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"Treat us Like People and We'll Respond Like People"

Exploring Future Research Areas for Mental
Health System Survivors

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ABSTRACT

This project aimed to examine the social position of people diagnosed with mental health problems, with particular reference to the relevance of the term 'disability' to their experience. With a view to achieving this, the study began with a theoretical analysis of the arguments of System Survivors, who contest that the situation and perspective of people with mental health diagnoses is so different from that of physically disabled people that their inclusion in this category further oppresses them. Socially critical theories of disability were also assessed with a view to assessing the possibility of cohesion. From this basis, in-depth interviews were carried out with seven people diagnosed with mental health problems. It was found that a massive divergence existed between the views of people interviewed and the ideas expressed in the literature. While Survivor literature is, if anything, more radically socially critical than disabilities discourse, ideas emerging from interviews were very grounded in individualised, medical understandings of disability and illness. It was concluded that this is likely to be because of a failure to grapple with the nature and implications of mental distress and that future research must endeavour to develop theories which are more relevant to people experiencing mental health problems, while maintaining a commitment to identifying and challenging oppression, particularly internalised oppression.

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INTRODUCTION

In the 1970's, both disability and mental health system survivors' activist movements began to challenge the way physical disability and mental health were perceived in a social context. Both of these movements have since continued to pursue these objectives. While both movements would agree that their experiences of oppression align to some extent, both have also maintained that their respective experience is fundamentally distinct from the other, and that the marginalisation of each group needs to be addressed separately and in a way which recognises its unique characteristics.

Despite this, from a legal perspective, mental illness has come to be widely accepted in contemporary society as a type of disability. Mental health system survivor literature maintains that the oppression of this group cannot be overcome through submersion in the disabilities movement (Plumb, 1994), contesting that this leads to an underrepresentation of the nature of their experience of marginalisation. However, it is also arguable that being included in the category of 'people with disabilities' plays a positive role in the lives of people diagnosed with mental health problems: creating access to much needed resources, contributing to stigma reduction and giving otherwise very marginalised people an identity they can make sense of.

The study begins with an account of dominant academic discourse, particularly focusing on how System Survivors' literature frames the social position of people

who experience mental distress, and asks to what extent, if at all, this aligns with disabilities theory. Against this background, the study will then highlight views expressed by people diagnosed with mental health problems, through reporting findings from a number of qualitative interviews, and identify which elements of academic discourse are most utilised by people with lived experience, examining possible reasons for this. The aim of this study is that this analysis will result in an identification of the direction in which future research in this area should move if it is to be of benefit to people with mental health problems.

LITERATURE REVIEW

Framework

The social model of disability has become the dominant, arguably even the standard, discourse within which disabilities are framed within society. In an academic context, the social model is far from universally accepted. Whether through continuing debates about the validity of a medical model (Bury, 2000; Williams, 1999), or through alternative frameworks posited as a response to problems perceived with the social model (Shakespeare & Watson, 2001; Finklestein, 2001b), the social model continues to be the standard against which other theories are positioned, even in the academic setting. Additionally, from policy-making, legislative and practitioner perspectives, the social model is virtually universally accepted as the appropriate approach to disabilities (PMSU, 2005; WHO, 2011). Since, on a practical level, this is therefore very much the standard that frames the experience of people classed as disabled (including people with mental health diagnoses), the literature reviewed will focus on a comparison, firstly of what Survivor literature says in response to social model thinking, and secondly on some more recent alternatives and adaptations to the social model, which arguably theorise disability in a more sophisticated way. The continued existence of medical models of disability is recognised, however the aim of this research is to assess the extent to which disabilities discourse is useful for people with mental health diagnoses. Because of the scope and length of a Masters dissertation, a detailed discussion of continuing debates within disabilities studies is considered superfluous. For the purposes of this

discussion, it will be adequate to analyse the situation of people with mental health diagnoses within the dominant framing of disability.

It is not necessary to provide a detailed account of social model thinking. The prominence of the concept is such that most interested people are familiar with its principles. In the context of this research, what is important is to use it as a starting point for assessment of how relevant it is to people with mental health diagnoses. The essence of the social model, quoted here in UPIAS' 'Fundamental Principles of Disability', frames disability as:

> The disadvantage or restriction of activity caused by a
> contemporary social organization which takes no or little account
> of people with physical impairments and thus excludes them from
> participation in the mainstream of social activities. Physical
> disability is therefore a particular form of social oppression
> (UPIAS, 1976: 20).

In terms of relevance to people with mental health diagnoses, Anne Plumb (1993) has identified the following three problems with this definition:

1. The acceptance of existent impairment, even if this is rejected as being the cause of disability.
2. The specification of a focus on physical impairment – at other points UPIAS have explicitly stated that, although they saw scope for solidarity with other oppressed groups, their focus was

specifically on the experience of the physically impaired (UPIAS, 1974)

3. The identification of exclusion from participation in mainstream society as the manifestation of the oppressive experience.

These points will be returned to and addressed in detail in subsequent sections, when the arguments put forward from a Survivor perspective are described. It is important from the outset, though, to highlight these areas as having specific relevance to the question of whether the category of disability is an appropriate vehicle for understanding the experience of people with mental health diagnoses. It is not without meaning that the UPIAS definition above appears in a document entitled 'The Fundamental Principles of Disability': This definition is the bedrock of the social model of disability. The points of divergence identified by Plumb highlight central elements of this definition as problematic for people with mental health diagnoses, indicating a fundamental difference between the way physical disabilities and mental health problems should be framed. The remainder of this chapter will unravel these points, before returning to ask whether it is indeed the case that a disabilities rhetoric is an inappropriate framework or whether achievement of a cohesion is possible.

System Survivors' Perspectives

Arguably the factor that distinguishes the experience of people with mental health diagnoses from other disabled people is the existence of legally sanctioned and socially approved withdrawal of rights, through the imposition of things like detention and compulsory treatment. While physically disabled

people's experience of inequality is generally based on some failure on the part of society to respond or behave appropriately, the existence of things like detention means that people with mental health diagnoses can experience oppression through the active removal of their freedom. For physically disabled people, equal treatment is an unquestionable right – admittedly, it is a right that is often denied, but the blame for this is very much placed on society, as is the onus to remedy the problem (UPIAS, 1976). For people with mental health diagnoses, equal treatment is a privilege one can be granted if able to prove oneself sufficiently rational: the blame and the onus to change reside with the person. The existence in law of provision for detention presents somewhat of a paradox in that, while one piece of legislation exists, which claims to protect the rights of people with mental health diagnoses, included under the umbrella category of 'people with disabilities' – the Equality Act 2010 (Crown Archive, 2013a), there simultaneously exists another piece of legislation, which allows for those people to be held and 'treated' against their will – The Mental Health (Care & Treatment) (Scotland) Act 2003 (Crown Archive, 2013b). Because of this deeply distinguishing aspect of the experience of people with mental health diagnoses, the background of legal provision for removal of rights is considered an appropriate framework within which to look at the Survivor perspective and it's divergence from disabilities literature.

The Mental Health (Care and Treatment) (Scotland) Act 2003 is purported, and indeed, generally held by mental health organisations to be a very progressive piece of legislation, whose main function is to safeguard the rights of people diagnosed with a mental disorder (SIAA, 2013; MWC, 2012). One of the key

elements of the Act that people with such a diagnosis regularly feel the effects of is the allegedly rigorous legal test that is required to be satisfied before a person can be compulsorily detained (Crown Archive, 2013b: Part7, Ch1). However, the claim to progressiveness is that the five-part legal test offers unprecedented protection of rights in that psychiatrists now have to prove to an independent panel of judges why the removal of freedom is really necessary before it is removed.

Because of the claim of the Act to focus on the protection and furthering of rights, the five-part test is a useful framework within which to look at the arguments of the Mental Health Survivors movement about their experience of oppression and exclusion. Although not everyone with a mental health diagnosis or everyone who would self-identify as a Survivor goes through the experience of detention, it is still arguable that the fact that there is legal provision for detention for such people creates at least the potential for a unique form of social exclusion, makes this a useful way to frame the position of all those diagnosed with a mental disorder.

A. The patient has a mental disorder

In terms of System Survivors' literature, this element of the test is rejected in two main ways, although there is a great deal of overlap across these. The first, and most radical of these rejections is the denial of the existence, at the very least in some cases, of disorder. Martin Luther King's widely cited speech to the American Psychological Association, where he proclaims that 'there are some things in our society, some things in our world, to which we should never be

adjusted… some things concerning which we must always be maladjusted if we are to be people of good will' (King, 1967:1), captures this standpoint eloquently. It is the view that what we call 'mental disorder' is more accurately understood as a 'sane reaction to an insane society' (Szasz, 1974: 27). In one sense this point of view encompasses the view that the world in which we live is, in many ways an atrocious place, where a great deal of things happen to which the reasonable, natural, human reaction is rejection, distress, maladjustment.

Looking at what this vein of arguments is saying on a deeper level, it is really hegemonic definitions of 'normality' that underlies the discourse. Whether the claim is that what's going on in 'madness' is in fact a positive experiencing of greater/alternative dimensions of life (Baker, 1991), that it is a counter-hegemonic way of thinking/behaving, or that it is a completely natural response to a highly problematic society, the point that framing this as 'mental disorder' is not only inappropriate, but oppressive and damaging, is not only an important one, but one which offers a positive framing of something which is otherwise seen as a problem. Dan Goodley suggests the prospect of seeing the non-normative 'not as pathological but as possibility' (Goodley, 2012: 66), in his positing of a post-conventialist discourse. Within this framework, the experience of the person labelled as 'mentally disordered' becomes the possibility of imagining alternative ways of being.

Second, is the perhaps somewhat more moderate, and indeed more widely held, acceptance of the existence of disorder but the rejection of a claim that this is biologically caused. This is the 'mental distress' (Plumb, 1994) model, which

argues that, although mental disorder is real, it is caused by social factors the vast majority of the time. There is a great deal of literature focusing on the subject of aetiology of mental health problems, which question the biomedical model of madness (see Laing, 1970; Bentall, 2004). Instead of a genetic explanation, which remains the dominant framing of mental disorder within mainstream psychiatry, the idea that mental health problems are socially caused is put forward.

