy*'. Thus, Susan implicitly draws upon the psychiatric distinction between the 'well' and 'ill' (or '*sick*') and positions the lack of psychiatric intervention after her discharge as an indication that she could not have been '*sick*'.

> *'…they released me about half-an-hour to an hour before the tribunal…with no drugs, nothing, no crisis team, nothing, they just released me just like that so you're telling me I was sick for a week, I don't think so, and not taking drugs, what a load of crap…'*

The effect of this story was to delegitimize her admission, which seemed reminiscent of very early attempts to contest psychiatry, such as the Alleged Lunatics' Friend Society mentioned in the Introduction. For instance, this Society challenged the accuracy of diagnosis, 'wrongful confinement' and conditions in hospitals rather than the nature of 'mental illness' itself (Cromby, 2013).

Arguably, constructing her experience as one of being wrongfully held 'hostage' made sense of Susan's reported motivation to challenge psychiatry as being prompted by her emotional response to this experience, which included being '*livid*' and as '*mad as shit*' about what happened to her.

Susan described meeting other people in the campaign group of which she is a part as a significant event. Susan told me that this experience had led to a shift from a focus upon herself to an appreciation of the '*bigger picture*' which was said to include the '*injustice*' done by psychiatry. Thus, Susan seemed to position meeting other people as contributing to her adopting a more politicised identity. In her narrative, Susan moved away from a personalised critique of her own experiences to talking about 'psychiatry' in general (e.g. '*it's wrong what they do, and I can't believe they've been allowed to do it for so long*').

Again, in the light of meeting others, Susan went on to tell me how her experiences '*could happen to anybody*', which I felt paralleled the construction of herself as a '*normal everyday person walking the streets*'; namely, anybody could be 'taken hostage'. In the excerpt below, I felt Susan was performing identities as both a parent ('*protect my family*') and a citizen ('*protect other people*').

> '*…I'm safer now knowing what I know than I was before…in ignorance, you know, so I can protect my family more hopefully…um, protect other people hopefully…*'

Thus, in a similar way to most of the other participants, it is Susan's own negative construction of psychiatry which is suggested to form the basis of her engagement in her activities. In addition, Susan explicitly identifies as a member of her campaign group, which seemed enacted in the shift in the use of the

pronoun 'I' to 'we' in her narrative. However, Susan constructs herself as occupying a '*unique*' position within the group and this suggested to me a sense of an informal hierarchy amongst the campaigners. Of particular interest here is that Susan's claims to legitimacy, as a campaigner, are different to those of other interviewees; namely, Susan positions her legitimacy as the result of being someone who was not '*crazy*' and who was in hospital for a short period, which contrasts with other interviewees, who claim legitimacy through 'expertise' or 'knowledge' gleaned as a result of experiences of 'mental distress' and substantial past contact with services.

> '*…people might listen to me more because I was only in there [number] days whereas if I'd been in the mental health system for like thirty forty years then people go oh you know she's got no insight, she's you know mentally ill…*'

In the light of holding this '*unique*' position, Susan talked about feeling a '*sense of responsibility*' and that she '*can't let anyone down*'. Drawing on a religious narrative, Susan positions any sacrifices that she has to make as outweighed by her sense of moral duty to others. Indeed, the effect of this was to place Susan in her narrative as someone selfless and self-sacrificing on behalf of others in need.

> '*…I told one woman about it…she said to me, "Oh that was God's will that it happened to you"…she said, "You're so eloquent about it and you can talk about it… that's why it happened to you" you know (3) let it be someone else, <u>let it be someone else</u> but I don't know (6) yeah, I can't walk away from it, it's too big…maybe maybe this is my peak (Susan laughs)… maybe this is what I'm meant to do, I don't know…*'

Susan constructed her engagement in these activities as '*totally not me*' and stated that she had '*surprised myself with the things I've done*', and thus constructs a discontinuity in her identity. Indeed, in this vein, Susan constructed her traditional role of being a parent as '*boring*' and positioned her engagement in campaign activities as giving her a different identity, providing a new (and better) meaning to her life:

'…I've learnt lots of new things…I've been places I've never been before... doing things I've never done before, my God, you know, to think I was just, sort of boring routine, getting up, getting the kids to school, going to work, going back (Susan laughs)… now I'm doing so much more and stimulating the brain…passing information around, thinking about things, and just buzzing.'

Susan talked about currently experiencing difficulties with other members of the campaign group, such as people not following through on agreed tasks. My reading of the excerpt below is that Susan constructs these conflicts to be a result of others in the group being '*so damaged*', which again implicitly positions Susan as part of a not '*damaged*' grouping. However, this '*damage*' is not used by Susan in the traditional psychiatric sense of individual 'pathology' but, instead, reconceptualises it as '*damage*' resulting from psychiatry itself.

'…they're so damaged some of them, really, and you think, those pigs that have done that to them, you know, those pigs (.) cos, you know, sometimes they can, it can annoy me sometimes when they do something wrong…I think well you've gotta think well they've been damaged by psychiatry and it's not their fault you know …'

I felt this construction moved 'blame' (or '*fault*') from the behaviour of these individuals onto psychiatry which appeared to further Susan's anger towards psychiatry (e.g. '*those pigs*'). Arguably, this narrative may thus help to sustain Susan's motivation in the face of difficulties within the group (Poletta, 2002). I thought that this construction might also enable Susan to keep a distinct position amongst the 'us' of her group whilst maintaining a common identification with her group about the 'them' (i.e. psychiatry) (Yuval-Davis, 2006).

2. <u>Catherine</u>

Catherine began by narrating her experiences of growing up and her journey into the psychiatric system. Catherine constructed a 'problem saturated' (White & Epston, 1990) account of herself at that time and, although she talked about

becoming involved in politics and starting at college, a sense of hopelessness and bleakness pervaded this early part of her account . Catherine positioned herself as an active agent in her narrative which had the effect of conjuring up a sense of Catherine holding herself responsible and/or to blame for her life experiences.

> *'…I felt very troubled and didn't understand…why my life was such a mess and why I couldn't make friends…'*

> *'…I just felt that I had no future…my relationships were messed up, I was er lost…I was going out with a really nice boy and that went wrong just because of my own depression and moodiness so I took an overdose…'*

Catherine told me that she went into psychiatric hospital in the 1970s as a young woman following an overdose. Catherine initially storied herself as relatively accepting and non-critical of events which took place, although her use of '*at the time*', say, indicated to me that Catherine now held a different position towards these events. I felt the effect of this benign presentation of events within psychiatry, such as the psychiatrist's advances, was to position Catherine as naïve and vulnerable, a young woman who liked to feel '*special*' which highlighted even further this abuse of power.

> *'…my psychiatrist decided he wanted to have an affair with me…I thought it was great at the time because I felt very special…'*

Catherine told me that she went in and out of hospital a number of times. At this early stage of her narrative, Catherine seemed to position it as a matter of personal choice and responsibility ('*I decided*') whether or not she went back into hospital. This reminded me of Smail's (2005, p. 32) idea of 'magical voluntarism' whereby change is deemed to be a consequence of 'will power' and structural inequalities are backgrounded.

> *'…I took another overdose but…when I was…re-admitted to hospital…I decided I didn't want to go through with that all again…'*

Unlike some of the other participants, Catherine did not perform this departure from psychiatry as a triumphant or cathartic moment, but storied it as leading to a timeless period where she was still '*very depressed*' and '*on hold*'. This sense of being '*on hold*' seemed enacted in her narrative by the way she skipped through ten years of her life – a marriage and birth of children - in around thirty lines of text. Catherine related how, after this '*on hold*' period of ten years, she began to make changes in her life. Catherine constructed this alteration in the way she felt by referring to the possible occurrence of biological changes (e.g. '*regeneration*'), which seemed to function as a way of managing the discontinuity between an '*on hold*' and not '*on hold*' self (c.f. Linde, 1993).

> '*…I'd made this sort of really big decision…that that I'm not going to kill myself so…all there is is to carry on…that's what I did. It wasn't great but I carried on and had two children…*'

> '*…I had this feeling I wanted to get involved with things…feeling I wanted to change the world started to come back…though I don't know whether that was like just kind basically regeneration of the neuro thingies…after the ECT but that's what I think, something happened, began to happen, some kind of re-growth...*'

Catherine told me that she re-engaged with politics and benefitted from different forms of therapy. I read the excerpt below as a powerful story of resistance to dominant societal narratives, such as narratives about women (e.g. '*too emotional*') and mental health (e.g. '*damaged*') (Adame & Knudson, 2007; Fischer, 2000). Arguably, Catherine portrayed how those around her (e.g. women and her therapist) helped her to contest these narratives. She constructs this process as '*enlightening*' and '*life changing*' but also as a '*big*' and '*painful*' process, possibly performing how deeply internalised these narratives had been for her.

> *'…sometimes I thought I was too um damaged or too emotional…to be doing this…I remember one group where I was sitting there…really quietly…and then I started to comment on everybody else…I realised that was really really out of order…so I learned something but it was very painful and I ended up in floods of tears…'*

Catherine told me about meeting other '*activists*' during her degree course and about her experience of joining their group. This is constructed as a '*mind-blowing*' experience and as '*open[ing] up such a lot of possibilities*'. Indeed, in her narrative, Catherine reported how '*[it] all started to come together*' and talked about a return to a '*real self*' through her involvement in different activities, which conjured up for me a sense of 'restitution' in her narrative (c.f. Frank, 2012).

> *'…so it all kind of came together…I was studying, having therapy and being in this group. I was able to pull all those strands together somehow and really make something of it…it was a very quick evolution into an activist...'*

Indeed, at this point in her narrative, Catherine appeared to re-construct her experiences in politicised terms, such as saying that when '*I started finding out about the class system, I began to understand why I'd had such a difficult life*'. Indeed, this shift from a backgrounding to a foregrounding of social inequalities seemed to me to be a significant feature of Catherine's narrative. Catherine narrated the possibilities that this alternative construction opened up, such as '*feel[ing] angry about things*' and '*fight[ing] back*'. This contrasts dramatically with the effects of constructing herself as a '*failure*', associated as it was in her narrative with feelings of '*depression*', '*anxiety*' and a lack of '*dignity*'.

> *'…before that I felt that somehow [it was] my failure but being able to sort of see it in political and mental health terms kind of gave me a concept for my life…which kind of gave me some dignity back, you know, I was able to feel angry about things…but now I could do something about it. I could fight back and I was going to fight back…'*

Catherine talked about how she completed a further higher degree and, indeed, illustrated the resources available to her constructions by drawing on Foucault and Kuhn. Catherine claimed an identity as someone who was '*quite a head person*' and described her research activities. In my reading of the excerpt below, Catherine staged a scene between herself and an unidentified '*you*'. Catherine seemed to draw on different claims to legitimise her views on psychiatry than those used by the other interviewees. Namely, she claims legitimacy as an academic and as someone in touch with the views of *other* 'service users' rather than basing her views solely on her *own* experiences, say. Thereby, she positions the views of 'service users' as a legitimate source of information. The effect of this narrative on me was to delegitimize the assumptions of psychiatry and to contest the '*usefulness*' of the psychiatric '*system*'.

> '*…you can't challenge the system: it's so big and mighty and powerful…but you can if you use that...Foucault discourse argument…it happened for a reason, it didn't have to be that way…but is it still useful? No, no, it's not useful. I can tell you it's not useful because I've talked to service users and they haven't found it useful…*'

Catherine told me that the '*human rights angle has been very important*' to her and talked about the impact of the *UN Convention on the Rights of Persons with Disabilities* (UNCRPD) (1960) upon her as shown in the excerpts below. I felt there was a change again here in that Catherine now constructed her experiences within a broader rights discourse rather than solely in relation to the class system. The theme of 'blame' (or '*fault*') appears again, but the locus of critique and change is shifted away from Catherine (or the 'class system') to wider 'society' (or '*human attitudes*'). I was particularly interested in how Catherine spoke about feeling '*stronger*' with the introduction of the UNCRPD, which arguably constructs the personal and political as intrinsically interconnected for Catherine in her life.

