

WOMEN'S VOICES:

AN ANALYSIS OF VIEWS ON SERVICE USER INVOLVEMENT IN MENTAL HEALTH CARE

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ABSTRACT

UK mental health policy increasingly emphasises the necessity to involve service users in aspects of service planning, practice and evaluation. There is also a growing self-organised user movement, demanding greater and more sophisticated levels of such participation. Despite this apparent consensus between policy makers and service users, explicit guidance for implementation is lacking and, arguably, staff resistance and other institutional barriers stand in the way of systematic and meaningful involvement. Historically, mental health services have reproduced various societal structural inequalities in the treatment of women service users, in particular. Service user perspectives, motivations and accounts of experiences of active involvement are relatively under-represented in the published literature.

This study utilised discourse analysis of texts generated by semi-structured interviews with stakeholders in mental health services to explore the ways in which these participants make sense of the notion of user involvement. The overall study included samples of both staff and service users. Twelve staff were interviewed including practitioners, managers and hospital chaplain. Eight service users were interviewed including, service users, service user representatives and a service user advocate.

The findings indicate three broad discourses in the service user narratives. The first discourse constructs different dimensions of identity. Second, is a discourse that expresses ideas coalescing around notions of gender. The third discourse constructs the organisation within which the service user activism takes place. The staff draw upon these same discourses, and also draw upon staff identity in relation to service users and service user involvement. These discourses are presented as affording potential to make a contribution to informed development of mental health services such that user involvement initiatives are better supported and sustained. They are also available to the user movement itself to draw upon in their ongoing political and practical engagement with services and forms of organised involvement.

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DEFINITIONS AND ABBREVIATIONS

Definitions

Ongoing debate exists over the correct terminology to apply to people who find themselves in need of mental health services. Favoured terms change over time, often in line with privileged ideologies. None however are without specific criticism, but authorship demands a choice is made over which terminology to use. The following working definitions are used in this study.

‘Service user’ denotes any person who is currently using mental health services, former users of mental health services, adult service user representatives, and advocacy workers. Alternative definitions are used elsewhere, such as ‘customer’, ‘client’ or ‘patient’. However for this study service user is adopted, since it is seemingly, the most widely used, easily recognisable and current term of reference.

‘Service user involvement’ describes active engagement. This can be the individual involvement of a service user in their own care, or with mental health services, or participating in an active mental health service user group.

The term ‘staff’ used in the study refers to statutory health care practitioners qualified and unqualified, mental health chaplaincy services, managers, senior managers and Trust Leads.

Abbreviations

DoH	The Department of Health
DA	Discourse Analysis
NIMHE	National Institute for Mental Health England
SC	Social Constructionism
(.)	a short pause in transcribed text, something like a comma
...	a longer pause in the transcribed text, something like a full stop

CHAPTER 1: INTRODUCTION

1.1 Introduction to thesis

As an introduction I will discuss the impetus for this study, briefly describe the appropriate methodology, outline the contents of the thesis, and end by sharing my personal location.

This thesis details how women staff and service users make sense of service user involvement in the mental health context. Mental health policy increasingly emphasises the necessity to involve service users in aspects of service planning, practice and evaluation (CMO 2001, DoH 2002, NIMHE 2002). However, according to Campbell (1996) ideological change is slow to shift the balance of power between the mentally ill and society without mental illness:

'Madpersons as empowered consumers of services and madpersons as equal citizens are two quite different propositions,... despite the good work of user/survivor action groups, current and former mental health service users are held in little higher regard now than they were in 1983'

People with mental illness experience different levels of inequality. The government has made explicit a concern that women in mental health care are treated as a marginal group (DoH 2002). However, woman's position contradicts statistical evidence of a higher incidence of women suffering with mental health problems (Kohen 2000, DoH 2002). Feminist debate confirms a view that woman's social construction affects pathologising women. Arguably, mental health practitioners find it difficult to think constructively about the effects of structural inequalities on the lives of clients, and have little awareness of the ways that mental health services and organisations are shaped by these inequalities.

There is a need to understand the complexities of service user involvement in such a context. There is a clear need to look at why service users become involved in service delivery, in particular women in mental health, in order to inform the organisation and the user movement. If women are to be supported in service user involvement, greater understanding is needed; this study seizes this opportunity.

The core research question that underpinned this study is:

- How is service user involvement of women in mental health services understood, in the context of one locality and organisation?

A social constructionist perspective underpins the study. Social Constructionism is useful because it does not present concepts as having an independent reality and as such does not set a fixed meaning to concepts expressed in data. Chapter 2: Background, deals with the two themes in the literature: psychiatry and the service user, and women and psychiatry. Chapter 3: Methodology will illustrate the philosophy and then outline the method application. Discourse Analysis methodology (Potter and Wetherell 1987, Burr 2000) is followed, using semi-structured interview data, from twenty participants (staff, service users, service user representatives and professional advocates). Chapter 4: follows with the presentation of available talk under the broad themes identity, gender and the organisation of service user involvement. Chapter 5: Discussion identifies various constructions of service user involvement from the available talk, and the impact such constructions have. Within this chapter the implications of the way people make sense of service user involvement are presented along with some thoughts about active user involvement at a local level. Some recommendations mark the end of the study. These are presented in a succinct way, in order not to impose any constraint on the discussion and available discourse found, but to add to the available talk with some suggestions to the NHS Trust concerning service user involvement.

This issue is of particular interest to me as a woman, as an Occupational Therapist working in mental health services primarily with women, as a manager of a team that makes continued efforts to gather service user views. Also, I was a mental health service user in-patient in the late 1980s, early 1990s. I chose Discourse Analysis as a method suited to studying the potential diversity of expression and the extent to which such discourse acts to construct the social world of staff and service users in mental health.

CHAPTER 2: BACKGROUND AND LITERATURE

2.1 Introduction

This study is concerned with the various ways in which service users and staff make sense of the issues concerning service user involvement, also called 'patient and public involvement', in the context of mental health care. More specifically, the emphasis here is women's involvement and how this is understood. As such, the background takes in the following four key areas of literature:

- Policy developments in mental health and wider health and social care;
- The development of a distinct service user movement and the relationship with psychiatry;
- Appreciation of the wider social factors in understanding the position of women in society. The competing theoretical perspectives that present to explain mental health of women, in particular; and
- The language that is used in this context, specifically drawing on the construction of difference.

Given the diversity of background literature, my search strategy proceeded in various ways. Searching electronic databases: MEDLINE, PsychINFO and Proquest was based on the following search terms: 'user involvement', 'service user involvement', 'mental health', 'women service users' and 'expert patient'. Subject 'Readers' provided a valuable resource for proponent speakers/writers on the subjects of mental health, user involvement and women in mental health. Bibliographies and reference sections throughout, would lead me into further studies. The DoH, NIMHE, Sainsbury Centre for Mental Health, and the Institute for Public Policy Research websites were searched for national policy, guidelines and study consistent with the search terms. Exclusions to my reading included: carer-focussed studies, work outside the western world and studies earlier than 1980. My supervisor guided me towards relevant material throughout the study.

2.2 Political ideas: policy

Generally policy follows ideology; however any one policy may be reached from different ideological standpoints. Post-war economics determined the impractical cost of maintaining large-scale hospitals and the consensus was for a western liberal

democracy with health care framed in an egalitarian model. This was coupled by post-war postmodernism presenting a worrying critique of mental health care emerging with the 'Anti-Psychiatry Movement' in late 1960s America. This movement challenged biological theory presenting a new construct of the mad person as experiencing intolerable distress contained by contextual, interpersonal and psychodynamic structures and processes (Burston 1996). People were making sense of madness very differently, controversially, as plausible. Foucault (1961) conjectured psychiatry to be a form of power (coupled with prevailing knowledge) existing in society, with the asylum symbolically promoting rationality, surveillance and discipline. Elsewhere, the asylum became regarded as a total institution... providing for those seen as unwanted threats (Goffman 1961). In Britain, convenience and public safety were increasingly recognised as goals that predominated in patient care. Observations of patients in institutional care reported apathy, social withdrawal and passivity as commonplace (Pilgrim and Rogers 2001). A moral authority for urgency in hospital relocations saw a political shift in the psychiatric discourse. 'De-institutionalisation' and 'normalisation' were advocated along with the dual responsibility of social services and mental health care. Psychiatric practice accentuated medical *and* social models of mental distress.

Worsening conditions in the 1970s led to government fears regarding the sustainability of a socialised welfare state. This consolidated an ideological shift towards a consumerist approach to health care by British central government, and shaped emerging policy. Explicitly, the message was one of sovereignty of the individual. Translated into legislation, 'The NHS and Community Care Act' (1990) talked of choice and the recipients of NHS services as customers. For mental health, the idea of consumer choice was, and still is, strongly contested: most significantly because coercive Mental Health legislation negates choice, the relationship between service users and professional is generally longer term than for physical care, minimising choice, and mental health status is associated with social stigma bearing upon employment, social and relationship choices. Central to this critique is the way services are delivered to people with mental health problems who historically have been seen as incapable of making choices (Pilgrim and Rogers 2001, Rankin 2004). Campbell (1996, p.223) comments with bitter insightfulness:

'although it is clear that the status of the service user within the mental health system has improved substantially over recent years, the status of the loony in the community seems to have gone in the reverse direction.'