For the purposes of a comparison with disabilities studies, the word 'disorder' can be substituted with 'impairment'. Although the idea of social exclusion is certainly central to disabilities' studies, the idea of the social penetrates deeper here, in that:

> Disablement in mental health isn't necessarily predicated upon a pre-existing impairment which is then oppressed or marginalised by society or social agents – *but rather constitutes the very thing that is deemed the illness itself* (Spandler, 2012: 15).

This is one of, if not the crucial point upon which arguments of advocates for a separate mental health agenda rest. Whether the person's experience is expressed as a positive alternative, or as distress, the consensus is that the impairment, not just the disability, is socially caused. Here, a key point of divergence from the disabilities movement arises. Whereas exclusion from ' the mainstream of social activities' (UPIAS, 1976: 20), is identified as the

manifestation of the oppression inherent to disability, it is argued in Survivor's movements that, when dissent/deviance from the structures of mainstream society is at the core of what's framed as 'disorder', 'then entry into, or back into, mainstream activities may not be our goal!' (Plumb, 1994: 15). The Survivor's movement involves a radical challenge to the underlying structures of society. Inclusion into existing society will never end the oppression of this group of people as it is existing society that causes the problem in the first place: in order for real inclusion to be achieved, a society characterised by inclusion, equality and autonomy would have to first be established.

B. Medical treatment, which would be likely to prevent the mental disorder worsening or alleviate any of the symptoms, or effects, of the disorder, is available for the patient

There is a great deal of literature that maps the problematic, minimally scientific development of psychiatry, as well as raising serious questions about diagnostic culture (see Bentall, 2004). These objections are most commonly centred around two major branches of questioning the claim that medical treatment is available which prevents or alleviates mental disorder, at least as often as it is claimed to be.

The first point relates to how 'disorder' is understood, as outlined above. If the mental distress is socially, rather than chemically caused, then a medical approach can never prevent this; it can only hope to alleviate the symptoms. Framing this problem existentially, R.D. Laing argues that we need to understand the person and his 'being-in-his-world' (Laing, 1970:17), rather than as simply a

set of disconnected behaviours and symptoms that are biologically caused and can, therefore, be biologically treated. One example of this is the way in which voice-hearing experiences are seen. Bob Sapey offers an alternative to a biomedical perception of voices, arguing that 'they are not without external stimuli. The main causes are considered to be life experiences, particularly trauma' (Sapey, 2012: 54). This vein of thinking, although not commonplace in psychiatry, is supported by some psychiatrists including, as mentioned above, Laing, as well as Marius Romme (Romme & Escher, 1989), who argue that, rather than simply being framed pathologically and subdued, the meaning of voices has to be understood. Seeing mental disorder/distress in this way creates the possibility for its origins to be overcome and avoids the de-legitimising effect of framing the experience as meaningless distress, as a medical based characterisation of illness does (Plumb, 1993).

The second problematic element here relates to whether medical interventions can alleviate symptoms, or at least whether they are the best way to do so. China Mills (2012) provides an enlightening description of a number of studies that call into question the reliability of neuroleptic and psychotropic drugs. It's not merely the case that the efficacy of such 'treatments' is in question: iatrogenic illness, either as a result of hospitalisation, or caused directly by side effects of drugs (the efficacy of which in alleviating any primary symptoms is highly questionable), is a real and serious problem for System Survivors (Plumb, 1993). While the rejection of the medical model is, in some cases based on the insistence that there is no impairment, this is not the only view. For a great number of people, the distress is real, even if it is not biologically caused. Anne Plumb

expresses the problem with a strict biomedical view, by expressing the
unsatisfactory options it creates:

> Should I be left alone, respecting my will to stay where I am
>
> for as long as I like? Or be forcefully taken for a psychiatric
>
> assessment, detained in hospital, and given strong
>
> neuroleptics, as happened. Or should there be another option
>
> – someone available to engage meaningfully with me, some
>
> temporary sanctuary provided while the next step is
>
> considered (Plumb, 1999: 468).

For Plumb, the medical framework creates a dichotomy, into which the real issue
cannot fit. It is not that, in rejecting potentially dangerous and dubiously effective
drugs that the person is asking to be left alone. Rather, the demand is that the
person must be engaged with meaningfully, that their distress be legitimised and
taken seriously, so that the underlying causes of distress can be addressed.

**C. If the patient were not provided with such medical treatment there
would be a significant risk to the health, safety or welfare of the patient; or
to the safety of any other person**

This question again calls into question normative ideas about behaviour.
According to Pilgrim and Tomasini:

> The issue is not that people jeopardize their health but the way
>
> they do this and in which context; it concerns the

discriminatory judgments about the manner in which risky

action manifests in society (Pilgrim and Tomasini, 2012: 73).

Risk-taking behaviour is widespread, arguably natural, for humans. Socially

acceptable examples can fall into the category of behaviour that is recognised to

be risky but is sanctioned nonetheless, such as smoking or drinking alcohol.   It

can also, however, include behaviours that are seen as positive despite the risk

they involve: things like extreme sport. An interesting demonstration of this,

primarily In relation to the idea of risk to others, are studies that suggest a

prevalence of traits characteristic of personality disorder among successful

businesspeople and politicians (Babiak & Hare, 2000). Key traits of personality

disorder include lack of empathy, lack of concern about the distress of others,

lack of guilt, intimidation of others and blaming others (NHS Choices, 2013).

Characteristics or behaviours, which in some instances would be symptomatic

of disorder can, it seems, often be overlooked when they serve to make an

individual socially functional.   The challenge here is not that there is no risk:

there is always some degree of risk in life. Rather, the fact that some risk seems

to be acceptable, while some is used as grounds for detention and enforced

'treatment', raises questions about how and why these standards are set. Again,

it seems to be that, more than risk itself, non-normativity is the threat.

D. Because of the mental disorder the patient's ability to make decisions

about the provision of such medical treatment is significantly impaired

The question of impaired decision-making abilities due to mental disorder once

again comes down to ideas of normativity. Framing bio-psychiatry as 'colonial

discourse' (Mills, 2012: 63), China Mills argues that these notions are formed by 'the pharmaceutical industry and psychiatry's complicity and power in framing what we can recognise as normal, abnormal or impaired' (ibid: 59). If we accept the premises of mental disorder and effective medical treatment, then coming to the conclusion that decision-making ability is significantly impaired and that intervention is therefore required, is not a great leap. However, the point is that this is not accepted in Survivor discourse. Foucault's 'Madness and Civilization' gives a detailed account of the evolution of modern day conceptions of madness: an evolution which has taken place in the particular context of post-enlightenment society, where reason has become the standard of normality (Foucault, 2001). If dissent or deviance from societal norms underlies what would, in mainstream psychiatric terms, be labelled disorder, then we can imagine where a rejection of this claim would come from. This can be illustrated by looking at how diagnoses have changed over time, depending on societal standards: we only need to look at the inclusion of homosexuality in diagnostic schedules well into the 20th century, or at the existence of Drapetomania (an 'illness' found in black slaves characterised by a desire to flee their master), as a mental disorder (Greenhill, 2013), to understand the difficulties of achieving objectivity in this field.

E. The making of a compulsory treatment order is necessary

The legal sanctioning of removal of freedoms is perhaps the most crucial point on which the experience of Survivors can be argued to be distinct from that of physically disabled people. Admittedly, some provision for this does exist in the form of the Adults With Incapacity (Scotland) Act 2000, where decision-making

powers can be granted to another individual or body where an adult is deemed

to lack capacity (Crown Archive, 2013c). Powers under the AWI Act are granted,

for example, where an adult suffers from a degenerative condition such as

Alzheimer's and are used in far more extreme cases than the Mental Health Act,

normally on a much more permanent basis. It is, therefore, relatively fair to say

that non-consensual treatment is unique to the experience of people diagnosed

with a mental disorder.   According to Pilgrim and Tomasini:

> It is *because* people with mental health problems are deemed to
>
> be inherently unreasonable that others assume that they
>
> should be 'justifiably' subjected to unequal treatment: their
>
> rights for equal treatment are held in abeyance, until they are
>
> deemed less of a risk to themselves and others. This is not then
>
> an expression of political ignorance and neglect (as has been
>
> the case often in relation to physical disability) but a deliberate
>
> and highly considered aspect of social policy (Pilgrim &
>
> Tomasini, 2012: 63).

Non-consensual treatment is not only a unique experience for Survivors: it

makes their experience of oppression unique. Whereas the exclusion physically

disabled people experience is normally rooted in society's failure to adapt to

their needs, Survivors undergo legally sanctioned, purposeful and positively

viewed exclusion. It is difficult to take seriously the protected status of people

with mental health diagnoses under the Equality Act or the UNCRPD (Crown

Archive, 2013a; United Nations, 2013), when another piece of legislation exists, which is routinely used to deny people fundamental freedoms.