> '*…it somehow validates what I'm trying to do…otherwise you can end up by being caught up in one little thing like user involvement…but there's*

always something much bigger that needs to be done, a whole shift in human attitudes to people with less power…'

'…when you get more rights you realise that you've always had those rights or should have had those rights and that somehow, yeah, it wasn't your fault, you didn't do anything wrong (Catherine laughs)…yes, it has made me feel stronger somehow knowing that the UN CRPD exists…'

3. <u>Edward</u>

'…I was abused, sexually abused, for a lot of years, and it was kinda that's irrelevant, it doesn't matter, it's because you've got a genetic and biological imbalance…'

In reply to my question about how he came to be involved in his activities, Edward linked a psychiatric construction of his experiences of '*voice hearing*' as a '*genetic and biological imbalance*' with a lack of interest by mental health practitioners in his experiences of abuse.

Indeed, by linking his experiences of '*abuse*' to '*voices*' in his narrative, Edward seemed to implicitly contest a psychiatric explanation of such experiences as 'chemical imbalances' (Adame & Knudson, 2007). I noticed how Edward switched from the first-person ('*I was abused*') to the second-person ('*you've got*'), which seemed to enact the 'silencing' 'voice' of those within psychiatry to whom, he told me later, he had been '*ready to disclose*' his experiences of abuse (c.f. Dillon & May, 2002).

Edward positions himself as in the '*throws of madness*' when he attended a Hearing Voices Network workshop at which he described talking to a psychologist:

'…I just said, you know, "Can I ask you a question? I'm a voice hearer and um nobody understands me it means I must be mad…when do I get my diagnosis of insanity?"…he looked me in the face and just said, "Edward,

just because you hear voices doesn't mean you're insane…it's society that
doesn't understand."…'

Edward positions being given this alternative construction of 'voice hearing' as a revelatory moment in his narrative (e.g. '*it began to make sense*'). I heard Edward give a similar account at a conference and wondered whether it served a powerful function for other survivors. Namely, Edward implicitly contests the dominant narrative connecting '*voices*' and '*madness*' whilst also providing survivors with an alternative understanding of their experiences. This is evocatively enacted by the way in which Edward claims an identity of someone who is '*insane*' in his story and then has this identity rebutted by the psychologist.

Edward talked about how this psychologist opened '*lots of doors*' for him which '*made it possible*' for him to meet a number of high-profile '*radical*' professionals and to occupy the positions he does now. Indeed, Edward's account illustrated the breadth of narrative resources available to his construction of identity. For instance, Edward's critiques of psychiatry often seemed to draw on broader critical psychiatry and critical psychology narratives, such as how '*schizophrenia does not exist*' (c.f. Boyle, 2002) or how '*fear*' underpins '*paranoia*' say (c.f. Johnson, 2009).

However, despite Edward positioning his affiliations with more '*radical*' professionals as positive, Edward constructs a position which makes a clear demarcation between 'us' and 'them' (Yuval-Davis, 2006, p. 203) and, in this process, positions himself alongside other survivors. Indeed, throughout his narrative, Edward consistently contested the taking-for-granted of the superiority of professional 'expertise'. For instance, my reading of the excerpt below is that Edward contests (and subverts) the traditional idea that '*value*' (and maybe 'expertise') is linked to qualifications and, arguably, constructs the idea that his '*value*' derives from his experience as a non-professional.

> *'…I only had to submit one more paper and I would have got my [degree]*
> *but I suddenly realised this is not what I want <Mmm> I'm losing my real*
> *value and my identity so I refused to submit the last paper….'*

Edward talked about how he had begun to '*do my narrative*' at universities fourteen years previously and how, at that time, there had been a '*culture*' of being treated like a '*pet loony*'. Edward commented on how this had changed over time and how he had begun to be invited to feed into curricula at universities. Indeed, in the excerpt below, Edward described giving a talk about alternatives approaches to 'voice hearing' and a psychiatrist approaching him to ask for his help. This passage reminded me of the changes mentioned in the Introduction whereby survivors were seen as possessing a marketable form of 'knowledge' and 'expertise' (Crossley, 2006, p. 203) and psychiatric expertise was being questioned (Crossley & Crossley, 2001). In this way, Edward positions himself as possessing '*ideas*' (or 'knowledge' and 'expertise') whilst the psychiatrist is positioned as repenting for his actions and desiring this survivor's 'expertise'.

> '*…and he [the psychiatrist] says [to me], "These ideas, I like them…I've destroyed so many lives with haloperidol and I retire in a few years, I want to build that legacy, can you help me build that legacy?"…*'

In a similar way to other participants, Edward described a closely connected personal and moral investment in pursuing his activities to challenge psychiatry:

> *Edward: '…I want to be seen for what I do….I want to be seen as Edward that'll rattle a few cages, will go the extra mile, and this guy wants change, change for the better <Mmm> and change for what the person wants not what he wants. That's the important thing.*
>
> *Jonathan: And where does that come from is is is that/*
>
> *Edward: I think it's through my, the injustices that I suffered <Yeah, Ok> more than anything, you know, I don't want anybody to go through what I went through as a child, you know, nobody should have to eat their own faeces…'*

This 'moral calling' is connected with his own personal experiences of abuse that are now constructed in politicised terms (i.e. '*injustices*'). I was struck in the excerpt below by the way in which Edward aligns the notion of '*duty of care*' with being '*proper human beings*' rather something which is done out of professional duty, say. Thus, as in Susan's account, Edward positions himself as finding a new (and more fulfilling) meaning to being '*human*' and way of gaining personal satisfaction in his life.

> '*…we've got a duty of care not through the system but through being proper human beings…somebody helped us we deserve to help them and I kinda got a real anger to change again…*'

Edward told me that he had almost '*walk[ed] away*' in the past. However, Edward gave me an account of visiting a psychiatric hospital in '*God's last place*' in England. Edward said that it had '*reignited the flame*' when he saw how people were being treated and that he had wondered to himself '*who's going to reach them*' if he walked away. Edward talked about helping the nurses there and said '*that's whats it about, the grassroots*'. As mentioned in the Introduction, I was reminded here about the way in which the types of role occupied by Edward are argued in the literature to have drawn people away from the 'activist' role (Crossley, 2006, p. 204). As such, I wondered if Edward's narrative was addressing such tensions, resisting a notion of his '*passion*' having waned, say, and claiming an identity as someone who is still remaining true to his values and '*in it for change*'.

4. Emily

> '*…I guess a good place start though is probably, um, back to the day when I kind of believed in all of the system stuff and the illness stuff…*'

Emily began by describing how she became involved in activism with the comment above. Emily's use of '*back to the day*' immediately indicated that she now occupied a different position in relation to the '*system*' and '*illness*'. Indeed, a feature of Emily's narrative was how she claimed, and then resisted, previous

identities given to her whilst within psychiatry. For instance, in the excerpt below, Emily claims an identity as a '*patient*' and positions herself as accepting of the way in which the staff responded to her distress. I felt accounts such as this served, in a paradoxical way, to powerfully critique psychiatry as it left me, Emily's audience, asking questions in my mind on Emily's behalf, such as, 'But how can being treated badly in hospital be right?'

> *'…I like went into hospital, thought this feels about right, I'm treated badly, um, people aren't asking about my history, it's irrelevant anyway because it's an illness and, um, I'm a patient <Mmm> I need people to take care of me and I just yeah found an affinity with that way of seeing things…'*

Emily gave the metaphor below to describe a progressive journey of reaching a point where she does not '*believe in schizophrenia, I don't believe I'm ill, I don't believe I was ever ill*'. Whilst the metaphor below initially conjured up for me a fairly tale image, Emily resisted this interpretation and stated that her journey had been '*messy*' and '*confusing*' and that there had been no '*magic*' about the changes in her life. I felt one effect of this narrative was to contest the supposed 'magic bullets' of psychiatry (Whitaker, 2005) or the 'technical fixes' (or '*tricks*' in Emily's words) of psychology (Pilgrim, Rogers, & Bentall, 2009).

> '…*imagine you're in this room…you don't really realise that those sort of rectangular things are doors…someone opens it or you open it a little bit…there's another room…and you still think, 'Wow I've found everything' and then you find another door and another door…and then eventually at some point you found the door to the outside and you go, 'Wow you mean there's grass'….I haven't been everywhere so there's still a lot of growing to do….'*

In particular, rather than citing moments of 'realisation' as other participants did in their narratives, I felt Emily storied her journey in terms of 'steps forwards' followed by 'steps backwards' and/or new challenges to face, but with an increased sense of possibility at each step. For instance, consider the excerpt below which refers to an occasion when Emily heard Ron Coleman talk at a

Hearing Voices Network event. I heard Emily give a similar story at a conference and wondered if this was a narrative with which other survivors could identify and might serve to 'normalise' setbacks (Poletta, 2002), as expressed in the idiom, 'two steps forward, one step back'.

> '…this little kind of like glowy hope ember thing just got ignited in me…and I thought well maybe there's another way…it got squished down very quickly because years of trauma and the psychiatric system don't exactly foster that hope but it was there…'

Emily described these 'steps forwards' in a number of ways in her narrative (e.g. '*grow[ing]*', '*finding myself*', becoming '*human*' and '*autonom[y]*'). Notably, Emily seemed to construct such changes as occurring in tandem with a process of distancing herself from psychiatry (e.g. medication, believing in 'schizophrenia' and the use of psychiatric services). Indeed, Emily told me about the way in which the language and practice of psychiatry kept her '*stuck*' and, conversely, how being treated like a '*human*' and as an '*equal*', by voluntary sector professionals and other survivors, helped her to become 'unstuck' or '*free-er*' to use Emily's words. This construction of becoming '*free-er*' outside of psychiatry reminded me of Dillon's (2011, p. 150) comment about how 'real recovery is only possible outside of traditional psychiatry'.

Emily cited taking part in a Hearing Voices Group as a significant event in becoming involved in activism. As per the excerpt below, Emily storied how being part of this group helped her to find her '*humanity*' and, simultaneously, to recognise the humanity of others and the '*injustice*' of their suffering. For me, there was a sense of a shift here in that Emily constructed her (and others') experiences in more politicised terms compared to earlier in her narrative.

> '…they helped me become a human…and find my humanity and I guess being with those group of people I also saw the injustice of the fact that those were humans in the group that had been treated really badly…'

However, at the same time, Emily resists a simple altruistic reading of her motivation for engaging in her activities. Emily illustrates this point by critiquing Judith Herman's 'survivor mission' (1997, p. 157):

> *'…I know it's talked about sometimes this idea of a survivor mission which sounds like we're kinda like this, like it's not about us, it's about other people, but I think there's a personal investment in this… because you know it's part of my journey, my life and everything and I enjoy it…'*

A particular feature of Emily's narrative was her reference to the notion of '*truth*' and the way in which she explicitly positioned psychiatric assumptions as a '*lie*' (e.g. 'voice hearing' as an *'illness'*). This construction also seemed reflected in how Emily spoke about how the alternatives to the psychiatric system, in which she is involved, are '*normal,*' '*common sense*' and '*sensible*' in comparison to psychiatric practices which she posited as '*weird*'.

> *'…it's really hard to live without meds initially…but it was also really freeing…it was a real struggle but it was very empowering and felt very real and honest that I think I'd been lacking in my journey that honesty and truth…'*

This construction of psychiatry as a '*lie*' also seemed to parallel how Emily constructed her own identity during her narrative. For instance, Emily refers to a time when she was working in her job whilst still believing in 'schizophrenia' and how this had felt like a '*dirty secret*' to her, almost as if Emily was living a '*lie*'. With this in mind, I wondered if Emily's narrative could also be conceptualised as a process of disowning the '*lies*' of psychiatry, say, and finding 'truths', such as '*it's not like you're well and ill, you're just you and you've got different parts and you've got to look after all those parts'*.

This notion of '*truth*' re-emerged in the context of Emily talking about some of the challenges she faces in her job, such as working with other professionals, as illustrated in the excerpt below. Emily appears to draw on this notion of truth to shift 'blame' away from individual professionals' behaviour onto the '*system*' and

'society'. Indeed, Emily explicitly comments on the effect of this construction in her narrative as enabling her to '*do my job*'.