Latterly, New Labour's, third way politics arguably represents a continuation of the former Conservative government rhetoric of consumerism and privatisation. However, Labour policy in mental health emphasises working with service users in health care highlighting partnership shaped by the *'goal of delivering more personalised responsive services and social inclusion'* (Rankin 2004, p.6). Plural and often seemingly contradictory ideologies exist; the individual has become a consumer citizen. Services are urged to make efforts to include individuals in both their own care and organisational decision-making.

Specifically, *'Patient and Public Involvement in the New NHS'* (DoH 1999, p.1) is guidance for Trusts to assess local progress on patient and public involvement, addressed by the dogma that the NHS needs to:

'ensure it systematically engages with and listens to, it's local communities...genuine not token'.

The guidance describes involvement as a means to tackle the social exclusion and health inequalities made explicit by the Black Report (Pilgrim and Rogers 2001). The guidance continues to advocate particular effort towards marginalized groups, suggesting under-representation is the result of lack of support, and it calls for key actions around educating staff about the benefits of service user involvement.

The *'Expert Patient'* (DoH 2001) makes explicit a widespread recognition of the service user, and their in-depth knowledge of living with mental health problems and of mental health services. The increasing population of people with chronic illness is reported as the inspiration for the Expert Patient's self-management programme, where self-management training aims to skill people in confidence, resourcefulness and self-efficacy. Arguably, it has the implicit aim of enabling people with chronic health problems to maintain or consider a position in the workforce; thus reducing social security costs.

Specific key government documents that focus on women are 'Women's Mental Health: Into The Mainstream' (DoH 2002) and 'Mainstreaming Gender and Women's Mental Health' (DoH 2003) which give attention to women's involvement- as the greater users of mental health services and as a marginalized group. The stakes are high; gender awareness, understanding, consultation, listening exercises and necessity to provide information, interpreting, or training to help women be involved in processes that may be unfamiliar or daunting to them (DoH 2002). It begs the questions, what if women do not want to be involved? Are we assuming that women differ from men with respect to these needs? Will consultation move into implementation? The overall message is for social inclusion with organisations urged to effect an Implementation Strategy and address resource management through involvement exercises. The importance is reiterated by the DoH (2003, p.11) statement that:

'The delivery of effective women's mental health care is dependent on... genuine service user and carer involvement'.

2.3 User Involvement: 'The Mental Health User Movement'.

Examples of collective user action are recorded as far back as the 17th Century (Campbell 1996) However, the User Movement in Britain is acknowledged as having gathered pace over the last 20 years, arguably in reaction to political and ideological developments such as; Anti-Psychiatry de-institutionalisation and the social model of disability (Campbell 1996, Pilgrim and Rogers 2001, Simpson 2002). As such, the User Movement can be regarded as a *new* social movement, where collective activity is organised around interests, often anti-authoritarian (Campbell 1996, Scott 1990, Pilgrim and Rogers 2001) and critically seen to hold a somewhat quixotic supposition by being in confrontation with elites (Scott 1990).

Campbell (1996) cites 'From Patients To People' (1985), an international conference held in Brighton as critical to the User Movement because the demonstration of powerful and effective User Movements in other countries highlighted the need for pragmatic development in the UK (Campbell 1996, Simpson 2001). The User Movement has responded by being open to invitation and accepting of invitations from health and social care, regardless of their diversity, making contributions to

range of activities (Barnes and Shardlow 1997, Harrison 1999, Mowell and Harvey 1999, Simpson 2001, Bertram 2002, Minett 2002, Tait and Lester 2005) beyond support, to consultation concerning the planning and provision of services, to research activity (Beresford and Croft 1993, Simpson 2001), to promoting a positive image of mental health and public involvement, to advocacy schemes, training (Read 2001, Minett 2002), and user-led services (Tait and Lester 2005).

The Sainsbury Centre for Mental Health (2002) identified 318 organised user groups representing 9000 service users (Campbell 1996). There is a body of research attempting to conceptualise user involvement activities into a framework (Pilgrim and Rogers 2001, Tait and Lester 2005). Beyond conceptualising, the key challenge appears to be an organisational one since statutory arrangements are inconsistent with the radical socialist ideology that the User Movement is founded upon (Pilgrim and Rogers 2001). However, there are few reports detailing user views and accounting the effectiveness of involvement (Crawford et al 2002).

2.3.1 Issues, levers, and barriers

The language used to describe people who use mental health services generally carries a subtext, and descriptors like patient, client, survivor, consumer and now service user are the subject of various debates (Chamberlain 1993, Everett 1998, Hugo 2001, Pilgrim and Rogers 2001, Read 2001, Simpson 2001, Minett 2002, Beresford 2005, Tait and Lester 2005). Campbell (1996, p.224) highlights the importance of language as contextual in the debate in his statement:

'madpersons as empowered consumers' and 'madpersons as equal citizens'

Moreover, Campbell highlights empowerment in relation to the position of mentally ill persons in society and in the context of user involvement activity. Empowerment means different things to different people and ideological paradigms such as citizenship and consumerism are embedded within ideas about empowerment. Consumerist empowering interventions focus efforts on access to resources, which may be achieved through financial wealth and means. Alternatively, trust and faith in medical knowledge may be seen as central to the doctor/service user relationship, some service users choose dependence on a paternalistic doctor (Lupton 1997).

Conversely, a more collectivist view would empower citizens with equal rights of participation in a western liberal democracy. It is argued that it is easier to devalue certain individuals' needs and disempower where consumerist ideology is dominant because disadvantaged groups generally do not perceive power among themselves in the first instance (Read 2001, Bertram 2002, Minett 2002). Hence, critics argue the contradiction between government asserting empowered citizenship from a consumerist political ideology (Holmes and Saleebey 1993, Servian 1996, Barnes and Shardlow 1997, Lupton 1997, Hickey and Kipling 1998).

Equal control between service users and providers is advocated (Read 2001, Rea 2002) and ultimately, user-led initiatives are reported consistently to have benefits such as gaining confidence through the solidarity of a group in the absence of restrictions by statutes (Barnes and Shardlow 1997, Mowell and Harvey 1999, Rose 2001, Simpson 2002, Forrest and Masters 2004, Tait and Lester 2005).

The Government is keen to iterate user involvement as a means of accountability, democracy and improved communication. Alongside that, the established benefits to service users range from personal gains such as confidence, self-esteem, increased social contacts, learning skills, increasing employment potential to gaining a financial supplement to benefits. Importantly, service users emerge as experts in their experience providing an alternative perspective for practitioners to reflect upon (Rose 2001, Simpson 2002, NIMHE 2003).

Elsewhere, conflict in service user involvement activity is predicted, perhaps echoing professional insecurity and ingrained staff cultures (Barnes and Shardlow 1997, Read 2001, Minett 2002, Wright and Rowe 2005). Practical obstacles for service users include sustaining mental well being (Secker et al 2001, Minett 2002), retaining social security benefit (Secker et al 2001), stigma (Read 2001, Secker et al 2001, Minett 2002, Tait and Lester 2005), and the confidence to develop an identity beyond mental illness when it is the status as mentally unwell that endorses a position as service user activist. In this sense, activism becomes an individual's choice activity, since according to Read (2001, p.18) user activism *'takes real desire, confidence and competence that not all service users have.'*

Resistance from the medical hierarchy, conceptual barriers, mental health legislation and token involvement have been variously suggested as barriers to progress (Wiles 1993, Barnes and Shardlow 1997, Read 2001, Minett 2002, Rea 2002, Simpson 2002, NIMHE 2003). Real progress is something the mental health User Movement sees as complicated by the contradiction from a government developing legal procedures for detention whilst providing guidelines on social inclusion, choice and involvement.

Over-involvement by small numbers, attracting new members, recompense to service users for consultation, the imbalance between the activity of user groups and resource allocation from statutory bodies, and the ongoing debate about defining people involved as activists are some current problematic issues within the User Movement. Now emerging in User Movement literature is the threat of fragmentation, leading to the need for unification and according to Campbell (1996, p.224)

'a coherent overall philosophy that can integrate a clearer range of discrete focuses.'

Arguably this issue is underpinned by debate within the User Movement. Tension surrounds the organisation of user involvement around an incorporated model as opposed to independent groups. Maintaining alliance with the state, or organisation in order to continue to enjoy resource and relative gains, without being incorporated is complex, and may be greater than the User Movement can resolve alone. It has much to do with consumerism and broader government ideology and with the way power is developed, located and distributed (Pilgrim and Waldron 1998, Pilgrim and Rogers 2001, Pilgrim 2005).

2.4 The position of women in society

Generally speaking, for most of history, women have been placed in positions inferior to men. Where men's activities as providers are esteemed, women's domestic activities are devalued. There is a sense that even childbirth a vital and valuable contribution to humanity, has been used as a reason to exclude women from public status and to sustain women in domestic roles (Lorber 1994). This social positioning and distinction is documented as far back in time as Aristotle who conceded that men were superior by nature: nature describing muscular strength and an ensuing mental

capacity. The goal of women's emancipation has generally been for equality: famously a particular kind of equality, voting rights, represented by the Suffragette movement of the early 20th Century. Even with the right to vote women continued to retain inferior status, arguably owing to political representation by men, who reflected a male discourse.