Mental Health and Social Structures

One of the themes that comes out in a great deal of Survivor literature, as can be seen from the points covered above, is the relationship between mental health problems and the underlying structures of society, either in that the causes of mental distress are posited as social, or that social norms are responsible for definitions of what it is to be mentally well and that these norms are oppressive because they stigmatise difference.   Kate Millett expresses the view of the phenomenon of mental illness being caused by oppressive social norms eloquently, defining Survivors as:

> Survivors of one of the meanest systems of oppression ever
> developed. We are the ones to tell the truth, to bring the word
> that mental illness is an illusion, intellectually and scientifically,
> but also a system of social control of unprecedented
> thoroughness and pervasiveness. It is our role to expose this
> illusion, while freeing us all, for we are all constrained,
> oppressed, limited, intimidated by this phantom of mental
> illness. (Millett, 1992[1], quoted in Plumb, 1994: 7)

Millett touches on a couple of very important points here. The first is the idea

[1] Millett, K. (1992) 'NAPSNews' (journal of the National Association of Psychiatric Survivors, North America).

that the 'phantom of mental illness' is something that affects us all. This is essentially the idea that, in a capitalist society, where acceptance of and compliance with norms is key to preserving the current structure, 'the phantom of mental illness' is something that hangs over everyone as a warning of the consequences of deviance from the norm. Mental illness and its consequences - loss of liberty, detention, and institutionalization – functioning as a repressive tool in the context of a capitalist economy are widespread in literature (Pilgrim & Tomasini, 2012; Althusser, 1971). Mike Oliver describes the function of the institution as successful in that it is repressive and ideological:

> It is repressive in that all those who either cannot or will not conform to the norms and discipline of capitalist society can be removed from it. It is ideological in that it stands as a visible monument for all those who currently conform but may not continue to do so - if you do not behave, the institution awaits you (Oliver, 1999: 7).

This, as Millett and Oliver highlight, is not just a problem to be overcome for people diagnosed with mental health problems, but for every member of an oppressive and repressive society, where the potential of such a diagnosis and the exclusions it would bring with it, removes freedom, in a meaningful sense, from far more than those who are actually subject to compulsory treatment.

This brings us to a very positive view of the wider role Survivor's movements can play in working towards overcoming oppressive systems, not just for people

who share their specific experience but for all those who undergo societal oppression. Millett's assertion that exposing the illusion is part of a process of 'freeing us all' calls back into mind the sentiment of Goodley, identified previously, that the opportunity should be taken to see the non-normative as possibility rather than pathological (Goodley, 2012). This is far from a new idea and is expressed powerfully by Bernard Shaw:

> The reasonable man adapts himself to the world: the
> unreasonable one persists in trying to adapt the world to
> himself. Therefore all progress depends on the unreasonable
> man (Shaw, 2004: 260).

Framed in this way, we can see the value of recognizing the unique experience of Survivors, not only for this group of people in isolation, but because of the potential their experience and struggle against oppression have to bring about positive change for all of us: through appreciating the specificity of the Survivor's experience, there is potential for imagining and creating universal change; change which is the only way inequality will be overcome for this group and for many other people.

Ways Forward for Disabilities and Mental Health

Potential Unifying Factors

Now that Survivor perspectives have been detailed, we can return to focus on disabilities studies with a view to exploring the potential of usefully establishing Survivors and Disabilities studies as a united discipline.

Despite its almost universal acceptance among practitioners and enthusiastic adoption by policy-makers, the social model is far from unquestionably accepted either in academia, or by the disabilities movement. Vic Finklestein has repeatedly expressed his view of it as insufficient, arguing that it has been useful to an extent in furthering the agenda of disabled people in a practical sense but is limited because, as a model, it can only serve as a tool; it cannot work, as a theory would, to explain disability. (Finklestein, 2001a). This 'theory of disability' is something that has not yet been fully developed. Arguably, its development has indeed been impeded by the prominence and perceived adequacy of the social model (Thomas, 2004).

Both Finklestein and Oliver have at least begun to move towards creating a theory of disability, though, and both have expressed the need for this to be framed within a materialist perspective (Finklestein, 1980, 2001b; Oliver, 2004). There are two important points that come from such a materialist view, which have specific pertinence for relevance to Survivors. The first of these is that, although the impairment is there, the idea of a causal connection between the impairment and oppression is strongly rejected. Impairment is virtually taken out of the picture so that the question of oppression wholly focuses on the structures of society.

Related to this is the second key point that, from this perspective, the answer lies not in reform granted from above, but in fundamental societal change. Oliver argues that the 'oppression that disabled people face is rooted in the economic

and social structures of capitalism' (Oliver 1999: 6) and that, therefore emancipation must be a result of political change, which 'will only be achieved through struggle, and that struggles will be by oppressed groups themselves against the forces that oppress them' (Oliver 1999: 19).

These points are important in considering similarities with Survivor arguments, in that impairment is wholeheartedly rejected as the cause of oppression, although it's existence is not denied and, within this view, the idea of inclusion within mainstream society dissipates in favour of the idea that mainstream society is, in fact the problem and must be changed if emancipation is to be achieved.

Another important point for consideration here is the idea that it is not only mental distress that is socially caused. Peter Sedgwick reminds us that 'opponents of a biological, mechanistic model of causation in the psychic illnesses find easy alliances with their opposite numbers in physical medicine' (Sedgwick, 1982: 196). It is undeniable that some physical disabilities are biologically caused, but there are also a great deal of studies demonstrating strong causal links between social and economic conditions and the development of physical impairments (Moncrieff, 2008; Wilkinson & Pickett, 2010). Considering this, the insistence on keeping impairment and disability separate, which often characterises disabilities studies encourages 'people to experience their economic distress as a psychological problem and to look into themselves as if they were the cause of social ills' (Parker, 1997: 27). While the shift in disabilities studies to reject the idea of impairment as causal in the

experience of oppression has been an important one, perhaps the further step taken by the Survivors movement to reverse the causality altogether and conceive of impairment as resultant from social oppression, is something that could positively contribute to the development of a rigorous social theory of disability.

The Case for Maintaining a Distinction

Despite the clear points of concordance that can be found in critical approaches to disabilities and mental health, especially based on a materialist perspective as outlined above, there are still many who are wary of allowing the struggle of Survivors to be amalgamated into the disabilities movement. Peter Campbell is one person who, while appreciating the benefits of working in solidarity with the disabilities movement, sees an important place for a distinct Survivors movement:

> There are dangers in gathering around a flag someone else has
>
> planted, just because it flies proudly and has colours similar to
>
> our own. But if we have doubts, the answer is not to be colour-
>
> less but to raise our own flag with our own true colours and fight
>
> on alongside (Campbell, 2001:1).

Although there are demonstrable similarities in agenda across the two movements, it remains undeniable that the disabilities movement has arisen out of the struggle of people with physical impairments and their particular experiences. It is arguable that, because of this, the development of the social

model has been guided by a view that is primarily oriented around physical impairment, and that policy and practice, which has been influenced by this model, is therefore designed to respond to the needs of physically impaired people. While much of the thinking across these two groups is similar, the fact remains that the experience of survivors is distinct in many ways from that of physically impaired people so, in order for their situation to be addressed, there is a need to maintain a distinct movement, which is shaped by the particular experience of people with mental health diagnoses.

This is certainly not to say that there cannot be a great deal of solidarity between these two movements. In fact, as has been identified above, the Survivor's movement has the capacity to make a positive contribution to the struggle of disabled people through the framing of impairment as socially caused, and through the potential for creating alternative views of what it is to be human through a commitment to questioning normative values. In other words, rather than a separate movement being perceived as a negative division, a distinct Survivor's movement, which is positively allied to the disabled people's movement possesses the capacity to strengthen the struggle for emancipation, not only for people with mental health diagnoses, but also for physically impaired people and even other oppressed groups.

RESEARCH METHODS

Methodology

The research methodology of this project is built around a belief in the potential for both emancipatory outcomes and contribution to wider knowledge created through the carrying out of research that recognises and values the expertise of first-hand experience (in this case, experience of the mental health system), primarily influenced by an emancipatory research methodology. The aim of the project is to gather experience-rich data from this expert group. It is believed that the value of the participation of individuals with mental health problems in terms of the importance of their contribution to the field of study in general, and of the emancipatory benefit that can potentially be created as a result, renders not only inclusion, but a guiding role, of such individuals not only worthwhile, but essential.

It is also believed that, alongside any longer term or wider-scale benefits potentially created by the carrying out of this research, participation in the project could also prove to be an emancipatory experience for participants on an individual level, through provision of the opportunity to express opinions in a context which perhaps differs from usual forums of communication open to participants. It is important that this experience has the potential to provide some participants with a unique scope for reflection on their experiences.

An emancipatory research methodolgy underlines this project. Based around a materialist, social relational understanding of disability as the result of oppressive social forces, this approach calls the researcher to go beyond merely a participative process, to one which facilitiates self-empowerment for the recipient of oppression (Stone & Priestly, 1996). Oliver (1992) expresses the importance of a reconceptualising of traditional research methodologies, even those which adopt participatory approach:

> It is to what can only be called the social relations of research production that the failures of such research can be attributed, and indeed, it is to these very social relations that attention must be focused if research, in whatever area, is to become more useful and relevant in the future than it has been in the past. (Oliver, 1992: 102)

A materialist analysis of the societal role of Survivors, as outlined in the first chapter of this paper, demands for two observations if research conducted in light of this analysis is hoped to be considered successful. The first of these is the recognition that research is often a player in the oppressive structure, where traditional researcher-researched paradigms serve only to perpetuate and compound the oppression of the marginalised. In order for the role of research to be be reversed from one integral to oppression to one which has the capacity to end it, a paradigm shift must take place. In order for research to be emancipatory, then, the traditional role of the researcher as the expert-observer must be transformed into one of facilitating the voice of the oppressed. This

means reframing the traditional 'subject' of research as the expert. This is in line with the idea, again expressed in the previous chapter, that real emancipation can never be granted from above, but must be achieved by those who are being oppressed.

This brings us to the second, and related, observation: that menaingful and effective research must be political, not detached, where:

> The researcher must be judged by the practical relevance of his/her research to the lives of research participants. In line with the social model, relevance means the identification and removal of disabling social and physical barriers (Stone & Preistly, 1996: 703).

Without, not only a recognition of oppressive forces, but a political commitment to their removal, academic research cannot rid itself of 'notions of detached objectivity' (ibid: 702), which are 'falsely premised, if not inherently oppressive' (ibid: 703).

Finally, Stone & Priestly's definition of an emancipatory methodology states that if reasearch is:

> ... to be taken seriously then there is a need to satisfy the rigorous demands of academe at the same time as furthering the political campaign for emancipation and equality (ibid: 715).