> '*…professionals, they're not meaning to do it, they don't actually know the truth either so it's a collective blindness to the truth but there's also this system wide societal thing that needs changing…so it's, uh, yeah, all of that really helped me get get to where I am now...*'

However, Emily wondered whether she is '*radical enough*' and if she should be '*shouting from the rooftops*' instead. Indeed, in the light of Emily's construction about the importance of living a '*truth*', I wondered if this comment about being '*radical enough*' might be interpreted, in this instance, as Emily's concern about whether she is being 'truthful enough'. Namely, is achieving a balanced position 'good enough' or is it equivalent to living a '*lie*'?

5. Geoff

Geoff began by narrating how he had a '*breakdown*' whilst he was a student and had gone into a psychiatric unit in the early 1980s. Geoff constructs his own experience on the psychiatric unit as relatively benign, commenting on how he was '*allowed*' not to take medication and was not given a diagnosis. Nonetheless, Geoff positions himself as someone who retains a critical view of the psychiatric system, such as commenting that similar practice nowadays would be considered '*negligent*'.

> '*…I went in voluntarily and I said I didn't want to take any drugs…and I was allowed to do that…fifteen years later…I think that would have been unheard of on wards and stuff…*'

Geoff told me about how he got onto the '*therapy trajectory*' and about his experience when training to be a creative therapist. Consider the excerpt below which highlights a theme which I felt ran through Geoff's account; namely, the way in which Geoff positions himself as occupying a qualitatively different space to those who do not have experience of distress or psychiatry, say.

'…there was quite a struggle for me around the whole thing of my identity…I was…the only person as far as I knew on our course who'd actually been in hospital…had been on that kind of hard edge. I mean people had had different kinds of struggles but, um, and it kind of really informed my work…'

Geoff gave me an account of his experiences of working in mainstream services as a creative therapy student. Indeed, in his narrative, I felt Geoff constructed a position in which he distanced himself from an alignment with psychiatric services and practices. For instance, in the excerpt below, Geoff places himself as a witness to events and conversations between people on the ward. In turn, this positioned me, his audience, as similarly a witness to events, allowing me to share in the '*disturbing*' scenes he observed. The way Geoff left his own voice out of this account seemed to enact a sense of powerlessness, a feeling echoed later when Geoff expressed pessimism about producing change by working within mainstream services. Indeed, Geoff drew on a metaphor of Nazi Germany which powerfully served to illustrate this pessimism. This also seemed to function in his narrative as a rationale for choosing not to practice in mainstream services and for beginning to engage with survivor groups during his training to be a creative therapist.

'…I remember this…oldish couple…"Doctor, we want to understand what this is about"…"Well, some people have a depressive illness"…and they coerced her into having ECT… and kind of laughed about it when they'd gone out about her resistance to it…kind of a chuckle…'

'...it's sort of extreme but it was like what I was expected to do was to be as a…therapist in that kind of situation was like being a manicurist in a gas chamber <Mmm> in a concentration camp…fiddling at the edges…the whole system was so destructive…'

As in the excerpt above, Geoff often drew on war-like metaphors, such as likening the psychiatric system to a '*concentration camp*' and its practice to '*indoctrination*' as well as his references to older survivors as '*veterans*'. This

evoked for me an image of a 'battle' between the psychiatric system and survivors, with Geoff positioning himself as a fighter on the 'side' of survivors.

Like other participants, Geoff talked to me about meeting other survivors as a significant event for him. Indeed, Geoff stated that his '*activism*' started '*probably from the time after college and getting involved in user groups*'. Quoting Erving Goffman (e.g. 1963), Geoff told me how participating in survivor groups helped him to construct his identity in a '*positive way*' rather than as '*spoiled*'. Geoff talked about how for him this positive identity was encapsulated in the term 'survivor'.

> '*…I think one of the things that sort sort of survivor stuff gave me was that really positive sort of idea and why I kind of like personally….the term survivor…it's it's a positive identity of our of our choosing…the user thing is what they call us really…*'

Note Geoff's use of '*our*' and '*they*' in the excerpt above that draws a line between the 'us' and the 'them' (Yuval-Davis, 2006, p. 203), which again has the effect of positioning Geoff on the side of survivors. Indeed, as in the excerpt below, Geoff arguably constructs his experiences as giving him particular 'knowledge' or 'expertise' which is inaccessible to those who have not been through similar experiences. This may have the effect of minimising within-group difference and strengthening the demarcation between 'us' and 'them', creating a 'united front against a common enemy' (Harper & Speed, 2012, p. 17). This seemed reminiscent of a 'politics of autonomy' which had been advocated within second-wave feminism (Warner, 2009).

> '*…I can connect to certain things…someone's going through. It will be different to what I've gone through but I can understand someone in a way that somebody who hasn't been there won't ever understand…*'

Geoff told me about how his initial activism involved developing information for survivors. Although Geoff resists an identity as a Marxist (e.g. '*I'm not really a strict Marxist or anything*'), Geoff frames these activities in Marxist terms (e.g.

'*owning the means of production*') and explicitly positions this as a way of contesting the idea of survivors as '*passive recipients*'.

> *'…that's what took me into kind of trying to give information out and working in a kind of political way…I'm not really a strict Marxist or anything (Geoff laughing) but owning the means of production…actually owning things ourselves and doing things ourselves…and doing things beyond the system…'*

Geoff talked about his work within '*user run*' services and, indeed, told me that '*…the important thing was…we were user run…this meant like all <u>all</u> of our committee…had experience of using mental health services…'* Thus, Geoff appeared to advocate more 'separatist' strategies' or a 'politics of autonomy' (Warner, 2009), exemplified by his description of '*the important thing*' being that '*we were user run*' and his emphasis on the '*<u>all</u>*'. Indeed, Geoff described having been inspired by Chamberlin's book (1978) *On Our Own* and, arguably, Geoff's narrative drew on similar ideas to 'patient controlled alternatives', which also parallels the call for women-only services within the feminist movement (Chamberlin, 1978; Warner, 2009).

Geoff directed his critique both at the psychiatric '*system*' and '*society*'. Indeed, in relation to the latter, I felt Geoff spoke as a 'citizen' at times, illustrated by his use of '*us*' in the excerpt below. Arguably, adopting this position enabled Geoff to speak to concerns typically viewed as being outside of the remit of 'mental health' (e.g. societal values).

> *'…the values that are oppressive and all those kind of things the the values that make us be be dissatisfied with ourselves, you know, is what kind of keeps this kind of this kind of system that we get running…'*

Geoff talked about leaving his previous post and now working within a mental health charity. In his narrative, Geoff seemed to negotiate the meaning of this change and of his involvement in this organisation. He gave an account of challenges he faced in his personal life and difficulties in his previous post, which

he constructed as leaving him feeling '*burnt out*' and '*disillusioned*'. Geoff talked about how things had '*bl[own] up in my face*' and also gave the metaphor below to describe this process to me:

> '…*I just kept going, I was doing something really good, maybe I was driving this ambulance across the desert… carrying people part of the way, whatever, as well as myself but I got to the end of it and I had a…total physical collapse and it's a bit like that mentally for me…*'

I felt that Geoff was drawing on metaphors of 'war' again here. Geoff commented on how he would prefer not to be working in his current post because of its '*top-down*' approach but is '*biding his time…working to get some money*'. However, Geoff said that his job was '*still on side of the angels*'. Thus, to draw on this 'war' metaphor, I felt Geoff was positioning himself as 'worn down' by the battle and needing time away to gather his 'reserves', and/or as 'retreating', but neither joining the 'enemy' nor 'deserting' the 'battle'. In adopting these positions, I felt Geoff was able to maintain his identity as someone remaining in favour of '*user run*' services.

In addition, Geoff commented on being in a '*middle age crisis*' and appeared to be negotiating in his narrative whether he would continue into '*something new*' in terms of activism or whether he has '*done his bit*' and would be better off changing direction:

> '…*[I] keep thinking of someone…[she] got out of mental health and I kinda wonder whether, um, there's a part of me that's…a bit disillusioned with with um or maybe I've done my bit…*'

Notably, in this regard, an important feature of Geoff's narrative to me was the way in which he made sense of this struggle over which direction to take in his life. Firstly, Geoff drew on a language of the 'self' (c.f. Crossley & Crossley, 2001; Rose, 1996), by saying, for example, '*knowing myself enough*' or '*it's a whole thing of how I talk to myself*', and talked about the usefulness of drawing on self-help techniques (e.g. mindfulness meditation). Secondly, I was struck by Geoff's

understanding of a 'survivor' as someone who is '*surviving*'. I wondered if this narrative introduced a sense of moving forward, which allowed for occasional setbacks and helped to make meaning of the 'crises' that Geoff reported to be experiencing (Poletta, 2002), similar to the expression, 'life is a journey'. Notably, this contrasts with alternative narratives which suppose an 'end point' (e.g. 'cure', 'recovered' or 'survived').

> *'…because some people say, "Oh where does that leave people who are still using services?", but it is you are surviving…not I have survived…'*

6. Alice

In response to my question about how she became involved in her activities, Alice began with an evocative account of experiences of '*extreme trauma*' as a child, as well as '*physical*' and '*sexual assault*' as an undergraduate. Alice constructed herself as a '*shattered child that grew up into a crushed and sort of devastated adult*' and drew on powerful metaphors of the 'undead' and 'destruction' (e.g. '*torn apart*', '*dismembered*') to describe this state to me.

> *'…I think I'd done what a lot of survivors do which is to try to bury the past and I had essentially buried it alive…it was almost like all that horror and shame and fear and grief and loss were all struggling and fighting to get out…'*

Alice talked about going into psychiatric hospital as an adolescent. She appeared to construct a narrative of these experiences which functioned to critique the psychiatric system. One way in which Alice did this was by describing herself as someone who '*initially believed*' in the '*psychiatric system*' and her diagnosis of '*schizophrenia*'. This was then followed by a description of the futility of such beliefs, which had the effect on me as the listener of undermining psychiatry's practices and claims to legitimacy.

> *'…there was certainly actually a large part [of me] that initially believed it because it's almost like the sound of science…and of course it would eventually transpire that none of the interventions which primarily was medication made absolutely no difference at all…'*

As with many of the other interviewees' accounts, Alice constructed her account in abstract, general terms, such as referring to '*psychiatry*' and the '*system*', as opposed to offering a more personalised critique of particular individuals (e.g. psychiatrists, nurses etc). Arguably, this has the effect of resisting an interpretation of the experiences presented as 'exceptions'.

Alice stories her journey out of this position as influenced by seeing a radical psychiatrist and reading a book he gave her, '*Accepting Voices'* by Romme and Escher (1993). Alice constructed this part of her journey, and the meaning of these events, by drawing upon religious metaphors in her narrative.

> '*…and it was like, you know, wandering in the wilderness for years and then, you know, as if somebody holds out their hand to you and says, "Come with me, I will lead, I <u>will</u> show you a way out of this"…*'

Indeed, Alice described it as a '*revelation*' to be given the idea of '*voice hearing*' as a '*meaningful experience*'. This was storied as a moment of enlightenment and reminded me of the biblical text, 'I am the truth, the light and the way' (John 14:6). Alice positions this construction as leading her to '*engage with [the voices]…[and] to take responsibility for my recovery*'. Alice moves from a powerless onlooker in her narrative at this point to claiming a more agentic identity, such as saying, '*I remember sort of feeling…if I can't find a way out <Mmm> I'll bloody well make a way out…*'

I heard Alice give a similar narrative at a conference and wondered whether her narrative may have particular effects on other survivors, such as also giving them hope and belief in there being a *'way out',* by offering this alternative construction of their experiences.

However, although Alice's narrative initially conjured up an image for me of a 'miracle', Alice contested such readings, by describing, for instance, how she only had the '*raw materials*' and how it '*took a long time*' for changes in her life to take place. Alice gives particular significance in her narrative to meeting '*critical*' professionals and individuals within the Hearing Voices Network. For instance, Alice gave me an account of meeting one radical professional:

> '…[I'd] been conditioned to believe that this was a terrible shameful, awful, disabling thing and you're either to be pitied or feared and here was somebody, you know, basically saying "Fuck that! (Jonathan laughing)…reclaim this experience"...'