World War II resulted in women extending towards a more public life and professional roles, where previously only nursing and teaching had offered women professional status. (Rinehart and Garner 1991) However, post-war political and social influences linked women's return to domesticity, and more specifically, motherhood in order to boost the population.

'Second-wave feminism' emerged in the 1960s with a new focus: 'sexism'. The effort was against the social conditioning that persuaded women that their place was domestic in the private domain, and their duty was to be attractive. Arguably, this socialisation effectively disempowered women, excluding women from public achievement (Greer 1971). At the same time, women were being sexually liberated by the invention of the contraceptive pill. The Equal Pay and Sexual Discrimination Acts of the 1970s legislated for equal rights for women in the public domain. Adversely, social action and campaigning were suppressed in the 1980's, and included a rejection of feminist ideology, despite a woman Prime Minister. Ideologically, consumerism prevailed and women's stereotypical (attractive and feminine) qualities were upheld in society.

Today, feminists dispute equality goals and instead espouse liberation. Equality goals may be considered ideologically conservative, stopping at providing women equal access to the present condition of men, which debatably would not eradicate the oppression that consumer marketing and society impose on women. As Walby (1990) contended women liberated from domestic life

'now have the whole of society in which to be exploited.'

Accordingly, feminists consider a different world is needed with different underpinning values; the weak unexploited and liberty championed.

2.5 Women and madness

Extensive studies have attempted to address gender differences in diagnosis, and the experience of service use. In general population studies, gender inequality in the *overall* prevalence of psychiatric disorder is inconclusive. However, research shows differences in the prevalence of certain mental illness types, particularly in relation to the epidemiology, and to a woman's physiology (Kohen 2000). Studies suggest that depression is twice as common in women than men, with even higher ratios occurring for other neuroses, culminating with a difference of 10 women to 1 man suffering with an eating disorder. Studies show that there are certain biological and physiological factors among women that have become pathologised as mental illness; depressive disorders in particular. Pre-menstrual Dysphoric Disorder and Perinatal Psychiatry are diagnostically exclusive to women. Borderline Personality Disorder is more commonly diagnosed among women with a ratio of 7:1 (Kohen 2000). For severe mental disorder, no consistent differences are apparent in the incidence. However, studies suggest that an earlier onset and a more severe disabling course for men leaves women living longer in the community with the condition. This therefore skews prevalence statistics. Women's longevity also impacts statistics for Alzheimer's Disease (Gold 1998, Rhodes and Goering 1998, Kohen 2000, Ramsay et al 2001, Ussher 2001, DoH 2002).

British Census data for residents in psychiatric beds have indicated that women outnumber men consistently and the gap is only recently narrowing. Busfield (1982) suggests that the gender difference data, taken together, appears to be narrowing because the assessment of violence, sexual violence and child abuse is being pathologised rather than necessarily criminalized, and these incidents are more commonly occurring for men than for women. Here, Busfield is alluding to mental illness as essentially a gendered construct in western society. General social theory argues that excessive display of gendered behaviour; for example emotional distress, passivity, dependence, hysteria and sexual promiscuity; are seen as unacceptable and as unhealthy whether manifest in a man or woman. Furthermore, where a woman's behaviour does not conform to society's expectations of femininity, she would be seen as deviant too (Busfield 1996, Chesler 1996). Society arguably influences sex roles and stereotypes from an early age. Chesler highlights this by the tendency to refer

girls to child health clinics for personality problems such as excessive fears or lack of confidence and boys for more destructive behaviours (Chesler 1996). To conclude, women are arguably, doubly susceptible to becoming pathologised through a differential association with acts of irrational and/or emotional behaviour compared to men. According to Busfield (1992, p.117) this is underpinning:

'the tendency to constitute the boundaries of mental disorder in ways that incorporate more of the terrain of women's than men's problems.'

The sustaining 'patriarchal' principles of Psychiatry and the medical model as the root of inequality is reflected by Ussher's (2000, p.78) acid statement:

'much of what has for decades been taken for granted has been dissected and discarded as biased, misconceived or misogynistic in the extreme.'

Arguably, formal diagnostic criteria are gender neutral, but case example and diagnostic glossary are gendered and gendered tasks are detailed. This then creates a gendered construct for psychiatric conditions and thus impacts the attribution by the Psychiatrist of mental illness more readily to women than would be for men. Feminist debate draws attention to ratios in statistical data; pathologising eating disorders, the exclusion of alcohol problems arguably further reinforces the social construction of women as mad (Busfield 1982, Showalter 1987, Busfield 1996, Chesler 1996).

Psychosocial models of treatment arguably sustain women in a position of social disempowerment. For example, Cognitive Vulnerability, Coping Styles and Perception of Control, all draw links between mental health experience and environment. Thus, possibly shaping the spiral '*revolving door*' for women in the mental health care system (Firestone 1971, Walby 1990, Ussher 2000, Giddens 2003).

Socio-economic factors further implicate this gender/health debate (Secker et al 2001). A study by Brown and Harris (1978) of the role of housewife identified issues pertaining to social isolation, low worth, lack of employment and responsibility for others were coupled with neglecting personal needs. The significance to mental health was established in a theory of depression called 'Emotional Labour' (Brown and Harris 1978). However, because men were not included in the study, critics

argued against susceptibility to depression as exclusive to women. Alternatively, from a socio-economic perspective, the increasing presence of women in the public domain and the breakdown of private patriarchy is being argued as narrowing gender difference in the occupying of psychiatric beds; thus showing some support for Emotional Labour Theory (Brown and Harris 1978). Key structural variables such as occupational class, the labour market position and employment status are potentially significant to the experience of mental illness. Psychosocial determinants of health include employment, social isolation, poverty, experience of life events, multiple life roles and (sexual) violence. Such variables are claimed to present greater risks for women by virtue of socio economic status in society (DoH 2002, Ussher 2000, Ramsay et al 2001, World Health Organisation 2002).

2.6 The construction of difference, language and the psy-complex

Social constructionist theorists reflect upon wider social divisions based on ideological constructions of the normal human condition. Dominant discourses and representations provide meaning and identity that are used to construct people against. As one element of the construction of difference, identity is not seen as fixed or discrete but rather something that can change and shift, depending on various influences.

Gender is a key element in the construction of identity, as a social category imbued by others with cultural expectations and as a primary marker of difference (Lorber 1994). As such, gender may be seen as a major aspect of structured inequality; devalued otherness.

The medical model assumes that autonomy and self-sufficiency are defining elements of the normal condition and it is against this standard that a devalued otherness may be constructed. Arguably, the psychiatric system is part of a wider system of social control or governance. It has been suggested that the aggregation of institutions and personnel employed in mental health care work, and framing the world in terms of what it is to be mad and sane has created this broad social construction referred to as the psy-complex (Pilgrim and Rogers 2000). A growing list of behaviours is considered the remit of psychiatric and psychological help, for example gambling and

sexuality. In this sense a blurring of boundaries is seen where psychiatric language has seeped out to become part of everyday talk and people frame their own or others' distress using mental health terminology, for example depressed instead of sad.

Language and 'buzz-words' do change; citizenship, empowerment, service user, mean different things to different people. Today, previously considered pejorative terms have been reclaimed, for example 'Mad Pride' to produce a potent statement. The psy-complex is surrounded by the recognition of social construction and the construction of difference, framed by a collection of terminology and discourse.

This study bears upon the construction of mental health user involvement, and of women users of mental health services. The literature supports the view of women as the weaker sex in society, and that this has become reflected by psychiatry, leaving women service users doubly disempowered. Mental health policies have impacted health care practices, and the way the mentally ill are positioned in society. In 2004, government turned its attention to women mental health users as a marginal group, and called for 'mainstreaming' the position of women, to influence equality along ideological goals of the consumer/citizen. The psy-complex shows us how language is intimately bound up with the construction of difference and with social change.

By studying the available talk of women, both staff and service users, I hope to shed new light on how women construct themselves as mental health service users in relation to their involvement in mental health services.

CHAPTER 3: METHODOLOGY

3.1 Overview of methodology

A qualitative approach, philosophically guided by social constructionism, was chosen for this study in order to explore the diverse and complex ways women in this mental health context express how they make sense of notions and aspects of service user involvement. Specifically, discourse analysis was utilised, following the methods described by Potter and Wetherell (1987) and Vivien Burr (2001). Semi-structured interviews with women were employed to generate narratives, which in turn were audio-recorded and transcribed to furnish textual data for analysis. The participant sample was primarily purposive, aided by an element of snowballing as the interviewing progressed. Analysis proceeded via cyclical reading and re-reading of the transcribed interview material.

3.2 Philosophy: Social Constructionism

Various practitioners of this philosophical perspective have utilised the chosen discourse analysis approach. Various terms have been applied to this relatively recent turn in epistemology, including post-modernism, post-structuralism, and social constructionism amongst them. Though they all, broadly speaking, address the same concerns there are some significant differences of emphasis.