While Stone & Priestly are right in stating that rigour is certainly not something to be rejected, it is proposed that a full embracing of non-normativity and its potential for creating change should penetrate even to a questioning and transforming of traditional forms of academia.

In terms of theory generation, this study is based around a grounded theory approach. This approach, where 'data collection, analysis and eventual theory stand in close relationship to one another' (Strauss & Corbin, 1998: 12), where 'theory is derived from the data' (ibid.), lends itself well to an emancipatory research methodology. Because theory emerges out of data analysis, where the study is shaped by themes that emerge out of the data, theory does not stand separate, but is in fact created through, the data collected and, thus, determined by the participants involved. Grounded theory has the benefit of being understandable to people who have an interest in an area but may not be familiar with the academic and theoretical discourse surrounding it. This is another key advantage from an emancipatory research approach in terms of considerations of the potential for direct benefit to participants involved.

Methods

Data gathering was performed through qualitative interviews with people with mental health diagnoses. Interviews were semi-structured, using a basic set of open questions, which can be found in Appendix I. Altogether, seven pariticpants were involved. Of these, five took part in face to face interviews, one in a phone interview, and one responded to questions via email. The two latter

arrangements were made to accommodate mobility/health issues of participants, in order that they could be enabled to participate when a face to face meeting was impractical. This is in keeping with an emancipatory reasearch approach as it is important that the researcher and the form the research takes are as flexible and responsive as possible, to allow people to participate in a way that they are comfortable with. It is important that the emancipatory view penetrates to every level of the research and that normative, potentially exclusory standards are not imposed.

Involved in the study were five female and two male participants, aged between 29 and 65. Of these, six had a diagnosis of Bipolar Disorder and one was diagnosed with Schizophrenia. All participants were based in the Central Belt of Scotland. It has been decided not to include any more specific information than this regarding participants as, due to the relatively small sizes of groups they were recruited through, it was felt that more detailed information could reveal identities of some participants.

Recruitment for research was carried out through Mental Health Peer Advoacy and Self-Help groups. The group facilitators were sent an overview of the study, which can be found in Appendix II, via email and asked to pass information on to members, who were invited to get in contact if they were interested in taking part. This served to protect group-members' anonymity as only the details of those who wished to take part were known to the researcher, and information on who was taking part was not passed back on to the facilitators. A number of groups – both more general mental health groups, and groups specialising in

different diagnoses, were contacted. Groups in Glasgow and Edinburgh, as well as some from other parts of Scotland were contacted. The involvement of a high proportion of people with a diagnosis of Bipolar Disorder, and of people from the Central Belt was not therefore intentional, but was the result of the responses received from groups contacted. It would be interesting to investigate possible reasons for this trend, however, this is boyond the scope of this dissertation.

Interviews lasted between 50 and 80 minutes, were recorded and transcribed. Participants were given a Plain Language Statement explaining the study and signed a consent form confirming that the nature and the aims of the research were understood, and that they were happy to take part. These documents can be found in Appendices III and IV respectively. Participants were offered the opportunity to verify transcripts post-interview. It was particulalry important to anonymise interviews due to the potential vulnerability of individuals involved and the sensitive nature of issues being discussed. Pseudonyms have therefore been used when referring to participants in the research. As well as this, other potentially identifying factors have not been included in the dissertation.

Once transcripts were created, data was analysed using a grounded theory approach, as outlined above. This involved coding data through identification of recurring themes, from which theories and conclusions were generated. A table detailing the regularity of occurrence of themes can be found in Appendix V. Because of the breadth of the topic and the limitations of a Masters dissertation, this study has been designed to take the form of a pilot study for a more in-depth

research project, where the aim was to identify potentially useful areas of research, which would be beneficial to explore in further detail.

Original Aims/Actual Experience

The original intention was to carry out a combination of individual interviews and focus groups, with a view, first of all, to assessing whether participants responded differently in group situations than in a one-to-one environment. It was originally envisaged that focus groups could lead to extended individual interviews. It was also envisaged, however, that, depending on participants, one approach may emerge as being more appropriate. While around twelve people initially got in contact to express interest in the study, a very small number of these were willing to participate in a focus group. It was therefore decided that individual interviews alone would be a more appropriate method for gathering data.

As has been mentioned above, attempts were originally made to contact organisations with a wide pool of members with different diagnoses. The reality was that the final participant group was largely represented by people with a diagnosis of Bipolar Disorder. In some cases, facilitators of other groups responded to the initial email, expressing that they would distribute the information, however no contact was made by any group members. In other cases, facilitators did not respond to the initial contact. There are potentially a number of reasons for this, which it would be interesting to further explore.

Additionally, all participants were living in the community, and none were under compulsory treatment orders at the time of taking part in the study – although

some had been in the recent past. More complex ethical issues are foreseen with recruiting participants who are currently in hospital – especially those under hospital based detention orders, but it is also appreciated that it would be interesting to observe the effect on data generated of including such individuals.

FINDINGS

Data from interviews was analysed with an interest in how participants understood their mental distress, in particular the extent to which they made use of the social model or whether their framework of understanding aligned more with alternative models. Themes fitting into three broad areas emerged, although there was considerable overlap across these. It emerged that social criticism was largely absent from participants' understanding of their condition. Discourse was dominated to a great extent by medical and individual frameworks. Overarching thematic areas can be categorised as Existence of Illness, Lack of Understanding and Individual Responsibility. The theme of Existence of Illness will be looked at first as it was important to most participants to stress the reality and physicality of their condition, and it became apparent that this was very much a structure within which many other aspects of their experience were perceived.

Existence of Illness

Severity

One recurrent theme across all interviews was the framing of the mental health condition as a real, physical illness. There are a number of aspects to this, but the first that should be noted is the idea of the severity of the condition. One participant expresses the extreme difficulty mental ill-health can bring:

I had a really terrible time with my illness, like I thought I was in

hell with my mania. I was really – it was awful: I was off for six

months basically when I was ill – it was really awful (Interview

with Scott, 30.9.13).

Although this was a recurring theme across interviews, participants also

identified positive aspects related to their condition in a number of instances.

Positives were identified by Scott, Martha and Suzie and included increased

creativity and insight (Interviews with author, 2013). However, Scott expresses

a strong sentiment that the positives in no way outweigh the negatives:

It's kind of like saying it's positive that someone close to you

died because you're more empathetic afterwards. It's like,

'well, I'm glad that I've got the empathy', but it's a horrendous

loss… who can say? But I would prefer never to have gone

through what I went through (Interview with Scott, 30.9.13).

Causes

One of the most important themes related to the physicality of distress was how

participants perceived its causes. The dominant idea expressed by participants

was that it was primarily genetically caused. Ideas varied from the belief that

genetic factors created a propensity towards developing a condition, which

could cause mental illness to develop given the right circumstances (Interview

with Ruby, 26.9.13), through to thinking that mental illness would be virtually

unavoidable if the genetic factors were present (Interview with Suzie, 27.9.13).

Most participants' ideas fell in the middle of this spectrum, conceiving of a combination of genetic and environmental causal factors:

> Different stresses seem to bring it on. And I think…. Well the way I see it is people have a tendency, you know, especially there's a genetic link, so they have a tendency to bipolar but it may never appear if you didn't put yourself through certain stresses or whatever (Interview with Ruby, 26.9.13)

Participants largely framed their distress within a medical model understanding of illness: often illness that could not be avoided and had very little to do with external factors. Furthermore, Ruby's statement in this quote that illness could perhaps be avoided 'if you didn't put yourself through certain stresses', highlights an individualisation even of external factors. This is something that will be returned to in the section on individual responsibility. Causality of mental distress was virtually never understood in terms of social barriers, yet this is so prominent in the literature reviewed in the previous chapter, both in a disabilities and a Survivor context.

Although causes were talked about by every participant, there was also a sense that these didn't really matter.   For example, Scott explained that, although he had thought about causes:

> It doesn't really matter what caused it. So, while my psychologist thought sexuality was probably a factor, it was a

kind of P.S., because it didn't really matter (Interview with Scott, 30.9.13).

Scott goes on to express a view that is shared by most participants:

I see my initial manic episode as being a response to all of that. And then I think once my brain was broken by that, it just - it's more likely to happen again (Interview with Scott, 30.9.13).

The idea of the broken brain is very important: whatever participants thought about causality, they all stressed the physicality of the mental health problem once they had it. For some, causality was important in this, as framing their condition genetically was part of an understanding of it as a purely physical condition. For others, understanding more about environmental causes had the potential to prevent illness for future generations, or could even help the already diagnosed individual to understand their illness and prevent episodes, again with the emphasis being on individual responsibility even when environmental causes are identified. However, even if this viewpoint was taken, the idea that once the illness was there the 'brain was broken' – a real physical condition existed – was common to most participants. This does bear similarities to the idea of mental injury espoused by Plumb (1994), where the reality of distress is by no means denied. However, as we will see in more detail later, the idea of injury framed in terms of personal responsibility, has very little in common with socially critical Survivor rhetoric.

Identity

This brings us to perhaps the most important theme in this area. The framing of the mental health problem as a physical illness was almost always closely tied to questions of identity. Suzie expresses a view shared by many participants:

> When things are really difficult, it's really helpful to have a
> positive attitude about the role my condition plays in my life – or
> could play – and it kind of helps me to put it in perspective that
> it's not my whole life - it doesn't have to dominate me, although
> at times it does…. I mean I'm not saying it never gets
> overwhelming, but yeah, I think its important to maintain the
> balance between what's you and what's the diagnosis (Interview
> with Suzie, 27.9.13).

A recurring theme in interviews was the idea of the impact of having a mental health condition, or experiencing symptoms, on participants' self-perception. This demonstrates an attempt to challenge feelings of individual culpability. However, instead of focussing on external oppressions, framing the distressing experiences on physical, pathological terms allowed participants to segregate this from their conception of their identity as a person.