In fact, I felt that Alice contested a construction of herself as someone to be '*pitied*' or '*feared*' and, indeed, this struggle over meanings seemed to me to form a particularly prominent feature of Alice's narrative. For instance, in the excerpt below, Alice rejects an identity of being '*mentally ill*' and instead claims an identity as a '*survivor*'. Alice constructs the implications of this latter identity as gaining '*admiration*' and '*respect*' from others rather than '*fear*' and '*discrimination*' that accompany a '*mentally ill*' identity.

I felt this paralleled Alice's comment later in her narrative about how one's '*story is a gift for others*' and the importance of '*public truth telling*' which reminded me of the phrase 'speaking truth to power'. Thus, Alice aligns her story with being a '*gift*' and/or symbolically representing a '*truth*', rather than representing a '*terrible, shameful, awful, disabling thing*' and/or something 'irrational' (Blackman, 2012). I felt that this was an important aspect because Alice's narrative is both a private one but, also, when used in public settings, may give hope and inspiration to others.

> '…I'm sort of speaking to the media and saying, "Yeah, you know, I've had these intense experiences but, you know, I'm not mentally ill, um, I'm a survivor"…therefore rather than sort of being…feared or discriminated against I've been kind of really celebrated in a way…'

Alice illustrates the narrative resources open to her through her contacts and reading; for example, she quotes and references authors such as Marius Romme, Judith Herman, John Read and Jacqui Dillon throughout her narrative. By drawing upon her own experience as well as this literature, Alice seemed to me to interweave her identities as a survivor and as an academic, and drew on both these identities to claim legitimacy for her views.

> *'…its been very heartening actually how positive the response has always been… and I guess in a way that does correspond to what research says…for instance, John Read has done a lot of work on this, that the anti-stigma campaign's that go by that mental illness is an illness like any other approach simply do not work…'*

Alice claims a politicised identity in her narrative, identifying with the politicised title of '*survivor activist*' and constructs experiences such as hers as '*human rights abuses*'. Indeed, drawing on Herman's (1997) concept of the 'survivor mission', Alice posits how constructing her experiences in this politicised way is a motivational factor in her work.

> *'…it's almost transcending your own personal tragedy by making it a basis for social and political action...'*

Also, note in the excerpt below Alice's use of the pronoun '*us*', through which she seems to position herself primarily as a citizen and, indeed, in her narrative, talks about a need to '*[get] this message to people who normally would probably never come into contact with it*'. Interestingly, in the second excerpt, Alice constructs her engagement in activism in terms of 'morals', which is explicitly contrasted with '*scientific models*' of distress.

> *'…on a sort of wider level seeing how mental health isn't just this niche concern of psychiatry and allied professions it it's a responsibility of us all, um, in terms of societies which…are unjust…'*

> *'…all victimisers and perpetrators ask is that the bystander…looks the other way…people who survive extreme distress… need…to have somebody bear witness to it…scientific models of distress offer a very incomplete response to what is fundamentally a moral task…'*

Alice constructed her own '*personal journey*' and her '*activism*' as interlinked. Alice said she had learned through '*activism*' about how to '*live well*' and had gained through it a sense of '*status*' and was '*in demand*' and '*valued*'. Indeed, Alice told me she felt that these factors helped her to manage in the '*other world*' of university when she later returned to start another degree. I was reminded here of Geoff's reference to Goffman's (1963) concept of a 'spoiled identity'. Similarly to Geoff, Alice positioned her involvement in the survivor movement as enabling her to construct a more 'positive identity' for herself.

> *'…through the activism work I was doing, the people I was meeting, I was learning so much more about just how to live well in a sense…I'm almost certain really I wouldn't have got through the degree without it…'*

I asked Alice if the way in which she is involved in her activities had changed over time and she drew on psychodynamic ideas, such as '*re-enactment*' and '*defence[s]*', to explain this to me, as shown in the excerpt below. My reading of this is that Alice constructs a position to indicate that she has overcome such '*defence[s]*', say.

> *'…I think there was a way I needed [the audience] to cry because I couldn't cry myself…it was almost like re-enacting it …[I] no longer need an audience to do that for me…it feels much more equitable…'*

I was reminded here of the literature base and the way in which 'activists' have been portrayed as 'sometimes pathological, usually irrational, and always deviant' (Andrews, 1991, p. 19). Arguably, this is doubly so in the case of '*survivor activists*' with whom Alice identifies. My reading of Alice's narrative is that it contests such an interpretation being made about her.

Lastly, Alice narrated some of the difficulties in her work, including '*reliving it*' and how '*it's tiring*' and can '*really just take over everything*', with most of her friends said to be like her - professionals, critical of psychiatry, or survivors. Alice talked about wanting to make more time for '*just joy and pleasure and fun*'. In light of Alice's construction of her motivations (e.g. a moral duty) and activism as a 'survivor mission', I wondered, 'How can one live one's life outside of activism without feeling as if one has become a bystander to societal injustices?'

7. <u>Sarah</u>

Sarah began by describing factors contributing to her '*psychosis*' as a teenager. She seemed to implicitly draw on a stress-vulnerability model (Zubin & Spring, 1977), such as talking about an '*extremely abusive childhoo*d', a confrontation at school leaving her '*no kind of place to feel safe*' and then her thyroid gland becoming under active '*…which can trigger psychosis*'.

Sarah positions an assessment by a psychiatrist as counter-productive and proceeded by describing being '*lost*' for fifteen years. Indeed, Sarah skipped from fourteen to thirty years-old in three lines of text, and described making suicide attempts, self-harming and repeatedly going into hospital.

> '*...[the psychiatrist] just made me feel really bad about, you know, myself and I didn't tell her what was happening to me and so I kind of withdrew withdrew further, um, and from the ages of fourteen to thirty I was just lost really…*'

Sarah identified becoming thirty years-old as a '*turning point*' in her life, which signalled a move in her narrative from constructing herself as reliant upon psychiatry ('*waiting for psychiatry to cure cure me*') to claiming a more potent and agentic identity ('*I have to take some responsibility*'). In a similar way to Catherine, Sarah stories herself as the agent of change ('*I just decided*'). Sarah reflected on how one needs to '*step out of your comfort zone*' and take '*risks*' to reach one's '*absolute potential*'. This seemed to me to be drawing upon a cultural narrative of 'choosing risk in place of safety…facing danger to discover strength'

(Reissman, 2002, p. 10). Indeed, Sarah appeared to position reliance upon the psychiatric system as futile through her ironic use of '*if I'm waiting…I'm going to wait a long time*'.

> '*…so I just decided to you know live or die like in order to live I knew I had to make changes <Mmm> because I said to myself if I'm waiting for psychiatry to cure cure me I'm going to wait a long time, I have to take some responsibility to get myself better…*'

Thus, in her narrative, I felt Sarah performed differing identities, one of which was, and another which was not, reliant upon psychiatry. Sarah performs how taking up this latter identity led to a 're-connecting' with characteristics (e.g. '*creativity*', '*extroversion*'). Thus, unlike other participants who described connecting with something 'new' (e.g. alternative understandings of 'voice hearing'), Sarah's narrative was more akin to a 'restitution' than a 'quest' narrative (c.f. Frank, 2012).

> '*…[I] became quiet and you know isolated and introverted but actually I don't think that was me…as a two-year old [I was] very extroverted and loud…and that kind of got suppressed…being thirty was a re-birth of who I already was ….*'

As Sarah positioned herself as becoming more self-reliant in her narrative, she no longer articulated herself in medicalised language (e.g. '*psychotic', 'paranoid*' vs. '*creative', 'curious*'). As a result, I felt Sarah's narrative constructed how becoming self-reliant (and/or less reliant upon psychiatry) led to a process of 'decolonisation' (Dillon & May, 2002) or, in Sarah's words, '*shedding a lot of skins that weren't mine really*'.

Sarah cited how re-connecting with her '*creativity*' led to her writing a book about her life which, in turn, coincided with her wish to get involved in challenging the '*mental health system*'. In regards to this, Sarah talked about her life experiences, such as being the victim of sexual assault on a psychiatric ward, as well as seeing '*horrible*' things happen to other people in hospital. Sarah positioned a

refusal to be a 'bystander' to others' '*suffering*' ('*one of the people who…watches*') as another characteristic which was '*already part of me*', and gave an account of how she used to '*stand up to someone else being bullied*' at school. In a similar way to other interviewees, Sarah intertwined this moral calling to engage in activism with a sense of personal fulfilment; namely, '*campaigning and challenging*' was positioned as one way Sarah was '*going to make my life story amazing*'.

> '*…that book not only changed my life in a kind of practical sense…[but] reading it was the first time I kind of felt empathy for myself…I just realised I'm going to make my story life story amazing from here on now so that's probably…[what] triggered interest in campaigning and challenging because I wasn't going to be one of the people who (.) who watches brutal things and says nothing…*'

Sarah talked about the way in which meeting people from a group inspired by a punk/anarchist philosophy was a significant event for her, both personally and in terms of getting involved in her activism:

> '*…I realised I wasn't the only person who felt the way I did, didn't feel as isolated, you know….I mean I realised I can never be normal and actually that's something I'm very proud of…*'

Indeed, Sarah claims '*madness*' as a preferred identity in her narrative. In the passage below, Sarah performs this struggle over meanings about '*madness*' in the context of a conversation, with her local mental health service, about putting on an event with '*madness*' in the title. Sarah positions herself as a representative of '*mad*' people, pitted against the '*they*' of the generalised '*mental health system*' and positions me, her audience, as a witness to an essentially moral story. In my reading, the effect of this excerpt is to contest pathologised readings of '*madness*' and to claim '*madness*' as a valid identity choice, which must be respected by other people.

> '…[They said] "Oh, you can't use the word madness". I said "Why not?" [They said] "You know, it's demeaning". I said "For whom?! Um, if somebody identifies as mad who are you to tell them that they're not…"'

Sarah described to me her past involvement with mental health trusts (e.g. teaching students) and national charities on 'service user' projects. Sarah referred to this as '*normal*' as opposed to '*in your face*' campaigning and positioned herself as in favour of the latter. In my reading, Sarah negotiated the meaning of her involvement in '*normal*' campaigning and, in particular, resisted a construction of herself as someone who is '*tokenistic*'. For instance, she emphasised her lack of identification with '*normal*' campaigning and referred to being '*blacklisted*' from working with particular charities for speaking out against them. Indeed, Sarah described being *'quite restricted'* now in employment opportunities within '*mental health*' because of her '*big mouth*'.

> '…I do the normal campaigning which is a lot of sitting around in in meetings you know trying to stay awake…my brain is not stimulated by sitting in meetings, my brain is stimulated by action…'

However, in the face of these setbacks, Sarah positioned herself as someone who was not perturbed and was driven forwards by a sense of moral purpose. Indeed, Sarah said these setbacks fitted with her expectations that her life would be '*zig zagging*' and how her duty to others trumped other concerns.

> '…I don't see life as pursuing a career and having a mortgage…life is to me actually being the best person, most compassionate person…and making sure that…other people don't suffer…'

8. Joseph

> '…I had a breakdown and ended up being treated in psychiatric hospital…that whole experience…affected me in quite a number of ways…it opened my eyes to what…seemed like quite a controlling approach to care…'

In response to asking Joseph about how he became involved in his activities, he began with the comment above and talked briefly about his stay in psychiatric hospital. Unlike some of the other participants, who described a process of others helping to 'open their eyes' to psychiatric practice, Joseph positions himself as emerging from psychiatry with an already theorised account of his experiences (e.g. he conceptualised it as '*quite a controlling approach to care*'). In a similar vein, Joseph constructed himself as a 'rebel' and, in terms of Joseph's journey into activism, seemed to draw on a narrative of being an 'independent, self-sufficient and determining man' (Reissman, 2002, p. 11).

> *'…a lot of people who do best…are quite rebellious…so if you're rebellious you can perhaps resist very top-down approaches to your management so luckily I was a bit rebellious…'*

Joseph describes how the survivor movement at the time '*didn't seem like something I could get involved in directly*'. For instance, Joseph comments on how '*I never really saw myself as mentally ill*' and contrasts this with people he met in the movement who, he said, accepted that they had a '*mental illness*'. Thus, in comparing himself to others, Joseph constructed himself in his narrative as not accepting psychiatric understandings of his experiences and being an outsider to the survivor movement. In his narrative, Joseph linked undertaking his professional studies with a desire to gain a 'voice'.