Common features include:

- an interest in diversity and complexity coupled with a rejection of the capacity of grand overarching theories to provide unitary explanations for social phenomena;
- acceptance of a plurality of competing explanations (in the extreme this allows for epistemological relativism) coupled with an acknowledgement that some discourses are more powerful than others, and these dominant discourses can in effect limit or close down alternative or oppositional talk;
- disquiet for claims made on behalf of the scientific enlightenment, especially with respect to objectivity and positivism;
- critique of modernist faith in a historical trend towards progress and providence;

- and, possibly most importantly, a view of the social world which privileges the role of language, not merely as a descriptor of how things are, but as the very mechanism by which we perceive things as they are (Potter and Wetherell 1987, Burr 2001, Stainton-Rogers 2004).

The latter point sees language and discourse made up of what we believe to be reality. From this perspective the positivist ideal of coolly dispassionate, rational, separated, objective observer is an illusion. The very subjectivity of the observer is what brings into being that which is observed or perceived. Likewise, we are only able to describe things in certain ways because we have the language to do so (Potter and Wetherell 1987, Burr 2001, Stainton-Rogers 2004).

This study will use the terminology of social constructionism where the particular emphasis is upon the sense that discourse constructs what we know as objective reality and side-step some of the debates and discontinuities evident in certain readings of the notion of post-modernity.

Constructionist theory aims to understand social phenomena and people's relationship to them in terms of the language or discourse used to describe, understand and disallow actions. From this viewpoint, our understanding of things around us, from material objects to social phenomenon, is rooted in our ideas about them, which are intrinsically linked to culture, society, peer groups and the company we hold. A 'table' is apparent as a 'table' because our culture has ascribed a certain meaning to it that we recognise. Racism exists because we have socially determined beliefs and ideas about people with a certain group identity. Social constructionism acknowledges the diversity and complexity of social worlds whilst rejecting the idea that single claims to truth exist (Potter and Wetherell 1987, Burr 2001, Stainton-Rogers 2004).

Science and technology enable the development of useful knowledge, but social constructionism rejects this knowledge as being absolutely enlightening because a dependence on objective science is like 'strengthening a powerful case' (Stainton-Rogers 2004). Stainton-Rogers (2004) affirms a constructionist perspective is much

more effective for studying how we live our lives and features of human experience as it enables research to address the kinds of practical issues and problems that actually matter.

A number of philosophers, notably Foucault, are credited with a significant contribution to the development of social constructionism (Potter and Wetherell 1987, Burr 2001, Pilgrim and Rogers 2001). Foucault theorised that the powerful discourses in history operated to construct variously; sex, crime and madness; offering insights into the distribution of power in society. Specifically, Psychiatry developed in the 19th century to construe the world in terms of those who are mad and those who are sane. Foucault theorised that Psychiatry produces a particular kind of knowledge that brings a power dimension with it. 'Knowledge is power' has become part of common language, but Foucault further argued that 'where there is power there is resistance'. Power is not the outcome of force. Power can only exist if there is an opposing resistance. The one precipitates the other (Burr 2001, Pilgrim and Rogers 2001). According to Foucault, the use of force reveals repression and authoritarianism, where the limits of power have been reached and resistance remains in opposition. Consequently power is present in different forms. Foucault differentiates between sovereign power (the power to punish and coerce) and disciplinary power (surveillance) (Foucault 1988, Burr 2001).

Specifically, Foucault argued that social governance is achieved through self-regulation of behaviour in the face of available social norms. This theory of 'Surveillance' emerged from analysis of the panopticon (prison watch-tower). People internalise the presence of a 'monitor' and control their own behaviour according to cultural standards; a form of power exists and socially unacceptable behaviours are suppressed. Foucault proposed that such cultural standards develop over time and that exploring the conditions within a culture at the time of an emergent social construction enables people to question the reality that emerges (Foucault 1988, Burr 2001).

3.2.1 Social Constructionism and language

For constructionists, language is the basis of what is understood as 'social reality'. Objects and phenomena are only knowable through the language or discourse that constructs them. Language is an active part of the world in which we live. Our 'discourse' can be seen as a social practice that arises out of our experience and constructs the reality we live in and how we see ourselves. Ussher (2000) talked about her research engaging the 'discursive construction of mental illness...of gender...and analysis of the relationship between representations of women and men and the social roles adopted by individual women and men' (Ussher 2000).

Gergen (1994) identifies five basic assumptions that underpin a social constructionist approach.

1. The terms by which we account for the world and ourselves are not dictated by the stipulated objects of such accounts. (p.49)
2. The terms and forms by which we achieve understanding of the world and of ourselves are social artefacts, products of historically and culturally situated interchanges among people. (p.49)
3. The degree to which a given account of the world or self is sustained across time is not dependent on the objective validity of the account but on the vicissitudes of social process. (p.51)
4. Language derives its significance in human affairs from the way in which it functions within patterns of relationship. (p.52)
5. To appraise existing forms of discourse is to evaluate patterns of cultural life; such evaluations give voice to other cultural enclaves. (p.53)

This perspective allows us to consider and reflect upon what is meant by such notions as attitudes and viewpoint. Simple qualitative methods, which are closer to the classical social scientific paradigms, assume that respondents to semi-structured interviews are offering their views or attitudes, and that these are uniquely traceable to the individual's consciousness. They are in effect seen as embodied and belonging to the individual who has articulated such views. Constructivist scholars see this analysis as too simplistic, and prefer to think of discourse as disembodied, having an existence beyond the consciousness of individuals in culture and media in their various forms,

but available to them to draw upon and express. The availability of a plurality of discourse exists for people to draw upon selectively, when seemingly expressing a personal viewpoint. As such this helps to explain why people can be in two minds or change their minds over time, especially as prevailing material conditions change. Simpler theories on attitude formation allow for much less flexibility. Similarly, thinking about complex interactions between social actors and available discourse, brings to the fore the function of different discourses and their role, for instance, in the transaction of power in social relationships. Social constructionist inquiry therefore requires arguably more sophisticated analytical approaches than previously employed social psychological in attempts to measure attitude or viewpoint. Discourse analysis is one such method that is more in tune with a constructionist perspective.

3.2.2 Discourse Analysis

Discourse analysis has an affinity with social constructionism because it accepts complexity behind talk. A person's spoken understanding of a phenomenon is separated from any 'cognitive' origin, discourse is seen as emergent from social psychological meaning; the way an object (or subject or experience) is defined is not created by an internal cognition, but rather, is determined from the meaning ascribed to it from culture and context inhabited (Willig 1999). In research, Billig (1992) refers to this as a 'kaleidoscope of common sense'. Participants in a study may draw on a number of different repertoires, flitting between them as they construct their sense of a particular phenomenon. The description 'interpretive repertoires' accepts that people across different groups may share language or that people may alter their repertoire in relation to their situation. This refers the researcher to the function of discourse (Burr 2001). A person's talk is seen as constructed by them to perform a particular action, though the 'function' is not necessarily intentional, but rather emerging through the social world inhabited.

In theory, repertoires in talk or text emerge through the analysis of systematic figures of speech or specific metaphors. One technique in analysis is to identify rhetorical 'devices', to hear the purpose attached to what a person conveys (Stainton-Rogers 2004). Such 'discourse markers' appear in talk, signifying there may be a hidden message.

- To indicate that the respondent does not entirely agree with the presuppositions of the question, for example “well...” Or that the answer about to be provided is not exactly what the researcher wants.
- To indicate what is heard is received as new or surprising. As in “Oh...”
- Or as a rejection of what the previous speaker has said, as in “Oh, no...”
- To indicate ‘hedges’ because the precise meaning of any particular preface will be dependant on the specific context in which it occurs rather than simply filling a gap as in “can”, “might”.

(Potter and Wetherell 1987, Stainton-Rogers 2004).

Excuses have been explored as an entity in discourse (Potter and Wetherell 1987). They appear in different forms and their function can be to depict how people see constraints on their actions. These include accounts that:

- admit an act was bad in some way but claim performance was influenced or caused by some external agency;
- present as a form of justification, an apology or a denial;
- scapegoat.

Potter and Wetherell also refer to the ‘Truth Will Out Device’ in a person’s repertoire (Gilbert and Mulkay 1984), to examine how a person makes sense of contradictions or problems arising within their repertoire. What appears in discourse is the speaker defending their argument but claiming to be open to any alternative argument that may challenge it. Analysis uncovers the speaker using the ‘Truth Will Out Device’ to allow their view to be upheld.

Recognising social constructs are rooted in ‘objects’ having a ‘practical’ reality where the meaning we ascribe will fulfil a pragmatic purpose. Analysis drawing on the function of discourse makes it a useful approach for examining talk at a macro level of interaction, where discourse is generally rooted in the power relations that support such ways of talking (though again not necessarily intentionally). This approach to discourse analysis is associated with Foucault, and takes in the historical context from which socially constructed discourses emerge (Harper in press). The descriptor ‘discourse’ (or ‘discursive resource’) is referred to more commonly than repertoire for this aspect of discourse analysis, and researchers refer to ‘constructs’ and

'deconstructions'; exposing interpretations by mapping relationships between discourses.