A crucial stage in this process, again identified by a number of participants, was getting a diagnosis:

I was over the moon when I got diagnosed. I had symptoms for

twenty years that were unexplained… so I was really chuffed

when I got a diagnosis because I could finally get the right

treatment for a start and, you know, it would explain some of the

things I'd done over the years – you know it would explain some

of the experiences I'd had (Interview with Ruby, 26.9.13).

Being given a diagnosis legitimised the experience in a way: there was still

definitely something wrong, but rather than an inherent abnormality, there was

something wrong with the body, 'like having a broken leg' (Interview with Scott,

30.9.13). The medical explanation offered by a diagnosis allowed participants to

isolate themselves from the distress.

Lack of Understanding

Disability

Participants' understanding of their relationship to disability is of particular

interest in relation to social factors. Generally nowadays, disabilities discourse is

very socially framed. It emerged in interviews, though, that rather than talking

about disabling barriers, participants saw disability as a practical benefit,

allowing them to access resources to which they would not otherwise be

entitled:

It can be a gateway, and I realise that. And so when I actually got

the diagnosis finally, I was very happy – because I knew then

that I would get the help and I was being refused help until then

(Interview with Pamela, 27.9.13).

Similarly, Peter identifies some practical benefits of being classed as disabled:

We've got a little form that asks you if you're disabled and I put

no. I mean certainly physically we're not disabled but people

with severe cases like myself do qualify for DLA, so there is a

disabled factor there... I think we deserve our bus passes - we

deserve our DLA – if that means we have to say we're disabled

then, yes. But if I look at myself – at a form like that – then I tend

to say no (Interview with Peter, 26.9.13).

This highlights one of the most dominant ideas expressed in relation to

disability, namely that participants did identify a distinction between mental

health problems and physical disability, and often this distinction meant that

they didn't really personally identify as being disabled. However, on a practical

level, things like access to support and benefits made being classed as disabled a

'practical necessity at times' (Interview with Pamela, 27.9.13).   This is crucially

related to the theme of physicality: whereas the dominant discourse in

disabilities studies for the past fifty years has been an insistence on moving

away from talking about the individual impairment, to a focus on the imposition

of social inequalities, there was a sense here that, for participants the 'disabled'

label is a tool that can be used to prove that they are ill. This turns the social

model of disability on its head somewhat, bridging the gap between impairment and disability, rather than separating them.

On the negative side of this, participants also saw the difference between physical disability and mental health problems as something that could sometimes cause problems in terms of their condition being properly addressed or understood:

> It's easier to see that people are struggling when they have physical disabilities but mental ill-health isn't and often brushed off as 'it's just the way you're feeling so just pull your socks up' (Interview with Julie, 10.10.13).

Despite this being identified as a huge problem, however, participants were very clear that the answer wouldn't be to create a legal separation between physical and mental health problems:

> I certainly don't think it would be helpful to make a further division. I think being a group of disabled people is fine – to be recognised as that and to be given the help that disabled people are given is fine. To be cut off into a little section – I don't like the sound of that at all. It sounds like segregation… I think that would make matters worse (Interview with Peter, 26.9.13).

Being included in this not quite adequate category was felt to be preferable to the prospect of further segregation. Again, this emphasises participants' apparent insecurity in being identified as ill, at least in the eyes of others.

Participants believed the catchall term 'disability' failed to really address the needs of physically disabled people, and saw this as further reason to keep the term, but to have a more nuanced understanding of different types of disability, for the benefit of everyone:

> I think you probably can campaign together – I think you
> should, but there should be very clear definitions of the
> different types of need – very clear. Because they are very
> different: somebody who is perfectly well mentally needs a lot
> of help physically will have a very different approach to their
> life to somebody who's got agoraphobia, anxiety and whatever,
> but can manage perfectly well physically. And so you've got to
> separate the strands. I think what's lacking in people's minds is
> the ability to say 'yeah, this person doesn't function the same
> and the reason is...', rather than just chucking them all into a
> pot together, saying 'oh they're all just nutters and cripples'
> (Interview with Pamela, 27.9.13).

There was a sense that the solution to this would be a clearer understanding of different types of impairment and specific restrictions caused by these. Again,

this diverges fundamentally from disabilities discourse, which largely seeks to overcome the idea that it is the impairment that causes restriction.

Stigma

Stigma was identified by participants as a serious and on-going problem for people with mental health problems, and forms a crucial part of the area of Lack of Understanding. Stigma was seen to exist on a number of levels; the first and perhaps most obvious of these being society in general. The effects of this are evident in Martha's account of a recent experience of stigma, when she alerted her alarm company after a fall:

> The first time I called them they wouldn't come near me, they thought I'd knife them. And I was actually left on the floor for twelve hours because they didn't know what to do. And so someone who was quite credibly saying to them 'please could you help me, I've fallen and I need help to get up' – and that was their function – but they were querying because they saw the label schizophrenia and didn't know what that meant, but they knew that the media would often say schizophrenics came up behind you and knifed you (Interview with Martha, 30.9.13).

The role of the media in the perpetuation of stigma was a recurring theme in interviews and was repeatedly mentioned by a number of participants (Ruby/Martha/Peter, Interviews with author, 2013). The reality of stigma was something that was felt to be a serious barrier, and something that participants

didn't really feel had improved much in recent years. Examples of direct experience of this ranged from being treated unfairly when applying for courses, or having to fight for recognition while studying (Pamela/Suzie, Interviews with author, 2013), to overt harassment from members of the public (Interview with Ruby, 26.9.13). Participants' exploration of stigma is the first area where we see an identification of external barriers, and a feeling that being treated differently is unfair. As was the case with the question of disability, though, the emphasis is on this being caused and perpetuated by a lack of understanding of the condition. There is also a sense that participants feel they need to prove themselves not to be a danger or a burden, to overcome stigma, which again fundamentally contradicts socially framed disabilities and Survivor discourse, which is based on the refutation of a need for individuals to become acceptable to an intolerant society.

Another area identified as being problematic in terms of stigma was the self-stigmatisation of individuals with mental health problems. Scott expresses the idea that people stigmatise themselves because of a lack of understanding of the nature of their condition:

> The overall thing on stigma I think would be understanding what
> it actually is – and that helped me: I stopped stigmatising myself
> when I actually understood (Interview with Scott, 30.9.13).

This idea is closely tied with themes surrounding identity and diagnosis: Becoming more aware of the nature of mental illness, largely through arriving at

a physically based understanding of it, allowed participants to accept their

diagnosis and to stop stigmatising themselves. This echoes the framing of the

physicality of distress as key to an accurate understanding of it and reconfirms

the individual focus, if not always as the source of the problem, certainly as the

locus of its solution.

The final area where stigma was identified as being a problem was among mental

health professionals. Again, Martha recounts an experience that illustrates this:

> A CPN once said to me 'if you're unwell and going down to
>
> your shopping area, I suggest – just so you don't draw
>
> attention to yourself, you go down with – these mobile
>
> phones are wonderful – you just put it to your head and keep
>
> it to your ear the whole time you're shopping and nobody
>
> will know any the worse of you'. And I thought, 'you little
>
> rat! You're stigmatising me immediately… the very person
>
> I'm relying on to fight my pathways for me when I can't:
>
> you're stigmatising me'! (Interview with Martha, 30.9.13)

Here, we begin to see hints of a social critique; perhaps because participants feel

that mental health professionals, at least, should understand the condition, and

since they shouldn't have the excuse of ignorance, their stigmatisation is seen as

unacceptable. Because professionals should be a step ahead of everyone else in

terms of understanding, there is an expectation that they should also be

responsible for helping people with mental health problems to challenge stigma.

There is an insistence here on not being obliged to 'fit in', on being allowed to be yourself, which is more closely aligned to literature reviewed than the individual responsibility-centred tone, which dominates much of the data.

Treatment

Although there was an expectation that mental health professionals should understand mental health problems – indeed this was perhaps the only group this was expected of - lack of understanding, or lack of appreciation of the entirety of the condition, by this group was identified as a serious problem by most participants, especially in terms of mainstream approaches to treatment.

All participants identified treatment as far too medical/drug-centred. Views on medication varied among participants: Some viewed it as necessary, and, indeed, positive (Interview with Suzie, 27.9.13), while others accepted that they needed some form of medication but had serious concerns about the toxicity and side-effects of many anti-psychotics (Ruby/Peter/Martha, Interviews with author, 2013).   Most agreed that some medications were better than others and that the worst medication-related problems were caused by psychiatrists seeing their role too objectively and prescribing medication without listening to the views of the patient:

> I think there's a kind of reluctance in some psychiatrists to
> consider how or whether medications are affecting people
> adversely – so I was on medication that didn't suit me for years,
> just because my psychiatrist refused to accept that they weren't

working, so medication's really important but responsible

prescribing's really important too…. Actually the medications

that have worked in discussion with my psychiatrist have

actually helped me realise and helped him to realise what I'm

actually dealing with – what form of it I actually have. So it can

be quite empowering and quite positive (Interview with Suzie,

27.9.13).

The idea that, while medication did have an important role to play, the role of

psychiatrist as 'the head of your care' (Interview with Suzie, 27.9.13) was seen as

problematic. Ruby describes psychiatry as 'scratching the surface' (Interview

with Ruby, 26.9.13): an idea shared by most participants, that much more than

psychiatry is needed, and that the patient should play an active role in their

'treatment':

 If you can have a decent doctor – a decent GP, a decent

psychiatrist – someone who is really a person who treats you as

a person, the whole result is much better. And it can work. So,

you know, treat us like people and we'll respond like people, and

not as the beasts you think we are (Interview with Martha,

30.9.13).

Even with professionals who should understand the physicality of the illness and,

therefore, it's separateness from the identity of the individual, participants still

felt labelled, misunderstood, stigmatised by these people. They still felt judged as

a person, or perhaps more accurately, judged as not fully being a person, because of their illness. Again, although this does begin to put an onus on someone other than the individual, it feels like this is articulated as a plea to be allowed to prove oneself to be capable of interacting on a human level, to be worthy of respect, rather than a demand to be treated with respect; a request to be given a chance to prove other people's prejudices wrong, rather than those prejudices being seen as intolerable.