> *'…I saw [my studies] as partly a way to get a voice…becoming more sophisticated and learning not to get angry and using strategies that people would then listen to me…'*

Indeed, in the excerpt below, Joseph gave a story about advocating for a friend at a tribunal, where I felt that Joseph portrayed the way in which he drew upon his position as a student to claim legitimacy for his views. This is unique amongst the participants who often (but not exclusively) claimed legitimacy through their 'expertise' by virtue of identifying as survivors, say.

'…I went into the thing and said I know that you know that I've been a patient, he doesn't want me to say I've been a patient but I have, I'm studying [subject], what you're doing here is wrong…'

Particularly notable in Joseph's narrative was how he drew on metaphors of espionage to claim an identity as a '*spy*' during his studies and how '*I wasn't an activist, I wasn't active, I was a sleeper*'. This brought up images of a fifth columnist or 'Trojan horse' to my mind and the idea that as a spy/sleeper one could be both in 'the system' but not of it. Thus, taking Joseph's narrative as a whole, I wondered if this construction served to maintain his identity as a '*rebel*' during his studies and contest an identity of being co-opted into the 'mainstream', say.

There were a number of features of Joseph's narrative which seemed to accord with this construction of himself as a '*spy*' and '*sleeper*'. Firstly, Joseph commented on how he waited until he had '*proved myself as a competent practitioner*' before revealing his identity as an '*ex-patient*'. Indeed, this makes sense as a '*spy*' because such a person would need to be careful about when and to whom one reveals one's 'true' identity. In addition, unlike the majority of other interviewees, Joseph articulated a point at which he became an '*activist*'. Arguably, this reflects the construction of himself as a 'sleeper'; namely, one can only be either 'inactive' (a '*sleeper*') or 'active' (an '*activist*'). Joseph said that this moment occurred following the public disclosure of his psychiatric background. Joseph described this disclosure, at a conference, as a cathartic moment and, indeed, it seemed reminiscent of a 'coming out' story.

'…it was very powerful for me emotionally so I cried a lot (Joseph laughs) including in the talk and I don't cry very much…bringing in that vulnerability in was quite powerful for me individually…getting that witnessed and acknowledged, my story really…"

In his narrative, Joseph reflected on his initial involvement in activism and narrated his journey into joining networks, explicitly drawing upon Georgiades and Phillimore's (1975) paper, 'The myth of the hero innovator'.

> *'…there's this conflict between society wants heroes…people want role models and stuff but actually that's quite an unhealthy position to take up and that we really need to be part of networks…'*

Indeed, Joseph seemed to construct himself as having been a young man trying to be a 'hero'. With his frequent references to his '*young age*' at the time, I felt Joseph presented this as a more 'immature' state. On the one hand, Joseph described how being a 'hero' opened up opportunities for him to '*be charismatic and…inspire people*' but, on the other hand, Joseph described being inundated with letters from families in need and, consequently, feeling '*a big pressure*' to be a '*role model of innovation*'.

In addition, as being a 'hero' arguably demands, Joseph presented himself as a lone figure working in isolation at this point in his narrative. Indeed, Joseph described being '*wary*' of becoming a target of criticism and *'being picked off as an individual'*, and drew comparisons between himself and others with radical opinions, such as R. D. Laing.

In response to these factors, Joseph talked about deciding to join networks. However, in relation to his narrative, I felt Joseph was negotiating whether or not being part of networks entailed a shift away from an identity as a '*rebel*' and '*spy*'. For instance, in regard to the excerpt below, I felt the meaning was ambiguous. Joseph starts off as if to say '*be part of*' but then changes this to '*embed myself in part of…*' Thus, it is unclear whether Joseph is constructing his membership of networks as a more '*healthy*' position or as a form of 'camouflage' to protect himself, or possibly both.

> *'…I was anxious to sort of be part, embed myself in part of, you know, networks and movements really and that seems to be how you influence change…'*

Joseph described how, more recently, he had become increasingly involved in alternatives to psychiatry rather than publicly speaking out as much as before against psychiatry. Again, I felt that Joseph was negotiating two potentially

contradictory positions here, that of a 'revolutionary' and a 'reformist', which he related to his role as a professional.

> *'…[being a professional]…has given me clout…I've been able to influence…on the other hand…there's an argument that you could be colluding with systems by being part of them. The enemy of revolution is reform so…I try to do a bit of revolution and a bit of reform…'*

In a similar way to Joseph's description of joining networks, there appeared to be two different narratives about this change in the form of his activism. On the one hand, developing alternatives was positioned as the 'better' route. However, Joseph also wondered if developing alternatives was a result of a lack of '*confidence*' in relation to being '*bruised*' by internal politics within his statutory organisation.

> *'…after a while it's easy to criticise the status quo but what are you going to do about it…I've become really more interested in, um, rather than embarrassing the status quo…well maybe embarrassing it in a different way by showing alternatives work…'*

> *'…I'm more interested in developing alternatives now and I don't know if that's partly because I got bruised in that kind of conflict…kind of knocked my confidence a bit…'*

In fact, like other interviewees, Joseph talked about how one can be vulnerable '*to accusations maybe if it's only in your own head of (.) not being radical enough*'. However, again, Joseph gave an alternative conceptualisation and wondered if he had become a bit '*obsessive*'. Joseph ended the interview with remarks about how he sees his role as a professional as achieving a '*balance*' and picking the '*right time*' to take a stand and protest (i.e. be a '*rock*'). Joseph reflected on this as the '*art*' of '*speaking uncomfortable truths to the powerful…[and] to the unpowerful*'.

9. **Thomas**

Thomas began his narrative by telling me that he had '*gone mad*' after graduating from university which he connected with the breakup of a relationship. Thomas described himself as someone who had '*always been a bit mad*' (e.g. '*I like punk music, I liked excess, I used to drink incredible amounts, stay up and, you know, break rules')* and claimed an identity as a '*punk*' from the start of his narrative. However, Thomas drew a qualitative distinction between '*being mad*' and '*going mad*':

> '*…I've always been a bit mad…but all that was completely different from what I call going mad…going mad was suddenly thinking children were invaders from outer space…'*

Thus, Thomas claimed an identity as someone who had 'gone mad' but who was no longer in this state, which was stated both explicitly and implicitly; for instance, he referred to '*looking back*' at his '*mad experiences*'. However, in his narrative, Thomas contests psychiatry's pathologising and stigmatising appraisal of '*madness*' and aligns it with '*excitement*', '*imagination*' and '*creativity*'. I wondered if this framing of '*madness*' contributed to Thomas's detailed and elaborate accounts of his '*insanity*'. Indeed, this gave the impression that these were experiences to be shared rather than to be ashamed of and hidden away.

> '*…I think these are amazing satirical insights, you know, that you could work up into a short story (Thomas laughs) or something, you know, they're imaginative and true in a way…'*

Thomas talked about the time he spent in both an '*open*' and '*closed*' psychiatric hospital in the early 1980s after university. Thomas's account of his experiences at this stage was personalised and descriptive as in the excerpt below. His was not a theoretical account at this point and he did not generalise his experiences by referring, say, to the '*system*' or to '*psychiatry*'.

> *'…somebody found that if you looked here you could see a a clock on a tower and this was terribly important because we were all asking each other what time is it because you're all on these, you've been given these drugs that knock you out...and your whole biological clock is all crazy…'*

However, I then asked Thomas how he reflected back on these experiences and he said that at the time '*I didn't really meet anybody who sort of said (.) we're all oppressed*'. Thus, I felt Thomas was positioning himself as holding a more politicised understanding now of his experiences than whilst in hospital.

Thomas talked about coming out of psychiatric hospital and his '*year of depression*' which he associated with taking a job in computing. In his narrative, Thomas drew a contrast between taking this job with his previous life-style of '*absolute rebellion and punk and left activism*'. Arguably, Thomas was positioning the conflict between this job and his preferred identity as the 'cause' of his 'depression'. In this way, Thomas's narrative seemed to be contesting psychiatry's understanding of 'depression' as caused by a 'chemical imbalance' independent of the contexts in which people exist (Adame & Knudson, 2007).

> *'…it's difficult for me to sort of distinguish having a regular job with computing from being really depressed…'*

Thomas described avoiding '*help*' from mental health services and, instead, drew upon the '*resources through my education*' to get him '*back on my feet*'. In particular, Thomas talked about giving himself a '*literary therapy*' and described authors with whom he connected, such as Iain Sinclair. Indeed, in his account, Thomas illustrated a very expansive knowledge of literature, music and politics and, thus, the resources available to his construction of identity. In addition, Thomas also claimed an explicitly politicised identity, identifying as a past member of the Socialist Workers Party and a Marxist.

> *'…but it was helped by reading Iain Sinclair…and thinking he's been there… you know the cushioned well-off people just don't understand <Mmm> what a bleak, you know, London is when you have no money*

> *<Mmm> and…what some people think of as mad is a sane response to a mad situation…'*

Thomas then described starting a different career, and talked about how he had later learnt about a punk/anarchist inspired survivor group through a friend and about how meeting people in this group was a significant experience for him.

Thomas positioned people within this group as '*equals*' and as individuals with whom he could relate, both in terms of music, '*attitude*' (e.g. *'we were ageing punks I suppose')* and politics (e.g. '*I think I just found a bit of active communism'*). The effect of this story was to conjure up a sense of this being a place where Thomas could just 'be himself'.

> *'…so there was a lot of that feeling of of not um of not showing, you know, not measuring up to other people's standards but of expressing ourselves…'*

Thomas talked about the activities he took part in alongside others in this group, such as campaigning about the links between suicide and poverty. Thomas positioned these activities as a '*combination of pleasure and politics*' and told me that it had felt as though they were '*inventing*' something '*new*'. Indeed, in accord with the construction of himself as a Marxist, there was a sense of 'revolution' and excitement in Thomas' narrative when he described his involvement in this group.

> *'…you were getting famous, you were publicising yourselves, it was a bit like a band and people start spraying your name up, you know, it felt like, we were reaching people…'*

Thomas only touched briefly on his activism within this group in his narrative and focussed instead upon the connections he said this group helped him to make between music, madness and politics, saying how it had '*showed me I could combine sides of me that previously I kept separate*'. Indeed, in my reading, there appeared to be a change in the way that Thomas conceptualised '*madness*'.

Namely, there was shift from viewing it within a psychiatric discourse (e.g. '*being mad*' vs. '*going mad*') to talking about '*madness*' at a societal level (e.g. to include capitalism, global warming) as in the excerpt below. Whereas Thomas began his narrative by talking about his own experiences of '*madness*', this shifted to commenting upon the relative 'sanity' and 'insanity' of everyday behaviour in society and its political implications. Arguably, this shift paralleled Thomas's change in the way he constructed '*madness*'.

> *'…people who think they are sane…are actually obeying a whole lot of rules which are probably going to destroy us as a species on the planet (Thomas laughs) because of climate change…and nuclear bombs and all the rest of it…'*

CHAPTER 7: DISCUSSION

In this section, I will review some of the broad similarities and differences between the narratives of the participants. As Riessman (1993, p. 52) suggests, I will move 'beyond the text and make inferences about context' and, specifically, the potential contextual influences upon the participants' narrative constructions. I also include a section on reflexivity, part of which includes considering my own role in the co-construction of the participants' narratives. Lastly, I reflect upon some of the limitations of this project and consider alternative approaches which could have been taken. I end by relating the findings to implications for research and practice.

Storying Journeys into Activism

Although there were unique aspects to all of the narratives, there appeared to be similarities in the way participants storied their accounts. Gergen and Gergen (1984) propose the existence of three forms of narrative - 'stability', 'regressive' or 'progressive' narratives. Based on my analysis, all the stories of the participants appeared to be 'progressive' and articulated a journey towards a more 'desirable self' (Riessman, 2008). In addition, many of the stories seemed to reflect modern society's dominant narrative in regards to '*thinking* about

humans as selves' whereby '[t]he self is to be a subjective being, it is to aspire to autonomy, it is strive for personal fulfilment in its earthly life…it is to find meaning in existence by shaping its life through acts of choice' (Rose, 1996, p. 151). However, these forms of storytelling can also be understood within the context of the survivor movement. Indeed, this 'progressive' element, and narrative about the 'self', is arguably reflected in descriptions of the survivor movement, such as the claim that its focus is on 'legends of oppression met and overcome' and upon the shift from being 'powerless victims to agents of change' (Bassman, 1997, p. 238; Campbell, 2008, p. 198).