Issues of identity, power, and knowledge; the relationship between such discourse and emergent constructs within the social world become the focus of analysis. In institutions, analysis enables the researcher to look at who would benefit and who could be disadvantaged by the emergent discursive resources, and to look at who would want to support or discredit the ways of thinking that exist within the institution (Foucault 1988). Foucauldian discourse analysis explores the systems within a culture and asks why such emergent discursive resources are being drawn on in relation to the social historical context. This study draws on the Foucauldian discourse analysis approach.

Data for discourse analysis can be gathered in various ways, from written text, from video, from interview. Discourse analytic interviews utilise open questioning and are semi-structured or minimally structured to enable participant free speech. Probing in an interview can stimulate observations on the way people make sense of the world. The analytic process proceeds via cyclical reading and re-reading of the transcriptions and where necessary going back over the taped interview. Emergent themes and constructs are coded and developed in an interpretive approach similar to the techniques of Grounded Theory (Glaser and Strauss 1967). Analysis is made up of two phases. Phase one identifies features that point to consistencies and variations across the data and formulate constructs. Phase two theorises about the function and effect of people's talk (Potter and Wetherell 1987).

3.2.3 Why a Discourse Analysis approach?

Alternative approaches were considered and rejected. In this research, using a survey method would fail to produce the participant's construct, because the concepts would be predetermined and any construct the participant would wish to use would be constrained (Harre 1979, Burr 2001). I believe that all talk is important. Discourse analysis supports this idea since it does not emphasise that the frequency of a discourse is in any way indicative of importance; that all talk has equal importance, offering a sense of the subject being studied.

Like other qualitative research methods, discourse analytic data are reported so that readers can judge the interpretations for themselves. Prominent discourse analysts consider it useful because it doesn't make claims to truth, merely exposes multiple realities that exist (Willig 1999). Theoretically, discourse analysis is about exploring how constructs emerge within a cultural context, about drawing on interpretations from a constructionist perspective, where findings cannot be traced back to one individual's mental construct. Therefore, this approach places no blame or responsibility on an individual, important in this study which seeks to encourage women's voices.

Discourse analysis was also seen as appropriate as an aim of the study is to move beyond critically appraising the discourse available towards transformative action concerning social and political practice, in this case within the institution.' Willig (1999) identifies three such directions for researchers to take defining these under the umbrella of 'applied psychology':

- Discourse analysis as social critique aiming to bring about improved understanding of whatever the phenomenon;
'Armed with the insights of discourse analytic work readers are in a better position to resist and challenge dominant (and oppressive) discursive constructions' (Willig 1999).
- Discourse analysis as empowerment aiming to address the issue of application by offering alternative to the dominant discourses or social practices in order to bring about social change.
- Discourse analysis as a guide to reform, aiming to expose the discursive resources that uphold power relations in institutions, in society, and to inspire positive change in social and political practice *'committed to radical social change'* (Willig 1999).

I would argue that this discourse analytic study connects with applied psychology, given that the implications for different groups (staff, service users etc) are set out as recommendations and further work at the end of the study thesis.

The choice of discourse analysis approach is overall suited to this study because the focus is to explore talk (on a subject not normally committed to paper), from a diverse group of women implicated by the subject (service user involvement), where the way

the subject is constructed is related to the culture in which it exists, with the intention of unravelling interpretations of the way talk and experience co-exist.

3.3 Reflexivity

From a social constructionist point of view subjectivity is the researcher's interpretation of the multiple constructions that exist in the data. As such, it is seemingly related to 'bias' and therefore must be explored. 'Reliability' and 'validity' are terms fundamentally incongruous with qualitative research and discourse analysis, given their scientific location. Discourse analysis research explores the social constructs of a phenomenon that exist at a given time. Data gathered are ephemeral in nature, describing the way things were at the time of the research. Therefore personal reflexivity engaging the researcher in continual evaluation of their own subjective responses necessarily runs through the researcher's whole research experience (Finlay 1998, Burr 2001).

Social constructionist practitioners refer to reflexivity variously (Harre 1979, Parker and Burman 1993, Finlay 1998, Banister 2001, Burr 2001, Conneeley 2002). Arguably, reflexivity assumes three uses: (a) the way the theory replays the participant's role, their relationship to the researcher and their relationship to their accounts; (b) reflecting on a given account as both a description of the event and a part of the event; and (c) because social constructions can only present from some such social construction. Consequently, reflection has useful and functional purpose (Burr 2001).

Ultimately, reflexivity demands self-awareness, acknowledging subjectivity and an ability to analyse the two together. Reflexivity is seen as a means of capturing and analysing the subjectivity of the researcher and is said to inform a deeper understanding of the data gathered. Using a 'third party' (for example a supervisor) is one way of exposing any subjectivity and brings an alternative subjectivity to the analytic process.

3.4 Feminist research

Feminist research is not recognisable by a specific methodology (Scott 1985, Burman 1994). Classically, the insensitive nature of quantitative research methods makes them less attractive to feminist researchers. The majority of feminist studies are characterised by working closely with research participants, using in-depth enquiry techniques and adopting a non-hierarchical approach. Qualitative methods correspond with exploring data from a feminist perspective. Researchers suggest the rejection of quantitative methodology in feminist research is a consequence of its 'high machismo element', a lack of opportunity to build rapport or indeed because women participants benefit from the opportunity to make connections, discuss and elaborate in a research situation (Finch 1985, Oakley 1985, Scott 1985). Consequently, feminist research is said to be recognisable by the position taken by the researcher and by features within the study (Burman 1994, Burman 1998).

Developing Harding's (1987) reference to 'feminist standpoint' research, Burman (1994) differentiates between three positions that may be taken.

- Research that supplements existing knowledge that addresses the dominant discourse by exploring the feminist perspective.
- Research that goes beyond the exclusion of women's experiences to making women's experiences and ideas the focus and identifying how they are different from men within the study context.
- Feminist post-modern research that highlights that there is heterogeneity among women as a group, i.e. gay women, black women.

Collectively, authors agree that feminist research is united in an endeavour to open up the debate about women's experiences and expose gendered meanings in our social world, with the ultimate goal of freedom and liberation from oppression (Finch 1985, Scott 1985, Burman 1994, Oakley 1995). Subsequently, research where the researcher and researched are women does not rightly qualify as feminist. A sense of connection and understanding between researcher and researched is given as paramount to feminist research. Feminist research is seen as creating sociology for women that articulates women's experiences, and research can simply be fieldwork on women (Finch 1985, Scott 1985, Burman 1994). Reflexivity is again a key

feature, not only to address the subjectivity of the researcher but in relation to consideration of these fundamental issues that are the essence of feminist research.

For feminists, interviewing women is a strategy for documenting political ideology, of being female in a patriarchal capitalist society because the woman-to-woman interview is perceived as generally frank and honest (Finch 1985, Oakley 1995). The ease of flow of information from an in-depth interview results from women being socialised into this form of imparting information. Many feminist writers have spoken specifically on the use of interview material, and issues pertinent to researching women (Finch 1985, Oakley 1995). The woman-to-woman interview is speculatively described as much political as methodological. From a feminist sociological perspective, gendered socialisation is a key feature for exposure via research.

All these philosophical issues have guided and influenced the methodological approach.

3.5 Organisational context

The presence of defined service user representatives goes back over a decade in the host organisation (the Trust). Service user representatives are office based within the hospital building, and were established through the support of the organisation Corporate Governance.

In 2001, the government reorganisation of health care provision instigated a partnership with surrounding mental health trusts to create a specialist Mental Health Trust. The organisation promotes service user involvement as a core interest. For example, The Trust's recent 'Patient and Public Involvement Strategy' talks about encouraging increasing numbers of service users into governance and development activities, rolling out advocacy services, and facilitating working arrangements with patient and public groups. The Trust intends that all service users will have access to Advocacy. Service user representatives are present on interview panels for senior management positions within the Trust. Trust wide strategic forums aim to have service user and carer representation.

3.6 Methodology: steps in my method

3.5.1 Ethical Procedures and Ethical Issues

I sought approval from the NHS Trust site, Local Research Ethics Committee and Faculty of Health Ethics Committee to undertake the study. In total, it took five months to achieve full approval from all the appropriate committees.

Ethical procedures were an important part of this study. Since the Research Ethics Committee considered potential participants as 'vulnerable adults', action to minimise the potential for hazards or risks was expected. Regardless of the Ethics Committee, my professional code of conduct necessitated ethical action.

Potential participants were approached with the study protocol, an information sheet, and a consent form. Informed consent was standard throughout the study. No one was included in the study where fully informed written consent could not be assured. Clarity and readability of all information was considered leading to separate information for staff and other potential service user participants. More than 24 hours was given before returning to ascertain consent to participate. This allowed potential participants time to seek further explanation about the research either from the research team, from an independent person (named on the information protocol), or to discuss with friends. It was made clear during recruitment stages that people would have the right to withdraw at any time without prejudice to their care, as indicated in the formal consent document.

To ensure data protection all copies of consent forms and data were held in a locked filing cabinet. Only the supervisory team and I had access to the raw interview data. Audiotapes were destroyed once the supervisory team and I accepted the presentation of the transcriptions.