In addition to feeling that they should be more actively involved in their care, participants also expressed that other, non-medical forms of treatment should be given more priority:

> I think you need all sorts of treatment – I think you need your medication, you need your psychiatrists… but I think a lot of self-help – you know a WRAP [Wellness Recovery Action Plan] of some sort maybe… I'm a great believer in talking therapies and I don't think there's nearly enough of it on the NHS… Basically because they're expensive - it's a long-term thing, whereas you can get someone on pills and, you know, that's it (Interview with Ruby, 26.9.13).

Most participants expressed that only a much more holistic approach to treatment could be effective; not only the delivery of things like talking and social therapies, but a more 'joined-up' approach, where all the different professionals involved in the person's care communicated and worked as a team. The stress on

the need for a more holistic approach to treatment suggests somewhat of a contradiction: although participants repeatedly stressed the physicality of mental health problems, this was not at all reflected in the way they thought about treatment. We have seen that a physical understanding of the condition is helpful on a number of levels: for overcoming threats to identity, for seeking acceptance within society, and for ensuring access to practical help. Could a recognition of the need for more than medication indicate an awareness of more complex, perhaps more socially situated, causes, beneath a discourse very much shaped by these practical mechanisms? This is a question that will be explored further in the next chapter.

Individual Responsibility

The previous two areas have largely covered problems identified by participants, and a framing of these in predominantly individual terms. With respect to ideas about how to tackle problems faced, themes surrounding the idea of the responsibility of the person with the condition were, again, overwhelmingly prominent in interviews.

Self-Management

This is a theme that was explored to some degree by all participants. The importance of self-management strategies in dealing with mental health problems has already been touched on under the theme of treatment, and was one of the most common themes to emerge from interviews. Participants spoke about various ways of self-managing, from formal activities like developing WRAPs [Wellness Recovery Action Plans] and risk assessments, to basic things

like very regular sleeping patterns, eating well, avoiding excessive drinking, avoiding too much stress (although not all), and general 'common sense' living (Scott/Peter/Suzie /Pamela, Interviews with author, 2013). As has been identified above, stress was seen as a trigger for episodes, so self-management often related to strategies of stress-avoidance, although it must be noted that a number of participants felt avoiding stress entirely was detrimental:

> It's really trendy at the moment to look at preventing symptoms as 'early-warning signs', and to kind of gear your whole life around preventing symptoms, which actually has a really negative impact on your life because it becomes all about your condition again – preventing it from flaring up and not about whether your life is stimulating you, and it's something you're enjoying and there's a lot rewarding in it (Interview with Suzie, 27.9.13).

Again, the theme of self-management is very closely tied to identity, both positively and negatively. In a negative sense, as Suzie highlights, self-management can become a threat to identity if the person is too focused on the prevention of symptoms. On the other hand, an approach to self-management, which takes into account the importance of a stimulating life, can be very empowering: The person is in control of, rather than being controlled by, the condition, and this strengthens the idea that the illness is not the whole person. This was something that was identified as dangerously lacking in early stages of diagnosis. It was believed that if patients were helped early on by doctors to

understand the nature of the illness and how to manage it, the person would

experience fewer feelings of negativity, guilt and confusion; would feel more in

control; and ultimately crises of identity could be avoided.

Work

One of the most prominent, and perhaps most surprising, themes relating to self-

management and individual responsibility was participants' attitudes towards

work.   The idea that accommodations should be made by employers and

academic institutions was expressed, but only to a limited extent:

> For people who are well and do want to work, I think
>
> employers have a big part to play. But I do think – I've heard
>
> or read or seen that their attitudes are improving and they
>
> will look at people who are skilled, who may have had
>
> breakdowns and think about getting them back into using
>
> their skills and getting them back into work… Just give them a
>
> fair level playing field and not rule them out because of a gap
>
> in their CV where they've been having health problems
>
> (Interview with Peter, 26.9.13).

Peter's attitude highlights two key points related to employers, which emerged

from a number of interviews. First, is the idea that employers are actually very

good at not discriminating, and are very willing to give people with mental health

problems a chance – again, we find the emphasis here on being given a chance,

rather than on demanding equal treatment. The second is summed up in the

phrase 'for people who are well': Peter thought that, although employers should not be put off by a gap in someone's CV, caused by a mental health problem, he believed employer's responsibilities of anti-discrimination should not be expected to extend beyond people who had rehabilitated, who were managing their illness: i.e. to people who were currently unwell:

> I think if I was an employer I would want some assurance that
>
> the person was on top of things – you know, I wouldn't risk
>
> taking on somebody who's still having mood swings – I think
>
> somebody who's turned a corner (Interview with Peter, 26.9.13).

A number of other participants shared this view. For example, Scott felt that it would be unreasonable to expect an employer to continue to employ someone who was off sick a lot:

> To decide that someone is off sick a lot before they kind of get
>
> pushed out the door is different from saying that's due to stigma,
>
> because a non-mental illness would also attract that. I mean,
>
> that's true – if you're not here then that's problematic (Interview
>
> with Scott, 30.9.13).

It should, of course, be appreciated that Scott feels someone with a physical illness would undergo the same treatment (and, perhaps in his opinion, should). However, the absence of expectation on employers to accommodate people who are currently experiencing symptoms is another attitude that highlights the

strong emphasis on individual responsibility expressed by participants. Once again, this is a significant difference in focus from socially framed understandings of disability, and also supports themes explored earlier in the chapter about a lack of discourse about social causes of mental health problems. The fact that participants don't see society as responsible for removing barriers supports evidence from interviews that society is not considered responsible for putting them there in the first place.

Peer Support

Another way in which participants saw people with mental health problems as having a role to play was in providing support to other individuals suffering from the same condition:

> You can empathise with them because you think 'I've been like that'. It's different with paranoia or whatever: I can't empathise with people who hear voices and things like that because I've never done it. But you can just sort of see... you take one look at somebody when they're paranoid and it's really obvious.... I mean, I'm not saying I know more than psychiatrists but you maybe see it from a different perspective' (Interview with Ruby, 26.9.13).

While participants generally saw peer support as a very positive, important thing, a number of participants identified the following problem, expressed here by Suzie, that it could pose:

I feel like I've made peace with the diagnosis and there are a lot

of people who are at different stages of doing that, and I don't

feel like I'm helping them along: In a way it was compromising

my own attitude (Interview with Suzie, 27.9.13).

This is one example of a number of contradictions identified by participants across various areas: here, as in arguably many ideas relating to individual responsibility, although the illness has been framed as almost entirely physical, an ambiguity emerges, where the importance of being mentally and emotionally reconciled with, and being in control of the illness, are not just add-ons, but are of crucial importance.

Education

Finally, participants identified people with mental health problems as responsible, and uniquely able, to combat stigma and increase understanding by educating people about mental health problems. A great deal of means and forums for carrying this out were identified, and ranged from simply being open and honest with people about your condition – Scott assimilated this to 'coming out' (Interview with Scott, 30.9.13), to delivering early education in schools, and to trainee and working mental health and general health practitioners, to being involved in policy consultation and forming awareness raising groups (All participants, Interviews with author, 2013).   Using lived experience to educate other people was seen by every participant as having huge potential to break down stigma, and to improve things for people with mental health problems.

Because of this, it was seen not only as an opportunity, but as a responsibility, emphasising once again the onus being on the individual, while questions of societal responsibility are almost wholly absent. Although all participants were in agreement about the importance of this, again a problem posed by the nature of mental health problems, highlighted this time by Martha, should be noted:

> You're taken on board on all sorts of groups – steering groups, provisioning groups and groups that want to have experience etc. If you're motivated, oh boy are you taken up… unfortunately this merely gives the authorities the idea that all mental health patients are very articulate, or are very willing to give forth their views. And really the situation of chronic mental ill health is the isolation of others, the lack of confidence, and the terrible feelings of hating yourself, and not going out – you're really so frightened, you won't think of going out (Interview with Martha, 30.9.13).

Once again we find a contradiction in that something, which is recognised as beneficial and necessary, is also identified as being potentially detrimental. This idea of a tension between the importance of self-management and responsibility and the fear that if one carries this out to well, either their needs or those of other people suffering with a mental health condition, will be further misunderstood and further neglected, is a theme which emerged from a number of interviews (Suzie/Peter, Interviews with author, 2013). This again emphasises that

participants seem to feel they need to prove how ill they are in order to get both recognition and support.

To end this chapter on a positive note, we will end with Martha's observation that experience of mental distress should not be limited in scope to difficulties, but should also focus on how the non-normative experiences of these people have the potential to inspire others. This is one way in which questioning standards of normativity is alluded to, something which at least begins to suggest that the problem may be located somewhere other than within the individual:

> Everyone now is levelled out to be normal – a sheep. And I
> don't like sheep: I like people who have something else - even if
> it's a psychosis - because they're different, and that's the beauty
> of life. And difference should not be covered over (Interview
> with Martha, 30.9.13).

DISCUSSION

Theory and Lived Experience

It should be clear by now that there is a stark contrast between the tone of the literature reviewed in the first chapter, and views expressed by participants. Firstly, there seems to be very little resonance with the Survivor standpoint. If we return to Plumb's (1993) summary of the key differences between Survivor and Disabilities studies, this contrast is clear. Plumb identified disabilities discourse as being irrelevant to the experience of Survivors because:

1. The existence of impairment is accepted, even if this is rejected as being the cause of disability.

2. Physical impairment is specified as being the focus – at other points UPIAS have explicitly stated that, although they saw scope for solidarity with other oppressed groups, their focus was specifically on the experience of the physically impaired (UPIAS, 1974)

3. Exclusion from participation in mainstream society is identified as the manifestation of the oppressive experience.

What emerged clearly from interviews, however, was participants' concern that they are seen as having an impairment, that that impairment is seen as thoroughly physical, and that often integration into mainstream society is seen as proof of recovery/management of the condition. Moreover, participation in

mainstream society in terms of society reconfiguring so that people with this condition or experience can participate in society as they are, is not really expressed. Rather, participants see the onus being on them to prove to society – and perhaps to themselves - that they are fit to participate; that they are capable of being normal.