In relation to the typologies of narrative genres mentioned in the Introduction, the majority of the participants drew upon elements of a 'quest' (Frank, 2012) 'enlightenment' (Thornhill et al., 2004) and 'revelation/purposeful suffering' narrative (Adame & Hornstein, 2006). For instance, Adame and Hornstein (2006, p. 144) describe the 'revelation/purposeful suffering' narrative as being one where 'a person's life is interrupted by an emotional crisis, but the experience is positive in the sense that it becomes a catalyst for a personal revelation or breakthrough'. The way in which most people draw on such a narrative is as might be expected for individuals engaged in activism. Nonetheless, individuals drew on this narrative genre in different ways; for instance, for some, this 'breakthrough' was storied as a sudden cathartic moment whereas for others it was constructed as a slow, gradual and even ongoing process.

Interestingly, many participants appeared to draw on more than one narrative genre. For instance, Sarah described re-connecting with 'suppressed' qualities, as well seeing her life as 'zig zagging', which appears to reflect both a 'revelation/purposeful suffering' and 'traumatic interruption' narrative to use Adame and Hornstein's (2006, p. 143) 'subjective experience of emotional distress' typology. Whilst typologies certainly have their uses (Frank, 2012), these observations arguably serve as a critique to research which positions individuals within a single narrative genre (e.g. Thornhill et al., 2004). Thus, this may have the effect of inadvertently simplifying the different narrative resources people draw upon to make sense of their lives.

Although much research on 'recovery' has adopted Frank's (2012) or Thornhill et al.'s (2004) typology (e.g. Carless, 2008), both these typologies assume the presence of an 'illness' or 'psychosis' as 'something' from which a person 'should' 'recover'. However, some participants in this study did not see themselves as either having an 'illness' or having something from which they needed to 'recover'. Such a view is arguably reflected in Adame and Hornstein's (2006, p. 145) typology in the form of the 'continuity' narrative in which 'there is no significant interruption or break in the person's life narrative and therefore no distinction between a pre- and post-distressed self'. Thus, on the basis of my project, this appears to be a particularly advantageous aspect of Adame and Hornstein's (2006) typology in contrast to the other two mentioned.

Adame and Hornstein (2006, p. 146) go on to describe 'types of emotional distress' narrative. This includes a 'psychiatric oppression' narrative mentioned in the Introduction, which they define as 'the feeling of being in some way abused, mistreated, coerced, or denied human rights by mental health professionals' (Adame & Hornstein, 2006, p. 146). This form of narrative appears to reflect that drawn upon by the participants in my study. Indeed, there were notable similarities between participants in their accounts of psychiatric practices, such as describing them as 'oppressive and/or 'unjust'. However, a notable observation made in my project was the variety of ways in which the participants' accounts contested the dominant narrative of psychiatry and the alternative identities which were claimed. These identity claims will not be repeated here but the analysis arguably echoes Sweeney's (2009, p. 23) point that there is neither a 'single voice' of survivors nor of the survivor movement.

In the Analysis, participants' different claims to legitimacy (or 'narrative resources') were discussed. These mirrored Crossley and Crossley's (2001) findings to a large extent. For instance, Crossley and Crossley (2001) describe how modern (as opposed to mid-twentieth century) accounts by survivors included 'theorisation and explanatory analysis' (p. 1483), identification with social categories (e.g. 'survivor'), and the location of 'oppression and ill-treatment within a corrupt "system"' (p. 1485). However, importantly, Crossley and Crossley (2001, p. 1488) point out how this 'voice' is a 'social, historical and political

construct'. For instance, as mentioned in the Introduction, one significant influence upon this 'voice' is argued to be the advent of consumerism and a change in Government thinking whereby survivors were seen to possess a marketable form of 'knowledge' and 'expertise' (Crossley, 2006, p. 203).

The Role of the Collective

A central feature across the majority of the participants' stories was the impact on them of attending or joining survivor groups or networks. Adame and Knudson (2007, p. 173) describe a similar observation, saying that 'people realize, sometimes for the first time, that they are not alone in their particular struggles'. Adame and Knudson (2007, p. 171) also suggest that a 'pull or calling to help others…often leads people to start or join survivor communities'. Whilst Geoff's narrative might partly match this description, many of the participants (Alice, Emily, Susan, Edward, Catherine) appeared to position the opposite line of causality to be the case; namely, it was meeting these collectives which led them to identify with others and to connect the personal and the political. This finding appears to add weight to the social identity literature, which suggests that one outcome of involvement in 'activist' groups, say, is a more 'radicalized self concept' (Drury & Reicher, 2000, p. 579). In addition, the findings here seem to echo Crossley's (2006, p. 4) suggestion that the 'the maturing of individual sentiments and inclinations into projects of resistance is very often a collective phenomenon'.

Although not a thematic part of the analysis, there appeared to be commonalities in the stories of members of similar survivor networks. For instance, the three participants, who talked about their contact with the Hearing Voices Network (Alice, Emily and Edward), all constructed their narratives in such a way as to highlight the links between life experiences (e.g. trauma, abuse) and 'voice hearing', and all constructed their 'voice hearing' as a meaningful experience. Arguably, such constructions draw on the wider narrative resources of the Hearing Voices Network (c.f. Romme & Escher, 1993). Similarly, Thomas and Sarah were both members of punk/anarchist groups and linked 'madness' with positive features, such as 'creativity' and 'imagination'. Arguably, this illustrates a

point made by Andrews (2013) who says that '[s]tories…are not just within the domain of the individual, but are built upon the collective memory of a group' and argues that narrative plays an important role in 'de-individualising that which is personal'. As such, the findings of my project highlight the range of contexts that might influence people's narrative constructions, such as their particular collective, the wider survivor movement as well as societal narratives. In addition, this project adds to the narrative literature, which argues that social movements can be viewed as 'bundle[s] of narratives' (Fine, 2002, p. 229). Implications of this are discussed below.

Stories of Involvement in Activism: Re-Conceptualising Recovery

A further feature of people's stories was the lack of reference to the concept of 'recovery'. This was surprising given the expansive literature on 'stories of recovery' within the literature mentioned in the Introduction. The participants did not construct their 'journeys' in this way but, instead, drew on terms such as 'growth' (Emily), 'healing' (Alice) or 'getting back on my feet' (Thomas). This highlights the dangers of inserting people's stories into 'professionally derived conceptual frameworks' such as 'recovery' which risks losing the meanings that individuals themselves may attribute to their experiences (Harper & Speed, 2012, p. 26).

Instead of using 'recovery', Adame and Knudson (2007) suggest the concept of the 'good life' as a useful alternative (McLeod & Lynch, 2000). To me, this appears closely aligned with White's (2004, p. 75-76) concept of 'intentional states' (as opposed to 'internal states'), which refers to people's 'beliefs, values, hopes and dreams…and, in more specific terms, what they are committed to in terms of how they wish to live their lives'. Indeed, a particularly prominent theme within people's accounts was the moral construction of their engagement in activism. Interestingly, Adame and Knudson (2008, p. 172) suggest that a 'good life' to their participants was 'less to do with personal growth and transformation and more with social activism and advocacy work'. In contrast to this proposition, a consistent theme in this project was how people positioned their own 'personal growth' and their involvement in 'social activism' as inextricably linked. This

mirrors Andrews' (1991, p. 171) study in which people's political work was 'not isolated from, but rather an integral part' of their lives. In addition, in relation to the literature on activism, this also contests the notion that those engaged in activism are simply 'nobly altruistic' (Blackwood & Louis, 2012, p. 72), which Adame and Knudson's (2007, 2008) research could be interpreted as implying.

Another aspect in a number of accounts was the way in which individuals positioned themselves as acting as 'citizens' during their narratives. This can be viewed as a political move (Andrews, 2007) and, indeed, a common theme across the interviews was a focus upon a need to change 'society' rather than 'psychiatry' alone. This highlights a number of limitations of the current literature base. Namely, as mentioned in the Introduction, a focus on 'recovery' may privilege people's relationship with the 'mental health system' rather than people's roles as 'citizens'. In fact, a number of participants told me that they had been asked numerous times by researchers about their 'recovery' but not 'what I do'. Indeed, they informed me that this was a reason for taking part in this project. As noted in the Introduction, Campbell (2008, p. 197) comments upon how 'people with a mental illness diagnosis…appear to think of themselves as service users first and citizens second'. However, in addition, individuals appear to be positioned as such within the literature. Implications of this are discussed below.

Managing Different Identities

Notably, many of the interviewees were employed in 'mental health' related jobs (e.g. Emily, Sarah, Geoff, Joseph, Catherine) and appeared to construct a tension between their 'preferred identity' (Madsen, 2007) and the services in which they worked. This was often positioned as giving rise to self-doubt in the form of 'Am I radical enough?'

Indeed, a similar tension has been reported within the peer-support literature (Mowbray, Moxley, & Collins, 1998). However, in relation to activism, I was reminded of Crossley (2006, p. 204) who commented on how '[e]xpanded individual opportunities and the availability of other ways of changing the system drew some potential activists away from the activist route'. Each participant in my

study constructed an account which contested an identity of themselves as 'colluding' or being 'tokenistic' (c.f. Campbell, 2008, p. 204) and appeared to claim an identity for themselves as 'radical' in 'non-radical services', with Joseph's 'spy' metaphor being a case in point. This was the case whether people worked within statutory or voluntary services. Minister (1991, p. 29) talks about the way in which stories are addressed to a 'ghostly audience' as well as to the 'audience' immediately present. In this regard, I wondered if these accounts were addressed to other survivors to indicate that they were still as committed to change as ever.

Catherine was an exception to this pattern in so far as she did not discuss such tensions. It is hard to draw conclusions from this but, notably, Catherine occupied prominent positions in different mental health charities as well as having a longstanding involvement with the survivor movement. I wondered if this might mitigate the need for Catherine to manage her identity in the same way as the other participants.

Reflexivity

Co-Construction of Narratives

In the light of the social constructionist epistemology of this project, I think it is important to reflect upon my own role in the co-construction of narratives (Riessman, 1993, 2008). Firstly, there are aspects of myself that may have influenced people's stories. For instance, many of the participants talked about UEL as somewhere 'critical', and/or knew my supervisor and were keen to ask after him. Furthermore, my project had an implicitly political orientation. Indeed, participants often began our conversation with critiques of psychiatry, such as the upcoming publication of DSM-V. It would therefore be unsurprising if a knowledge of my university and of the political orientation of the project influenced participants, and possibly contributed to participants feeling comfortable to share critical and politicised stories in relation to their journeys.

In addition, I was younger than all the participants, I am just setting off into my career, and am sure I came across as excited and optimistic about the possibility of change in the psychiatric system. In contrast, many of the participants had been working for change all their lives. They often began with exuberant accounts and it was only at the end (sometimes when bringing the interview to a close) that different stories of frustration, disillusionment and 'burn out' emerged. I wonder if these latter narratives were less forthcoming in the light of their awareness of my enthusiasm and, possibly, political naivety. Maybe they did not want to burst my bubble? On the other hand, I wonder if beginning with an invitation to talk 'about the kind of things you've done' inadvertently set up an expectation that they needed to prove that they had done, or were doing, 'enough'. This may have influenced participants' reticence about discussing their doubts about change earlier on in the interview as well as their reflections on whether they were 'radical enough'.

Thomas stood out amongst the participants. I found myself frustrated during the interview and felt that we were talking two different languages. The more I asked about him about his 'journey', the more he talked about Marxist theory. In order to make meaning of this experience, I searched the literature and found that Andrews (1991, p. 150) reported a similar feature with her group of activists; for instance, she comments upon how 'the most revealing information which emerged from the direct questions on self-description was the lack of relevance and/or importance attributed to this category by the respondents'. With this in mind, I returned to the interviews and noticed the high degree to which I had focussed upon self-descriptions with the participants (e.g. 'what was that like *for you*' or 'how did that change *you*'). Unwittingly, I may have been reproducing the 'radically individualistic' nature of Western psychology with my focus upon the individual's '*personal* journey' (Adame & Knudson, 2007, p. 160). Thus, on reflection, my frustrations may actually have reflected Thomas's implicit contesting of this modern 'self' (Rose, 1996).