Copies of the consent form, information sheets and my interview guidelines are included in the appendices (see appendices i, ii, iii respectively).

3.5.2 Sampling

The inclusion criteria were:

- Women
- Adult age, 18 years and above
- In the context of a single borough mental health services, participating in the health relationship as service user, former service user, staff
- Full informed consent.

I used a purposive sampling technique. The relevant 'person locations' (Stainton Rogers 2004) were identified in advance, and individual potential participants were identified either from personal knowledge or snowballing technique (Cormack 2002). Snowballing occurred on three occasions during the study data gathering. During my second interview (from the staff group), the interviewee told me of another staff member they had been liaising with exploring women's service user involvement. On another occasion I had interviewed a service-user who suggested I visit a small user group and I subsequently recruited three service users. The third occasion came from a staff member who nominated a colleague.

The sample is diverse across person locations in the research setting, with a total sample size was 20 women, as broadly anticipated. At this point, I was aware of reaching saturation in the emerging data content. (A breakdown of the person locations and data generated is available in appendix iv).

3.5.3 Protocol for Meeting Participants

I discussed the research in full with each potential participant, allowing them to ask questions and clarify details. Potential participants were given the relevant copy of the study information sheet, study protocol and blank consent form, with an agreed time to follow up.

3.5.4 Interview Setting

The environment was considered for every case. Where possible I would offer refreshment and aim to create a welcoming atmosphere for the interviewee. Privacy and minimising distraction were considered in the set up. There were occasions

where the interviewee determined the venue, either their home or office. This compromised my control over the environment conditions, but positively impacted on the comfort of the interviewee (Oakley 1995). On occasion it would lead to complications such as background noise or interruption that diverted my attention during the interview to the potential 'quality' of the audio-tape that would result. On all such occasions the tape was unaffected.

3.5.5 Interviewing

Typically, discourse analysis relies upon texts such as written reports, articles, books and films (data that has been produced for its own end not created purely for research purposes). However, it is not unusual for researchers to elicit their own texts. I used an interview technique to gather accounts of a specific topic (user involvement) especially from the perspective of women users who typically would not independently commit their views to writing. The marginalized and disadvantaged groups (service users) were heard equally to the more powerful group (staff), offering their knowledge for examination, enabling this research to explore the power/knowledge couple and exploring relevant constructs such as identity and patriarchy, and social relationships. The interview schedule was formulated through reading literature, discussions with my supervisor and from my own thoughts about the aims of this study. The schedule consisted of broadly arranged topic areas used to guide ensuing questions.

3.5.6 Pilot Study

On completing a plan for the interview topic areas, two pilot interviews were carried out. The pilots were beneficial in preparing my introduction to participants. I was able to develop confidence with the interview equipment and consider setting up the interview environment. They gave the opportunity to address interview style, develop composure, to consider my involvement in the interview and my role as interviewer in general.

3.5.7 The Interviews

Each interview was recorded using a compact audio-tape recorder with a table-top microphone attachment. A brief recap on the research background and protocol preceded every interview.

The loosely structured interview guidance minimised my control over the discourse, it facilitated sensitivity and informality during the interview. Where possible I intended the interview to flow as a conversation and enable the interviewee to relay their story and experience (Scott 1985, Oakley 1995). The interviews elicited individual accounts on various issues connected to service user involvement. Responses were not always clear or necessarily obvious. I learned to use DA techniques; follow-up questions and probing for deeper explanations in order to explore talk to its full potential (Potter and Wetherell 1987). The guide I used led me to ask interviewees:

- what they understood about the concept of service user involvement
- how they made sense of service user involvement in the organisation
- a service user representative role in the organisation
- what sense was made of a person in a representative role
- what the name 'service user' suggested
- the pressures and gains of involvement
- how advocacy was understood

Gender was addressed specifically towards the end of the interviews, asking interviewees to reflect on meaning attached to being a woman in relation to the way they talked, considering for example if there were differences for women. Each interview ended with me asking the interviewee to talk a little about what they considered had influenced the things they said in the interview.

I allowed time at the end of every interview for closure with the interviewee, and any self-reflection.

3.5.8 Transcription

The Trust's secretarial support was initially purchased to transcribe data using typical transcribing foot-pedal equipment, primarily for speed. On receipt of the first

transcribed interview I recognised a distance between talk and text created by my lack of involvement at this stage and so explored alternative options. As a result, I was transcribed all data by listening and reading each interview directly on to a word document using 'Dragon Naturally Speaking 7.0' software. On reflection, despite the vast amount of time taken transcribing data, I feel this was a satisfying method since this allowed for analysis to begin during the transcription hopefully minimising discontinuity or imprecision between the live/recorded interview and the data transcript.

The tapes were transcribed verbatim (interviewer and interviewee talk) and aspects of the conversation were added such as pauses, laughing, particularly soft or loud spoken parts. The data was anonymised during transcription, and each interview was labelled with a letter and number.

Twelve women staff were interviewed and eight women service users / non-staff. The non-staff group interviews were comparatively short, excepting one interview from an employee of NIMHE that generated 34 pages of text. In total the transcriptions generated 110,871 words for analysis (see appendix iv).

3.5.9 Analysis

Analysis started with transcription, reading and recognising what each person had to say (Potter and Wetherell 1987). Following that, I read all the transcripts thoroughly one by one, recording the general points to jog my memory on a separate sheet and attaching it to the front of each interview. I had the tapes to hand to clear up any ambiguities in the transcripts. During the analysis I continued to read methodology theory, which gave me insight into the questions I could ask as I was analysing the data.

I re-read the interviews picking out recurring statements that appeared to represent similar ways of talking about the issues surrounding service user involvement. This involved identifying general themes on separate pieces of paper using open coding and giving themes a title. Each excerpt was recorded according to the original

transcription and page number to facilitate tracking. There were examples where the same excerpt had significance more than once, so it appeared in more than one list. At this stage, I was analysing the staff and the non-staff group separately. I was becoming immersed in the mass of material, possible analyses and interesting themes for discussion.

Thematic organisation followed. I started to draw on the messages behind the mass of data within the general themes, to either collapse themes together or expand, thinking about data collectively. I considered resonance with the background material, and the function of the discourse, facilitating themes for discussion. This study's usefulness to the mental health Trust regarding service user involvement was a secondary issue in my thoughts, but the emergence of discourses available in and around the organisation inevitably offers conclusions and recommendations.

Supervision assisted in discussing the emergent themes and analysis and facilitated confidence that the themes identified accounted for all of the data. Supervision would lead me back into the original text, analysis, background or methodology. As expected, analysis was a time-consuming and lengthy stage of the research process, but analysis was also exciting, at times unnerving, and altogether educative.

3.5.10 Reflexivity

Throughout the research a reflective diary, including records of feelings, analytical notes and ideas was kept to assist reflexivity. A full reflexive account forms Chapter 7 of the thesis.

I was aware of potential 'insider status' (Conneeley 2002) as a clinician in the Trust where the study was carried out. However, I would question the extent to which disciplines like Occupational Therapists are fully fledged insiders in the psychiatric institution, because they are not ward based and the professional education has a different knowledge base to nursing, fundamentally grounded in developing skills and independence of people in our care. Despite this, I was mindful that interviewing women nursing staff, colleagues, clients, service user representatives and management could lead people to make assumptions about the study.

Openly thinking about my involvement with the study was vital because a discourse analysis approach necessitated constructing interpretations of the data. The ability to reflect on my own position, identify aspects of my own social identity which may influence the study, needed to be addressed in order to trace possible influence on the analysis.

3.5.11 Supervision

I made active use of supervision throughout the study. An organised approach facilitated outcomes from meetings with my supervisor over two years of study. I have mentioned the benefit of supervision to analysis earlier. Overall, the supervisory relationship brought insight, experience and knowledge to my studentship. Open discussion facilitated progression through the research process, encouraged deeper enquiry, challenged my emerging research knowledge and offered reassurance for me to expand ideas and have confidence to progress.

3.6 Study Limitations: Reflection on the Study

The use of interviews may be criticised. Critics of discourse analysis question the extent to which original talk from interviews has become mediated discourse through the process of transcription and further through the use of voice-activated software. To balance this argument, I undertook all stages of the transcription myself, whereas transcription becomes, in effect, the beginnings of the analysis process.

Critically, there is a lack of interpretative validity to the study at the time of writing. This is because of funding limitations and time constraints. I do intend to share the study with the Trust, service users and service user groups after the viva in order to discuss the sense that has been made of service user involvement.

Certain critics may question empirical generalisability of this study due to the sole focus on women. Certainly, within the findings as I discuss later, the impact of gender socialisation is constructed here and echoes the background discussion, which I feel enhances the overall credibility of the findings. Women to women interviews were deliberate, methodologically, to give a platform to women's voices.

The word limit has not allowed for a deeper critique of the background literature or to engage in depth in a reflexive discussion.

Finally, my position as a novice researcher is worth reflecting on. From my perspective, the unknown is a limitation. I have experienced challenges over the two years of study, for example; transcription, and limited contact with other students; this has impeded progress according to the planned time line, and has at times led to my own disquiet. The use of voice-activated software was a pragmatic means to manage transcription, and more generally, I feel maintaining a time plan and time schedules facilitated my focus. I feel the research experience is a great learning curve in research methodology, research practice and in understanding myself.