Because of the denial of impairment, or at least its framing as entirely socially caused, Survivor discourse is, if anything, more radical than a great deal of socially based theories of disability. In interviews, there is almost a complete absence of any discussion about social factors causing either impairment or disabling barriers. Participants talked about stigma but this was seen to be caused by a lack of understanding of the impairment, and the solution perceived to be a responsibility of people with mental health problems to remove this lack of understanding by proving themselves to be capable. This is a far cry from the majority of disabilities discourse, which stresses that the impairment is private and all that society should be concerned with is it's failure to accommodate difference (UPIAS, 1976). In interviews there was very little blame placed on social structures and very little expectation that society should provide solutions.

In fact, what emerged from interviews was that participants' views were most closely aligned with medical models of illness and disability. This is something, which although still present in academic discourse to an extent, is held by many to be an out-dated and oppressive framework within which to understand disabilities. Because of this, it was decided that the medical model would not be

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reviewed at the beginning of this dissertation. I considered returning to the first chapter and revising it in light of what emerged from the data, but decided not to do this as keeping the original framework powerfully highlights the disparity between academic discourse and that which was found to come from lived experience. This disparity, and potential reasons for it, will be the subject of this final chapter.

False Consciousness and Emancipatory Research

Before engaging in such an exploration, it is important to re-assert belief in the importance of an emancipatory research methodology and emphasise that it is not seen as helpful to view participants' lack of use of dominant academic frameworks as indicative of their ignorance. 'False consciousness', where the obscuring of the real source of the oppression is inherent to the experience of oppression, is posited by Mike Oliver (1999), James Charlton (1998) and others. While it is certainly worthwhile investigating the 'internalised oppression' described by Oliver and Charlton, where the nature of the oppression itself prevents people from seeing it's real cause, and results in self-blame, to assume this is what's happening is patronising and dangerously simplistic. An approach to research grounded in an emancipatory research methodology does not presume academia's privileged access to knowledge. Rather, recognising the value and importance of the views of people with lived experience, it must address the disparity by considering why it exists. Of course, it is a possibility that there are disabling barriers so pervasive that they cause internalised oppression, and that this could be responsible for the tone of the data – not to consider this would be naïve. However, the idea that existing academic

frameworks lack meaning for people with mental health diagnoses, and that this could be at least partially responsible for their lack of use of them, must also be explored.

This is not to say that the idea of internalised oppression should not be taken into account at all, especially when it comes to mental health. In reference to Spandler's claim that disablement in a mental health context is 'the very thing which constitutes the illness itself' (Spandler, 2012), we need to question more deeply what this means. Parker identifies this particular manifestation of oppression as constructing a place 'for people to experience their economic distress as a psychological problem and to look into themselves as if they were the cause of social ills' (Parker, 1997:27). This reflects Millett's statement that Survivors are 'survivors of one of the meanest systems of oppression ever developed' (Millett, 1992[2], quoted in Plumb, 1994: 7): what system of oppression could be meaner and more effective than one which generates the complicity of its victims, one which creates the conditions where they perpetuate their own oppression? Survivor literature argues that framing mental health problems as 'an illness like any other' is essential to this system: framing mental distress medically means that those suffering distress – the victims oppressive social structures – blame themselves for their suffering. This applies not only to medical models but also to the social model of disability because, within this framework, the impairment is still seen as physical; it's only that the impairment is denied to be causal in the experience of social oppression. Survivor literature

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[2] Millett, K. (1992) 'NAPSNews' (journal of the National Association of Psychiatric Survivors, North America).

says the impairment and the disability in mental health are inseparable: the disabling, oppressive structure causes the impairment and therefore, if seen as an illness at all, should be seen as 'an illness like no other' (Mills, 2012: 60).

If the nature of the illness is inseparable from, indeed if it is a result of oppression, as Survivor literature argues, then only a theory which takes into account the specific nature of this oppression and this suffering can engage on a meaningful level with people experiencing it. In order to assess whether this is happening, we must try to understand the nature of mental distress not only through the lens of academic theory, but through the experiences and thinking of people with mental health problems. In this light, the most important questions that must be asked is: why do people with mental health problems need to see themselves as physically ill, and accordingly: what is lacking from Survivor discourse that means it is not being used by these people? It should be noted at this point that a sample of seven people is far from guaranteed to be representative of everyone with a mental health problem. The limited scope and time constraints of this project are recognised and a study that explored these themes with a larger pool of participants would certainly be valuable. Similarly, it would be useful in a more extended study to carry out purposive sampling in order to ensure inclusion of participants with a wider range of diagnoses, as well as from more varied cultural, socio-economic and geographic backgrounds. With particular reference to diagnosis, it has already been noted that the vast majority of participants had a diagnosis of Bipolar Disorder, although a range of generic groups, and groups specific to other diagnoses were contacted. In a study with adequate scope and time, it would be interesting not only to endeavour to

include participants with a variety of diagnoses, but to investigate possible reasons for the greater difficulty in engaging participants with diagnoses other than Bipolar Disorder. Nonetheless, it is believed that the data collected in this study can and should be viewed as a valuable reflection of the views of at least some people with mental health problems. In particular, this is supported by the fact that very clear themes emerged across all interviews, where participants shared very similar views and concerns.

In answer to the questions posed, the first theme that must be addressed is that of the severity of mental illness. It emerged as critically important for participants to communicate the just how severe and destructive their experiences were, and central to this was their understanding of it as physical. We have seen from the data that there is a concern that, if not seen as disabled, participants wouldn't be able to access life-enhancing, sometimes life-saving, resources. So there can certainly be argued to be a practical element to the physical framing of distress: the distress really exists and a fear exists that if this is not understood physically, no help at all could be accessed. This is reflected in Suzie's concern that her ability to manage her condition most of the time excludes her from getting the help she needs, especially when she's in crisis (Interview with Suzie, 29.9.13). However, this is still too simplistic. Although there was sometimes an understanding of the disabled label as descriptively inadequate yet practically necessary, this was certainly not always the case: participants really did identify as ill, and often as disabled. The concerns voiced by Martha might illustrate deeper reasons for the importance of identifying as ill:

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Really the situation of chronic mental ill health is the isolation of

others, the lack of confidence, and the terrible feelings of hating

yourself, and not going out – you're really so frightened, you

won't think of going out (Interview with Martha, 30.9.13).

This resonates with the Survivor idea of the inherent connection between

impairment and disability but, crucially, it communicates this idea while also

stressing the severity of the experience. By no means is all Survivor literature

completely ignorant of this, but things like Szasz's description of mental illness as

a 'sane reaction to an insane society' (Szasz, 1974: 27) and King's proclamation

that 'there are some… things in this world to which we should never be adjusted'

(King, 1967:1), risk framing the experience as something closer to dissent, where

the real and often desperate distress is relegated to the background. Perhaps this

highlights one problem with socially critical understandings: No solution is

offered for the immediate problem of suffering.

One of the other key themes emerging from interviews – the question of identity

– highlights another serious issue with Survivor discourse's capacity for

application as a tool for understanding the experience of mental health problems.

Participants' emphasis on identity was overwhelmingly focused around a concern

with separating themselves from the illness: Framing their experience medically

allowed them not to blame themselves for it. This directly contradicts the

Survivor rhetoric of an unawareness/denial of social factors inevitably resulting

in self-blame (Parker, 1997). There was certainly an absence of recognition of

social blame but, for most participants, the assertion that they were not the

illness; that it was some genetic or physical defect that was situated in their body but was not an essential part of them, that caused their condition, was crucial. In fact, when it came to questions of identity, participants identified things like work, interests and relationships - in other words, social things – as integral to their essential nature far more than physical aspects of themselves. When this is added to the concern for relief of suffering, perhaps opting for a physical over a social framing of the problem is understandable. It's probably fair to sum up participants' overarching concerns as being around the severity of their distress and the fact that it's not their fault. It is arguable, therefore, that from what's available, the medical framework is the most empowering option for people: it allows them to separate the distress from their identity by blaming it on a defective body, and being seen to be ill allows them to seek at least limited help. Alternatives frame the cause of distress externally to the person, arguably more accurately positing them as a victim of oppressive structures, but it is also arguable that these don't offer much in the way of relieving the suffering of the individual.

Does this mean, then, that Survivor discourse has it all wrong? Far from it: rather, academic and layperson thinking are concerned with two different aspects of the same issue. The former focuses on the causes and, therefore, the ultimate long-term solutions to mental distress; the latter is more concerned with understanding the suffering of individuals, with a view to alleviating it in an immediate sense. Both are meaningful and both are necessary. What is needed ultimately is the development of a theory, which is rigorous enough to investigate and hopefully overcome underlying causes, while being related enough to the

reality of the experience to be meaningful and helpful to people undergoing it; what is needed is a theory that meaningfully addresses both the causes and the symptoms of mental distress.

Conclusions

The aim of this project, because of the extent of the area of investigation and the limited scope of a Masters dissertation, was to identify future areas of research that would be useful for people with mental health diagnoses. Overcoming a serious disparity between academia and lived experience through striving to create a theory which can be more meaningful to people experiencing mental health problems is an important challenge to be left with and, while providing an answer to that question is certainly beyond the scope of this project, perhaps the beginnings of a solution can be offered. Crucially, it is posited that the question of self must be looked at more closely. It is posited that the both the academic and lay understandings are beginning with a misleading abstraction of personhood. Without risking oversimplification, social relational understandings of mental illness can be argued to frame the person as an isolated, private individual entity, who society happens to (Thomas, 2004; Finklestein, 2001a). On the other hand, what emerged from interviews with participants was a Cartesian mind-body distinction, where the person is, if anything, essentially social, and mental illness is the trapping of this person inside a defective body.