In retrospect, I may have also have co-constructed 'revelation/purposeful suffering' and 'progressive' narratives with the participants (Adame & Hornstein, 2006; Frank, 2012; Gergen & Gergen, 1984). Frank (2012, p. 47) comments on

how such narratives are 'based on an explicit or implicit journey metaphor'. Indeed, this was the premise of my study – 'journeys into activism'. In addition, my training as a therapist and my narrative interviewing style may have led me to move participants away from 'problem-saturated' narratives and, instead, to a focus upon 'preferred lives' (Madsen, 2007). Andrews (2007, p. 6) comments on how there were 'certain stories which [she] was more receptive to hearing than others'. Indeed, I was biased in my interest to hear stories which linked the personal and political. On reviewing the interviews, I noticed how I readily picked up on such connections, drawing people from their activism back to their 'selves' and then back again to their activism, such as in the excerpt below with Alice.

> Jonathan: *'….I guess you've spoken there about, um, how… Judith Herman kind of framed things quite… politically in that way and… [that] that…did have a considerable impact personally [on you], I I guess I'd be really interested to hear a a bit more about that, about that kind of, what that meant personally…'*

Personal and Professional Dilemmas and Reflections

The process of this research had a significant impact on me both personally and professionally. It was a privilege to hear people's stories and, in every case, I found myself in awe of what each person had achieved. Indeed, through this process, it has in a sense 'radicalised' or 'committed' (c.f. Andrews, 1991) me further in the pursuit of challenging injustice and social inequalities. It has also made me appreciate the wider role of survivor groups and networks, as communities which help people through their struggles, provide people with new meanings to their experiences, and contribute to a process of 'consciousness-raising' (c.f. Adame & Knudson, 2007).

This project has re-affirmed the vital importance of the link between the personal and political for me. On approaching qualification, this has highlighted again the need to address such links in my clinical work (c.f. Carter & McGoldrick, 1999; Hagan & Smail, 1997). Furthermore, this project has made me consider my engagement with the survivor movement and campaigns in a different way;

namely, I now view my involvement not just in terms of being a psychologist but as a citizen as well (or 'human being' to use Edward's words) (c.f. Harper, 2010).

This project also gave rise to a number of dilemmas for me. The participants provided accounts (arguably 'testimonies') of cruelty that they had experienced at the hands of others, such as organised abuse, torture and assault to name but a few. Although I have tried to give some description of these experiences, I felt that these were inevitably backgrounded due to the focus of this project upon identity construction. This has made me reflect upon, and become particularly aware of, how the choice of research question and epistemology are not neutral decisions but also morally and politically laden (Dallos & Stedmon, 2006; McKinnon & Miller, 1987; White & Epston, 1990).

Lastly, participants often told me (at the end of the interview) about how they were not 'just' an 'activist' but had other identities as well - parent, spouse, artist and musician, say. This made me reflect on the potential for research to inadvertently 'colonise' people's experiences (e.g. 'patient', 'survivor', 'activist') (c.f. Dillon & May, 2002), instead of appreciating the complexity of lives and the range of the contexts out of which people act.

Limitations

Methodology

Although not aiming to be 'representative' as such, I feel a strength of this project was its achievement in recruiting participants from a range of different backgrounds (e.g. age, sex, social class, educational level, geographical location and forms of activism). This arguably enabled a diverse range of viewpoints to be heard. However, although one participant was recruited from a black and minority ethnic (BME) population, it was not possible to recruit anyone specifically from a BME survivor group. This is disappointing since this group is under-represented both in research and in the survivor movement (Thornhill et al., 2004; Wallcraft et al., 2003). In addition, none of the participants in this project reported that he/she currently used psychiatric services. Including such individuals could have been

particularly interesting in relation to how these individuals negotiated their position within psychiatry whilst also campaigning against it.

Riessman (2002, p. 5) critiques the use of 'single in-depth interviews' which she argues have replaced 'ethnographic observation ("deep hanging out")'. Indeed, I am aware that many of the participants interviewed in this project often address the public, using their 'story' as a prominent part of this. In retrospect, using these accounts could have provided an interesting alternative source of data. Arguably, given this often 'public' nature of many of the participants' forms of activism, this would have been more appropriate than 'private' interviews.

In addition, as mentioned earlier, most of the participants positioned themselves as part of a collective and referred to these groups/networks as being particularly important to them. As such, I wonder if an alternative way of collecting data for this study might have been to run focus groups with different collectives of survivors, say. Although I argue below that this project does have 'pragmatic use', I might have also developed this project in consultation with different survivor groups, to help enable it to be as 'pragmatically useful' as possible to the participants in their pursuits.

Analysis

Given the space constraints, it was not possible to present extended sections of the transcripts as is advised for narrative analysis (Riessman, 1993). As such, this inevitably impacted on the 'transparency' and 'persuasiveness' of this project. Also, this meant that my own voice and interpretation was privileged and that the reader has limited means with which to evaluate the meaning of people's narratives for themselves (Riessman, 1993). Furthermore, in the process of paring down people's narratives, the ambiguity of meaning, dilemmas and subtleties in the stories were often lost. This led to a more simplistic reading of people's complex lives than I would have preferred.

In addition, due to time constraints, only a few performative features of people's narratives were included in the transcription. Indeed, these aspects are argued to

be important in terms of the effects of narrative; for instance, Langellier (2001, p. 150) comments on how 'the narrator takes experience (the narrated event) and makes it the experience of those listening to the story (the narrative event) in the enactment of performance'. However, whilst these might have been included in the transcript, they would not have caught the looks of disgust or the averting of gaze, when describing experiences within psychiatric hospital, or the broad smiles and glints in the eye when talking about attending a campaign rally. During the interviews, such 'visual' features felt intrinsic to the meaning and impact of people's narratives. In this respect, Riessman (2008, p. 142) describes a 'visual turn' in the field of narrative analysis and, as such, I wonder if video recording our conversations or participants' public addresses might have been a productive alternative.

Implications

Future Research

As discussed above, this project has highlighted some of the dangers of adopting a research focus based upon the concept of 'recovery' and, as such, adds weight to Harper and Speed's (2012, p. 22) comment about how 'more sophisticated understandings of experience [are needed]…[which are] framed in people's own words, using the language that survivors themselves use'. An interesting alternative direction for research would be to examine constructions of the 'good life' (c.f. Adame & Knudson, 2007, 2008; McLeod & Lynch, 2000), 'preferred lives' (Madsen, 2007) and/or 'intentional states' (White, 2004). In addition, a shift in thinking about people's identities beyond that associated with the psychiatric system (e.g. viewing people as citizens) also seems warranted on the basis of this project.

Furthermore, this project has highlighted the importance of thinking about people in the context of the collectives to which they belong in order to make sense of their narratives. Drawing on the ideas of Schwartz (1996), Fine (2002, p. 238) describes how '[s]tories contain explicit and implicit morals that are to be taken as guides for actions' and function as a 'lamp that directs group action'. Thus, it

would be particularly interesting to see how these collective stories both contribute to an individual's construction of identity as well as guiding his/her actions (c.f. Rappaport, 1993). Such a study would add considerably to the narrative literature on social movements.

Notably, this project focussed solely on those who are challenging psychiatry in some way. However, there are survivors and survivor groups who are advocates of psychiatry. Indeed, Adame and Hornstein (2006, p. 148), in their analysis of first-person accounts, identified a 'psychiatric empowerment' narrative in which the writers felt 'that their treatment—whether psychotherapy, medication, or ECT— was their salvation from emotional distress.' Interestingly, in relation to abortion, Ginsburg (1989) compared the narrative constructions employed by right-to-life versus pro-choice women activists. Thus, in a similar way, one could explore the similarities and differences between the constructions and claims to legitimacy made by those who are challenging psychiatry and those who are supporting psychiatry.

Practice/Policy Implications

This project repeats the message made elsewhere about the importance of survivor groups, and the wider movement, in people's lives (Adame & Knudson, 2007; Adame & Leitner, 2008). It would be of value to raise awareness amongst clinical psychologists about the significant role of such groups and networks; psychologists could, in turn, let individuals under their care know about the availability of this resource.

At the same time, as many authors have noted (e.g. Adame & Leitner, 2008; Chamberlin, 1978; Harper & Speed, 2012), it is important for the practices of the survivor movement not to be co-opted into the mainstream, 'professionalised' and/or simply viewed as 'technical fixes' or 'alternative interventions' (c.f. Rappaport, 1993). Clearly such a view would be a serious misreading and underestimate of the significant function such networks play, both for survivors and in society.

This project also highlights the need for clinical psychology to take seriously the impact of issues of power and structural inequalities on people's lives instead of 'psychologising' social problems (Hagan & Smail, 1997). Indeed, many of the arguments about psychiatry may apply equally to clinical psychology. For instance, Newnes (2004, p. 358) argues that clinical psychology has co-opted the language of psychiatry for professional interests and 'have acted in ways that oppress rather than liberate those who require their services'. Nonetheless, it is important not to homogenise clinical psychology as there are notable exceptions, such as Holland's (1992) White City 'Social Action Psychology' Project. The final 'steps' of this project included moving from a psychological understanding of the women's difficulties to developing a 'collective' voice amongst the women so that, together, they could demand changes, that affected their lives, in their communities. Building on such innovative practice would appear a useful way forward for clinical psychology.

Lastly, this project has implications for those engaged in activism and the resources upon which they can draw to sustain their activities. For instance, the concept of 'burn out' (c.f. Pogrebin, 1994) often appeared in the interviews. Indeed, Holmes, Newnes and Dunn (2010, p. 6) refer to this when they say that 'one outcome of speaking out is, however, exhaustion'. Indeed, this indicates the important role survivor networks also play in helping to sustain their members in their activities. In addition, there are resources available for 'activists'; these highlight the impacts of engagement in activism, which are often taken for granted, as well as self-help material from which such individuals and collectives might benefit (c.f. Pogrebin, 1994).

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APPENDIX 1: LITERATURE SEARCH STRATEGY

The literature search comprised two stages in order to identify literature relevant to this project.

An initial exploratory search of the literature was conducted. This involved searching in PsychINFO and Google Scholar for 'Psychiatric Survivor AND Activism AND Narrative' which reflected the primary interest of this project. Relevant papers emerging from this search were read and references were followed up. In addition, articles and books recommended by my peers and supervisor were also reviewed.

From this initial search, key terms used within the relevant articles were recorded. A more in-depth search of the literature was then conducted using these key terms from 1990 to present day:

*Survivor activists (also ex-patient activists, mental health activists, consumer activists)
*Survivor narrative (also activist narratives, illness narratives, stories of recovery, narratives of recovery, journeys of recovery, psychiatric narratives, patient narratives, narratives of resistance)
*Survivor movement (also ex-patient movement and mental health movement)
*Social movements (also social change movements, narrative and social movements, protest narratives, protest stories, political change narratives)
*Activism (also narratives of activism, collective protest, collective action)

The databases used included, Ingenta, PsychINFO, Pubmed, Web of Science and Google Scholar.

Papers were included if they were in English and related to 'psychiatric survivors' (rather than, say, 'torture survivors'). Again, references within relevant papers were then followed up. In addition, within my university cohort, four of us using a narrative analytic framework set up a support group, in which we exchanged articles and books.

APPENDIX 2: RECRUITMENT ADVERT

Have you been involved in challenging or developing alternatives to the psychiatric system?

Could you meet for a short interview with me to talk about your experiences?

My name is Jonathan Buhagiar and I am a trainee clinical psychologist at the University of East London. I am running a project exploring the experiences of people who have had contact with mental health services and are now involved (or used to be involved) in activities to challenge or develop alternatives to the psychiatric system.

Examples of such activities might include demonstrating or campaigning, involvement in an activism group, teaching or training or even developing a new service. In essence, I'd like to hear from anyone involved in activities to challenge the psychiatric system in some way!