CHAPTER 4: FINDINGS

4.1 The Service User Group: Overview

Three broad discourses were evident in the transcribed interviews with service users. The first constructs different senses of identity amongst service users. The second expresses ideas that coalesce with notions of gender. The third discourse makes sense of the context within which the service user activism takes place.

4.1.1 The construction of service user identity

Some of the way people have made sense of identity resonated with general, societal constructions of mentally disordered individuals, including various negative references to stigmatised identity and labelling as mad. A sense of passivity and disempowerment emerged as part of this discourse. This was associated with questioning the contribution service users can make. And interestingly, there was a general lack of confidence in organised service user involvement. Such talk suggested service users may be buying in to views from elsewhere about people with mental health problems.

Alternatively, the construction of identity of people who are active in service user involvement was a more hopeful one: moving away from passivity to a confident individual. Confidence may have started from attaining insider knowledge, which in turn impacts motivation to get involved, ensuing further confidence. People found value in their sense of self through meaningful occupation. Active involvement, solidarity and connectedness with wider community action groups strengthened a sense of citizenship as part of this identity.

Interviews were replete with discourse that spoke of individual difference, where there was a rejection of the idea of representativeness, and heterogeneity was asserted. A sense of confusion abounds with names and terms ascribed to service users. As such, service users attempted to make sense of ascribed terms, like '*representative*'. The relative usefulness of given terminologies was questioned in the talk. Effectively, this discourse presented a juxtaposition of esteemed and valued normality set against a devalued 'otherness'.

Well I know myself that I am manic depressive bipolar affective disorder(.) because I have all the classic symptoms of it and episodes(.) but I don't particularly like the fact that I am labelled...as manic depressive (.)and there was a period in time when some doctors said that you should take off the labels and not label people(.) but once you have been labelled you are that label basically...(SU1, p.1)

...part of the difficulty around stigma and discrimination is that for many years we have tried to identify a boogie man in society(.) and that has been different groups at different times(.) it has been single parents at some points(.) it has been many more god at other points (.) it is being a whole range of things(.) and one of the ones that rolls out every now and again is the lunatics escaped from the asylum scenario and that is reinforced through film media and everything else... so I think it's very hard for people to come out as people who have experienced mental health services and have something to say about it (.) and certainly from my experience I find that if I am standing in front of a group of doctors during teaching(.) and I regularly do this on mental health act section 12 approval course(.) I stand there and say hello I am [name] and I'm a member of the mental health act commission(.) they will treat me entirely differently from how they treat me if I stand up and say hello I'm [name] and I am the user of psychiatric services(.) and I find that deeply frustrating because I think my use of psychiatric services for me isn't the be all and end all of who I am... (SU4, p.9)

if you haven't got a kind of meaningful existence or what is seen as a meaningful existence it is very very hard (SU4, p.17)

The notion of a stigmatised identity was compounded by experiences of services. Various institutional effects or barriers were talked about to leave service users feeling that they didn't have a valued contribution to make; “helpless” or even “abandoned”.

If you don't know what all your treatments(.) or what it's all about and you're helpless you feel like you know(.) if you go to the doctor and he says just take these tablets can you say well what is it?... It doesn't matter what it is(.) just take these tablets(.) you know you're totally ignorant (SU3, p.14)

the first time you do go in and you come out you're not(.) you're still very vulnerable and that is how it felt(.) it felt like I had been thrown back into the big wide world and abandoned (.)and it was like get on with it now because you are all right you have been in hospital and now we are sending you home(.) get on with it ...and it's only with going in however many times I went on that I learnt how to stand on my own feet(.) (SU7, p.3)

A sense of powerlessness in relation to other people (professionals, staff and carers) was constructed. Identity ranged from incompetent to angry:

I think what tends to happen is (.) where an individual feels things are not right and not satisfied with services (.) the response would be to pathologise that and dress that up as part of the problem (.)and you know as recently as two years ago(.) from the um after being on the waiting list at the regional psychotherapy service for two years(.)I finally got offered a service by them(.) and what they(.) my first meeting with my clinician(.) my therapist(.) he asked me what I did and he said [name] your battle is with psychiatry...and it was like well no(.) I'm just having I'm telling you what I do for a living... I'm not actually battling with any thing (.) you know(.) and he was just kind of pathologising the whole thing...and I think that is deeply undermining and deeply devaluing (SU4, p.7)

I think there's more fear by the users that their voice won't be heard as much with the carers present (SU2, p.9)

you feel frustration of people who don't feel a part of the care and their treatment ...and they don't feel their views are listened to(.) (SU6, p.10)

These evident feelings of powerlessness translated into a dismissal of the worth of user involvement. For one service user this was grounded in lack of confidence in one's own peers. The result was effectively acceptance of the organisation's right to order governance:

Well I don't think it should be left up to [managers], but somebody's got to make a decision, somebody has got to make a decision, somebody has got to manage something haven't they? You can't just leave it all. I imagine it would be bedlam if it was left up to the patients to run the hospital. (SU1, p.4)

Similar deference to professional power was evident in this contribution from a service user who implied that to take on board a teaching role might require the confidence and esteem of assuming a professionalised role or status:

I would give the doctors more training on different issues erm that's what I want to do when I'm older I want a lecture in personality disorders... I want to train as a nurse but and as a service user having views from both sides I think. (SU5, p.6-7)

In apparent resistance to all of this a more positive sense of identity was assumed, one that was brokered by rejecting attempts to corral people into a single service user identity (especially a stigmatised or damaged identity). The range of service user experiences and diversity amongst different service users was remarked upon and individuality was celebrated in the talk. More often than not, these expressions

represented clear contradictory constructs to some of the discourse on passivity and difference.

...I'm not saying it would be the same for everybody (.)I mean some people might say I don't want to get involved (.)I just want to go and have my treatments and go away(.) but I think everybody should have that choice for being involved(.) and then it's up to them if they want to or they don't... that's what I feel anyway(.)that everybody should get a chance to voice what they think... (SU3, p.15)

I tend to see it I prefer to see it as what we can all bring...everybody has a role to play when you have use services (.)everybody has a role to play potentially in feeding back about your experiences(.) and then what you bring to that(.) what you bring to the pot then is experience (.)which is you know you were first to bring up a perspective because we are not homogenous group(.) (SU4, p.12)

This celebration of difference did not preclude an acknowledgement of commonalities of experience:

I think I'd expect I think it's the same for men and women(.) mmm ... anyone with mental health problems I think it affects you in exactly the same way... (SU8, p.6)

Generally expressed, involvement in day-to-day care seemingly increased esteem and confidence, which encouraged wider involvement in the user movement...

you see people who come and start to get involved in things who are very timid and shy uncertain about their own ideas and whether their views have any validity... and you see changing them over a period of time where their confidence grows(.) and they feel validated by what they do(.) and that very powerful that is really powerful. (SU4 , p.17)

Gaining insider knowledge was seemingly a prerequisite to such empowerment and user involvement.

you just want to find out more about it to see you can help yourself... and the more you know about it the better you are able to cope with it I think(.) and understand it more(.) because people with mental health problems they don't know what they're going through(.) they can't understand themselves anyway and I don't know what causes it or what brings it... and so the more information they get about it can help them to understand it more and cope with it. (SU8, p.3)

if you go to the doctor and he tells you well these tablets are for this(.) because you know you've got this(.) if he explains it all (.)and explains what it can do to you and what you can do for yourself(.) then you feel more content and

accepting(.) you accept it then don't you(.) that this is what is wrong with you(.) this is what I have to do and you can get on with your life... (SU3, p.14)

I feel it was very handy that I did a Counselling Course (SU2, p.6-7)

Similarly, service users drew upon solidarity as part of a user involvement group as an enabling and motivating condition.

so I think people did need to come together in groups(.) to get a kind of sense that it is not just me that feels like this... there is a strength in numbers and I think as a group of people we can challenge things... (SU4, p.7)

It's a commitment... its just you get sort of involved in the whole sort of user movement sort of... very often your strength comes from that than the Trust you're associated with... I know in the early years I was in Birmingham living ... I'm giving this up! ...You know (.) you could just as easily(.) you know sit at home and get your knitting out you know(.) and then you know you'd be walking along the corridor and someone would say guess what's happening now(.) they're making a video about user involvement(.) you know the mental health task force(.) and all of a sudden you become inspired again... (SU2, p.7)

To an extent a valued identity was socially constructed here, in terms of meaningful occupation or of employment. The very act of involvement may have offered the opportunity to construct a positive sense of self, in contrast to the previous denigrated notions of service user:

for people who stay around and have positive experiences of involvement(.) or engagement(.) it is very valued for them and you know you could start seeing it as a therapeutic tool in some respects... (SU4, p.18)

More than meaningful occupation or self-esteem the User Movement offered opportunities to engage in transformative action resonant with ideologies of citizenship.