Marx, who was, it is important to note, a founding proponent of the idea of false consciousness, famously said of the person:

It is not the consciousness of men that determines their being, but, on the contrary, their social being that determines their consciousness (Marx, 1973: 67).

Understood within a materialist understanding of the world, where the physical is inherent to the social, where social relations necessarily involve physical subjects, being comprises physical and social elements, a conception of personhood that attempts to abstract the self from either physical or social forces, is inadequate and ultimately nonsensical. Human beings are complex and oppression is not a simple case of villains and victims. Both of these understandings posit a 'clean', innocent self, victim to an alien force.

It is concluded, therefore, that while academic discourse on mental distress is not necessarily wrong, it is not looking at the whole picture. Academic discourse has a lot to learn from its inability to reach ordinary people – or from their reluctance to engage with it – and crucial to this is allowing the voice of lived experience to highlight what's missing. It would not be constructive to demand a throwing out of the entirety of academic theory, because false consciousness has to be recognised, at least as a possibility. However, while false consciousness is a phenomenon that must be recognised, the temptation exists for academics to adopt an emancipatory approach to research but to fall back on the idea of false consciousness whenever experience contradicts theory. Lived experience is valuable and can and should meaningfully inform theory. In this case, both forums have part of the picture, but both are in danger of being blinded to the real nature of the problem if cohesion is not achieved. To answer

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the initial research question, then, an area of research that would be useful to people with mental health diagnoses would be the seeking of an understanding of mental distress which marries theory and lived experience, which is concerned with both causes and symptoms, and which is therefore capable of ultimately solving the problem, while also having scope to make sense of and alleviate suffering in the meantime.

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Appendix I

Interview/Focus Group schedule

Project Title: **Exploring future research areas for mental health system survivors**

Researcher: Marie-Claire Lacey

Nb. Interviews will adopt a semi-structured format. Therefore, it is not possible to provide a decisive list of questions. What follows is a list of topics it is envisaged will be covered in the research. This is an outline of questions that will be explored in focus groups: depending on emergent themes from these groups, questions for interviews may be modified. It is not planned that further ethical approval will be sought for this, however, questions will be formulated in consultation with the project supervisor.

1. How did you get involved in this group? What do you see its role as being? Does it fulfil this role?

2. Do you think 'mental illness' is a useful term? Why/why not? Are there preferable/more accurate terms?

3. What do you think about the way society defines/treats people diagnosed with mental health problems? How do you think society should treat these people?

4. Thinking about the people in this (group), in what ways is society successful/unsuccessful in responding to people in this group? How/how much has this changed over time?

5. What do you think the role of mental health workers is/should be? How effectively is this role carried out? What improvements/changes should be made?

6. What do you think the role of social workers is/should be? How effectively is this role carried out? What improvements/changes should be made?

7. Do you see people with mental health diagnoses as a unified group, or do you think there are important divisions in this group?
   - eg is there a significant difference between people diagnosed with schizophrenia/depression/personality disorder?
   - do things like class/gender/race make a difference?

8. Do you see people with mental health diagnoses as part of the wider group of people with disabilities? What are the similarities and differences?

9. Do you think it's useful or detrimental for people with disabilities and people with mental health diagnoses to work together as a group towards shared goals?

10. How would you see positive changes being achieved for people with mental health diagnoses in society? How do you see society changing the way it interacts with this group of people?

11. Do you think research has a part to play in this? What kind of research, eg would more research by people with mental health diagnoses make a positive contribution?

12. What areas of research would you identify as being useful?

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Exploring future research areas for mental health system survivors

A study into the perception of mental health problems in a social context

This study aims to explore the experience of living with a mental health diagnosis. I would like to find out how people who have been involved in the mental health system perceive this, and how accurately they think society understands it. Through finding answers to these questions, I hope to be able to identify areas for future research that will be useful in providing society with a better understanding of the experiences of people with mental health diagnoses.

I'm looking for people with lived experience of the mental health system to take part in focus group and individual interviews exploring these questions. You have been approached because, from your involvement in (group), I have assumed that you have had some sort of lived experience of Mental Health problems, or the Mental Health system.

 Participation is completely voluntary. If you do decide to take part and then change your mind, you are still free to withdraw at any time without giving a reason.

All information collected about participants during the research will be kept confidential.

If you are interested in taking part, please contact me, Marie-Claire Lacey (0610595l@student.gla.ac.uk), (07915970832). I also have an information sheet with more detailed information about the study: If you would like to look at this before deciding, please also get in touch.
If you would like any more information about the study, or have questions at any time, please also feel free to contact me or my supervisor, Dr. Jo Ferrie (jo.ferrie@glasgow.ac.uk).

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PLAIN LANGUAGE STATEMENT

Project Title: Exploring future research areas for mental health system survivors

Researcher: Marie-Claire Lacey

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.
Thank you for reading this.

Purpose of the study
In the 1970's, both disability and mental health system survivors' activist movements began to challenge the way physical disability and mental health were perceived in a social context. Both of these movements have continued to work towards these goals.
While both movements would agree that their experiences of oppression have some things in common, they also both agree that there are many aspects of each experience that makes it very different from the other. Both disabilities and mental health activists believe that the struggle of the two groups for rights and equality need to be separate and need to respond to the unique nature of each group's experience.
Despite this, from a legal perspective, mental illness is normally treated by society as a type of disability. Mental health system survivors' movements believe that their oppression cannot be overcome through inclusion in the activism of the disabilities movement, as they believe that this doesn't represent issues that affect them adequately.
This project aims to respond to this problem by investigating the views of people classed as having Mental Health problems on how they think they are and should be seen by society, and how problems they experience as a result of Mental Health issues can best be overcome. This project is part of a Masters dissertation and will aim to use the views expressed by the participants to highlight possibilities for useful further research in this area.

Why have I been chosen?
We believe that first-hand experience is a unique and valuable source of knowledge. You have been approached because, from your involvement in (group), I have assumed that you have had some sort of lived experience of Mental Health problems, or the Mental Health system. Because of the type of group you're involved in, I have also assumed that you

already have an interest in the rights of people seen as having Mental Health problems, and therefore, might be interested in taking part in this study.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?
I will invite you to take part in group/individual interviews, where we will discuss your perspective on the issues highlighted above. The interviews will be 'semi-structured', which means that I will come with some ideas of questions I would like to ask but this won't be rigid: The issues and ideas we talk about will be largely shaped on your thoughts about the general area of research. Interviews will be recorded and recordings will be stored securely and only accessed by myself and my supervisor. The recordings will be destroyed when I don't need them anymore and no later than one year after my dissertation has been submitted. Interviews should take no more than an hour.
I am looking for around ten people to take part in the study. I am sending this invitation through (group) and asking you to respond if you want to take part so that I will only have your contact details if you wish me to.
Because (group) has a relatively small membership, it's possible that other people in the group might become aware that you are taking part in the study. If you don't have a problem with this, that's fine. However, if you would rather others didn't know you were taking part, or would rather not take part in group interviews for any reason, let me know and we can work this into the arrangements for your interview.

Will my taking part in this study be kept confidential?
All information, which is collected about you during the course of the research, will be kept strictly confidential. You will be identified by a pseudonym and any information about you will have your name and address removed so that you cannot be recognised from it.
The only time I would breach this confidentiality would be if you told me something that I believed put you or another person in danger, for example if you told me you planned to harm yourself or someone else. In this case, I would have a responsibility to report this.

What will happen to the results of the research study?
The results of this study will be published as part of my Masters dissertation through the University of Glasgow. This project may also be published in academic journals or presented at conferences. Published work may use direct quotes but pseudonyms will be used to ensure participants cannot be identified. The aim of this project is to identify areas of further study, which I hope to conduct as part of a PhD, so the results of this study might also appear in my PhD thesis.

Who has reviewed this study?
The project has been reviewed by the Glasgow University College of Social Sciences Research Ethics Committee. This means that they have looked at my proposal for the study and don't have any problems with me looking at the areas I want to look at, or with me inviting you to participate.

Contact for further information
If you would like any more information about the study, or have questions at any time, please feel free to contact me, Marie-Claire Lacey (0610595l@student.gla.ac.uk), or my supervisor, Dr. Jo Ferrie (jo.ferrie@glasgow.ac.uk).

If you **have any concerns regarding the conduct of the research project you can contact the College Ethics Officer by contacting Professor John McKernan (John.McKernan@glasgow.ac.uk).**

University | College of
of Glasgow | Social Sciences

Consent Form

Project Title: **Exploring future research areas for mental health system survivors**

Name of Researcher: Marie-Claire Lacey

1. I confirm that I have read and understand the Plain Language Statement for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I consent to interviews being audio-taped.

4. I acknowledge that I will be referred to by a pseudonym in any publication arising from the research.

5. I acknowledge that I can request copies of interview transcripts to be returned to me for verification.

I agree / do not agree (delete as applicable) to take part in the above study.

_____   _____   _____

Name of Participant   *Date*   *Signature*

_____   _____   _____

Researcher   *Date*   *Signature*

> 1 copy of this agreement will be given to the participant and 1 will be kept by the researcher

Table Showing Regularity of Themes in Semi-Structured Qualitative Interviews

INTERVIEW DETAILS		THEME - NUMBER OF OCCURENCES									
PSEUDONYM	**DATE / TYPE**	Severity	Causes	Identity	Disability	Stigma	Treatment	Self-Mgmt.	Work	Peer Support	Education
Peter	26.9.13 *In person*	2	5	4	8	8	12	9	7	2	4
Ruby	26.9.13 *In person*	2	4	5	4	13	10	6	4	4	10
Pamela	27.9.13 *In person*	1	2	3	11	10	8	2	2	4	2
Suzie	27.9.13 *In person*	4	7	9	6	13	18	9	2	2	6
Scott	30.9.13 *In Person*	3	17	18	9	10	14	16	6	3	8
Martha	30.9.13 *Phone*	1	8	5	2	17	18	3	3	5	9
Julie	10.10.13 *Email*	0	2	2	1	3	3	2	0	4	3