I'd like to learn about how people's life experiences informed their journeys into becoming involved in such activities and what sustains them in their activities. I hope to use this learning to raise awareness about people's experiences of the mental health system and about the activities people are involved in, which could be useful for others who have had similar experiences.

If you decide to take part, I'd like to meet you for a short interview (about an hour). This would be whenever and wherever is most convenient and comfortable for you (I am happy to travel outside of London). The content of our conversations would remain totally anonymous and I would reimburse you for any travel expenses you might incur in meeting up with me.

I would like for the interviews to be completed in the next month or so. If you're interested in taking part and/or would like to find out more about the project then

please email me at psyactivism@hotmail.co.uk or call me on 020 8223 4174 and I'll get back to you to talk about it further.

Thank you and I look forward to hearing from you.

APPENDIX 3: INTERVIEW SCHEDULE

1. Can you tell me a little bit about the kinds of things you've been involved in?

Prompts:

What kind of things do you do/have you done?

How long have you been involved?

What would you call what you do?

[The aim here was to gather stories about the kinds of activities people are involved in and how they think about, or define, these activities].

2. Can you tell me about the life experiences that led to you getting involved in these activities of change?

Prompts:

What were the reasons for you getting involved in your activities of change?

Did earlier life experiences or experiences of the mental health system, say, inform your involvement?

Has the way you've been involved in your activities changed over time?

Have the reasons for you being involved changed over time?

[The aim here was to develop stories about the person's biographical trajectory into their activities, about how the person's involvement has changed over time and about the reasons for this change].

3. Can you tell me about what it's been like for you to be involved in your activities of change?

Prompts:

Has the way you think or feel about yourself changed since being involved in your activities of change?

What's it been like to meet other people involved in activities similar and different to your own?

What are your thoughts about people with experience of the mental health system who aren't involved in activities of change?

What difficulties have you faced in remaining involved in your activities of change and what has helped to sustain you?

[The aim here was to learn about the impact of being involved in activities on the individual, how they construct their identity by asking about their relationship to others, and what difficulties they've encountered and what helps to sustain the person in their activities].

APPENDIX 4: ETHICAL APPROVAL

SCHOOL OF PSYCHOLOGY
Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

UEL
University of
East London

www.uel.ac.uk

School of Psychology

Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

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The University of East London has campuses at London Docklands and Stratford
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POSITIVE ABOUT DISABLED PEOPLE

APPENDIX 5: INFORMATION SHEET

UNIVERSITY OF EAST LONDON

School of Psychology

Stratford Campus

Water Lane

London E15 4LZ

Researcher

Jonathan Buhagiar

jpmbuhagiar@hotmail.com

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this research study. The study is being conducted as part of my professional doctorate in clinical psychology at the University of East London.

Project Title

Journeys of change of individuals with current or past involvement in the mental health system

Information Sheet

Thank you for taking the time to read this information sheet. I am inviting you to take part in a study looking at the experiences of people with current or past contact with the mental health system who are now involved in activities to challenge the language or practice of the psychiatric system, or to create

alternatives to the psychiatric system. This information sheet will explain why the research is being done and what it will involve.

Who am I?

My name is Jonathan Buhagiar, I am a trainee clinical psychologist at the University of East London. You can contact me with any questions by telephone or email (contacts details at the top of this page). My work is supervised by Dr David Harper who is also at the University of East London.

What is the purpose of this study?

There has been very little exploration of people with experience of distress and the mental health system who then begin, or join, an activity of change, such as those mentioned above. This would be helpful so that more can be known about how people's life experiences informed their journeys into projects of change, what challenges the person faced and what sustains them in their activities. Such learning could then be used to raise awareness about the possibility of these forms of activity for those who have had similar experiences, and to learn about what may help others involved in activities like yours.

Why have I been chosen?

If you are someone who has had experience of the mental health system and would describe yourself as involved in activities of change like the ones mentioned above then I would like to invite you take part in this project.

Why will happen if I agree to take part?

If you decide to take part you can choose if you would prefer our interview to take place in a quiet room at my University in East London, in your home, or in a quiet room in any organisation that you're affiliated with (whichever is most convenient and comfortable for you). I would like to interview you for about an hour. I will ask you about what it's like to be involved in your particular activities of change and

what life experiences informed you getting involved in them. I will be more interested in what you've got to say than in having a long list of questions to ask you so my intention is for the interview to be comfortable and conversational. With your permission, I will tape our interview to save me from having to keep lots of notes. After that I will write up the study for my University course, submit it to a research journal and then present it wherever possible to raise awareness and celebrate those involved in such activities. In addition, you will also be offered a copy of the final study as well.

Will my participation in this study by kept confidential?

The anonyminity of everyone taking part will be assured. Nobody other than me will have any identifying information about you and all potentially identifying information will be removed at the point of transcription. After this, it will only be myself, my internal supervisors and examiners who will have access to the <u>anonymised</u> transcribed material. When I write up the study, I will assign you a pseudonym (false name) so that you will not be referred to by your real name, and any other identifying information will be anonymised too.

Do I have to take part?

There is no obligation to take part. You will not be disadvantaged in any way if you choose not to continue. If you do decide to proceed then you can withdraw from the study at any time without any disadvantage to yourself.

What are the possible disadvantages and risks of taking part?

In the unlikely event that you were to experience any discomfort during the interviews you would be very welcome to contact me or my supervisor, Dr David Harper. I can also provide contact details for supportive organisations should you wish to gain further advice or support.

What are the possible benefits of taking part?

You may find that it is interesting and enjoyable to have the sorts of discussions involved in the interview. The study will also contribute to learning about people's lived experiences and journeys into projects of change, as well as helping to raise awareness about the possibility of such activities to others and about what can be done to help sustain other people involved in similar activities to yourself. I will also reimburse you for any travel expenses you might incur in meeting up with me.

Thank you very much for reading this information sheet.

APPENDIX 6: CONSENT FORM

<u>UNIVERSITY OF EAST LONDON</u>

School of Psychology

Stratford Campus

Water Lane

London E15 4LZ

Researcher

Jonathan Buhagiar

jpmbuhagiar@hotmail.com

<u>Consent to participate in a research study</u>

<u>Journeys of change of individuals with current or past involvement in the mental health system</u>

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher will have access to any identifying information about you and all potentially identifying information will be removed at the point of transcription. After this, it will only be the researcher, the researcher's internal supervisors and examiners who will have access to the anonymised transcribed material. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS)

………………………………………………………………………………….

Participant's Signature

…………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

…………………………………………………………………………………..

Researcher's Signature

……………………………………………………………………………………

Date: …………………..…….

APPENDIX 7: 'WORKED' TRANSCRIPT: ALICE

89 Alice: Cheers. Um, and he made it very clear right from the beginning that,
90 um, he completely believed in my capacity to recover. That recovery was not
91 just possible it was inevitable, um, he looked beyond this by now extremely
92 degraded, sort of floridly mad exterior and just saw this young woman in pain
93 underneath, um, and I used to say that [person 1] saved me but I think in a
94 way he did something much more powerful in that he empowered me to save
95 myself, um, and I didn't actually work with him for that long because [deleted
96 for anonymity] but before he left he gave me a copy of, um, Accepting Voices
97 by Marious Romme and Sandra Escher and that was an utter revelation, um,
98 because [person 1] had also made this position clear but it was almost like
99 this recognition that voice hearing isn't, you know, this meaningless aberrant
100 symptom of psychosis to be endured, it's a complex and significant and
101 meaningful experience to be explored, um, and it was like, you know,
102 wandering in the wilderness for years and then, you know, as if somebody
103 holds out their hand to you and says, "Come with me, I will lead, I will show
104 you a way out of this", um, and I remember sort of feeling, you know, I will find
105 a way out of this and if I can't find a way out <Mmm> I'll bloody well make a
106 way out, um, and it took a long time, you know, I had to do <Mmm> a lot of
107 this work on my own because certainly at that time the idea that you could
108 work psychologically with, um, so called schizophrenia was was not common
109 currency <Mmm>, um, although certainly [person 1] didn't subscribe to that
110 kind of mechanistic way of working but again I didn't really see him for that
111 long, um, but after he had left it was almost like raw materials to really try and
112 do something about this, um, and I, you know, began to to work to try to
113 understand more about the voices <Mmm>, to engage with them, to accept
114 them as part of myself, to take responsibility for my recovery, um, to learn to
115 see the voices as clues to sort of internal and emotional conflicts and so on,
116 um, and it was during that process that I met err [person 2] and that was also
117 something that [person 1] facilitated [deleted for anonymity] [I was] really
118 blown away by him actually and just in terms of what he'd achieved and how
119 frank and open he was about his own experiences and his complete lack of
120 shame <Mmm>, um, because I think I'd certainly, my initial experiences in
121 mental health, although not in [location], um, had been conditioned to believe
122 that this was a terrible shameful, awful, disabling thing and you're either to be
123 pitied or feared and here was somebody, you know, basically saying "Fuck
124 that!" [Jonathan laughing], you know, um, reclaim this experience, um, and
125 this real sort of celebratory attitude, um, but also this real politicised <Mmm>
126 element that what is happening in psychiatry is wrong, you know this, there's
127 parity to other civil rights movements <Mmm> that this is a human rights
128 abuse, um, and we got on very very well [deleted for anonymity] [he] asked
129 me to present at a conference that was happening in [location] about
130 recovery, um, and that was the first time I'd ever spoken in public about my
131 experiences <Mmm> and I was like reading off this piece of paper for about
132 ten minutes and getting this really lovely positive, affirming response from the
133 people that were in this workshop, um, and then [person 2] asked me to go to
134 [location] with him, um, to another conference this time that had been
135 organised through the Hearing Voices Network.

Comment [jb1]: I heard Alice give a similar narrative at a survivor-run conference – might this serve to offer other survivors hope and belief in recovery?

Comment [jb2]: Draws upon dominant narrative of psychiatry (e.g. florid, mad) and then claims an alternative identity (e.g. young woman in pain).

Comment [jb3]: A religious story? Many references to such in this section (e.g. 'revelation' – ln 97).

Comment [jb4]: Positioning herself as aligned with the Hearing Voices Network in her narrative.

Comment [jb5]: Contests psychiatric narrative of psychosis and very poetically offers an alternative narrative. Seems to draw on the wider narrative of the Hearing Voices Network.

Comment [jb6]: Powerfully draws upon a religious metaphor here to illustrate a change in 'selves' (c.f. Linde, 1993). Use of direct speech and emphasis.

Comment [jb7]: Contrasts with earlier account of herself as passive and at the mercy of others. Alice moves towards a more agentic self. Functions to highlight the effect of this alternative construction of her experiences?

Comment [jb8]: Alice's description initially conjured up the image of a 'miracle' for me. Alice contests this here. Made me think about other interviewees (e.g. Emily, Sarah) who described no quick fixes. Contests psychiatry's magic bullets/psychology's technical fixes?

Comment [jb9]: Meaning ambiguous. Think she is referring to psychological interventions for schizophrenia as mechanistic. Positioning herself as critical. Would this same story be told if she did not know that I was critical of psychiatry/psychology too?

Comment [jb10]: Again, this seems to reflect the wider narrative of the HVN and reminds me of Dillon & May (2002) and Dillon (2011).

Comment [jb11]: Alice contrasts the characteristics of this person, who is a survivor, with the dominant narrative of psychiatry in the sentences below (e.g. pitied, feared, shameful).

Comment [jb12]: Behavioural term. Brought up an image for me of Alice being brain washed by psychiatry? Claims and then contests this identity. Rhetorically accomplished by the use of "Fuck that!"

Comment [jb13]: Direct reference to Dillon & May (2002)

Comment [jb14]: Noticed how I pick up on and tend to reinforce the more politicised elements (e.g. Mmm after 'civil rights movements', 'spoken in public').

Comment [jb15]: Significant shift in Alice's narrative to adopting an explicitly politicised position which continues throughout her account from here after.

Comment [jb16]: Alice refers many times to the importance of other people in her narrative, particularly professionals critical of psychiatry and other survivors.

Comment [jb17]: Strong sense of progression – 'progressive' narrative? (c.f. Gergen & Gergen, 1984)