I suppose you can see it as an element of change(.) an element of they have received services in some cases(.) they have been good(.) in some cases they have been bad(.) but they want to be partners in change(.) and see justice... and I think there is something of wanting to see justice really(.) and I think that's probably one of the big attributes that strikes me... maybe people do have different motivations ...it is the same as any other community activity (SU4, p.16)

This construction of identity associated with service user activism was not necessarily uncomplicated. Improved social status may a positive gain, relationships with

managers may be uncertain and onerous bureaucratic commitments can be the downside.

a lot of people do like to sit on the committee because then you can call yourself a director or a trustee ... you know you can have a grand title to go along with it and some pretty crappy responsibilities!... which are usually performed quite badly (.)but I don't think finance is the motivation here(.) I think partly though once people get involved and start to feel valued and they have a certain status(.) and you know(.) they are on first term names with you know the chief exec and the management board of the trust(.) and that has that's quite a sexy place to be... (SU4, p.20)

as long as they understand where you are coming from (.)you're not there to make things easy for them(.) you're probably there for the opposite(.) and you're not trying to be a friend with them(.) you're just well doing the job for the sake of putting it nicely sort of...(SU2, p.4)

Well yes(.) there are definitely positives [to being paid]... It would encourage more people(.) but then again we'd get back to(.) would it be the actual work that caused people to do it or would it be the money?... I think if its something that they want to do(.) and its something they can do you feel you're getting a personal reward for doing it (SU2, p.4)

There is a sense of confusion regarding the political correctness of labels: such as service user, client, and consumer. Service users attempted to make sense of their selves through what they do, but bureaucratic systems led to uncertainty:

[My role] is a bit confused at the moment because it's changing in the way we're acting... but for the past number of years(.) its been (.)erm (.)as a voice for other service users...Yeah, I don't like it being termed that you're representative of other service users because everybody's so different(.)Its just having a voice for those who in that stage of their life aren't(.) or don't feel like being able to speak up (.)just being their voice ... but I'm representing myself(.erm(.) I prefer to be everybody's voice... (SU2, p.1)

I think most people don't know what to say (.)and most people will fall on calling themselves representatives when the reality is that they are not... and I think it is misleading for them... and I think it is misleading for the people around the table(.) because what it allows is(.) some people to sit back around the table(.) for some people to sit round the table and say well you're not representative of my service(.) (SU4, p.14)

Seemingly, terms of reference have become part of a broad social discourse within the institution of mental health services. There was acceptance of the need to use defining terms but resistance to some because of expressed connotations, in some sense surprisingly different to received political correctness:

I don't mind any of them (.) I mean patient(.) I know people think it's too passive which I guess is true...but sometimes I think they're just trying to(.) I don't know(.) the problem is client is(.) I don't know it just seems a bit...I don't mind whatever I'm called really(.) I am a patient and I am a client(.) I am a service user... being called a service user makes me feel greedy (SU5, p.2-3)

This appeared especially where the term implied a role that is at odds with the value ascribed; similar to representation empowering others. The choice of term for users of services was not too important an issue. However, there was a strong notion that language was understood as a means to distract from the real business of making a difference.

it has been the subject and destruction of huge amounts of time within the service user movement... and I use the term service user movement just because it's probably the most defined term (SU4, p.10)

I think it' scares people in terms of mental health service staff when people talk about surviving... but sometimes they not talking about surviving psychiatric services(.) they're talking about surviving mental health problems(.) which is the kind of huge thing its own right... and other agencies(.) I think for example the National Schizophrenia Fellowship rethink used to talk in terms of sufferers(.) which I think creates for me the kind of notion of victim(.) erm (.)and I don't think we have a ready term really to describe... I think in America it often gets talked about as consumer... but we are not always willing customers in this process you know(.) so I think customer to me(.) I am a customer of the supermarkets but I don't have to go to a particular one(.) and I don't have to buy particular things (SU4, p.11)

4.1.2 Gender constructions: women on women

Gender is not the primary discourse from service users in their talk about user involvement and their positioning as service users. At times a rejection of gendered differences and a valuing of heterogeneity and collectivist ideals was discussed. Consequently, in many regards, the discourse of gender offered further ways of exploring the discourse on identity.

However, consideration of the notion of gender afforded additional insights into the experiences of women in society, as service users, and as service user activists. A comparatively poor construct of women emerged against men as capable, confident and relatively free from domestic commitments. Interestingly, a gendered construct of women's madness appeared in the talk. However, this was balanced by the

apparent appeals to commonality of experience beyond gender. Women were constructed as marginalized and discriminated against. This marginalisation extended to the position of women as activists in the User Movement, though conversely, feminine qualities were celebrated as assets for activism in the health care setting.

I don't know that it is any harder for women than men(.) because men will suffer with illnesses the same as women ... everybody's illness is their own anyway isn't it... (SU1, p.12)

When service users made reference to gender this resonated with the ways in which women in mental health services and institutions were variously constructed as mad, bad, sad, and helpless:

I know when I first went to hospital I had all these horrible thoughts of what this place was going to be like(.) and it just didn't resemble that!... I must have been brought up to think you only go there when you're really bad(.) and you're a lunatic or a madwoman (SU7, p.3)

women I think internalise their mental health problems more than men(.) and kind of have greater sense of poor self-esteem(.) more self-doubt(.) less confidence(.) and less feeling of validity that enables them to go out(.) and kind of voice what they want (SU4, p.29)

ideally we should be able to engage much earlier(.) and we should be valued more... and I think that's doesn't happen(.) and I think that doesn't happen particularly to women(.) although I don't know maybe I'm just talking from personal experience there(.) in that sometimes when you go for help(.) we are told we're going to early and we've got to allow it to become more of a crisis (SU4 , p.34)

There were many references specifically referring to women as passive, echoing the previous discourse on identity:

my gut feeling would be that those who shout loudest get it(.) and my guess would be it's not always women... I mean there would be some women who do... but I suspect it's not always women that do that (SU4, p.34)

Beyond passivity there was the sense that historically, women typify madness or weakness:

I guess there was kind of sexism in white middle-class psychiatry previously which allowed for women to access services as the weaker sex... the ones who were kind of more affected by mental ill-health... (SU4 , p.30)

This was juxtaposed by a sense that women cope better with hospital...

I think it's very humbling for a man...I think women do cope better than the blokes that I have talked to in mental health... and they(.) they are more upset about the fact that they have got a mental illness rather than trying to improve... they're more upset with the fact that they have got it (.)and how could they because they are a bloke(.) they don't get things like that (.)mental health problems(.) and I think it does hit them harder going into hospital I think women to cope slightly better (SU7 p11)

... confirmed by a view of men as less able to cope because the label of mental disorder challenges accepted notions of masculinity.

I know men do suffer as well but they tend to hide it and be macho... not wanting to let to many people know (SU3, p.11)

One such discourse viewed women's disempowerment as a condition of male dominance in psychiatry:

probably a lot of the doctors are men(.) so I think maybe some of the doctors(.) perhaps take men's opinions more seriously... but I mean I don't know(.) I can't(.) I've got nothing to compare it with (SU5, p.6)

I had a vast increase in my tablets after having words with my consultant (.) and telling him that I really can't understand why he keeps taking me in hospital(.) because they're not doing anything much about my tablets(.) and I don't feel any better... and suddenly he increased quite a lot(.) the strength of my tablets(.) and I felt absolutely wonderful(.) and I knew that I was going to be discharged... I went in and I actually told him that I had come in for discharge (giggle) (.) and he said right you're telling me (.) I said yes because I feel normal again(.) and that time I didn't feel abandoned (SU7, p.3)

More than this, women service users made sense of disempowerment as similar to the inequality of other groups in society:

when they discovered that is the cost of halal meals was going to be met out of the general catering budgets(.) and that that would reduce the amount for everyone else's meals(.) there was this resistance to it ... similarly about the sports facilities(.) they were all located on the north side of the site(.) which is the male side of the site(.) and swimming facilities were there(.) and it was decided that they would try closing off the facilities for two sessions a week so that women could be brought in to use those facilities... there was only about 40 odd women and 500 odd men(.) or something like that(.) and the men were just complaining(.) you know two sessions a week out of 10(.) that's just not fair and just kind off(.) there are(.) there are major issues about levels of disempowerment within the service user movement(.) and they may be located in round things like gender(.) and ethnicity(.) also I think around age. (SU4, p.30)

Wider gender inequalities and the gendered division of domestic labour were seen as a potential impediment to women's involvement:

Something very basic(.) you know(.) if you do go to use a user group meeting (.)and count round the table(.) the number of women might be fairly equal at the kind of level of the get-together of service users... but when you look at who goes out and does some of the work(.) or the more kind of high-profile work(.) my view is it tends to be men(.) erm (.)and I think that's because men are more comfortable(.) erm(.) or may have had professional lives previously that had kind of given them those experiences (SU4, p.29)

women are limited by their roles in family life you know(.) in terms of (.) well perhaps I wouldn't mind going to that meeting (.)but I've got three kids to look after you know(.) and are you providing childcare?... Have you got a crèche? You know and that kind of (.) and so I think it's hard (.) and I do think it's generally harder for women to get involved (SU4, p.30)

you've still got the house to clean(.) the cooking(.) the washing the ironing(.) and then looking after the children and seeing to their needs(.) and then looking after your husband and seeing to his needs(.) and I don't think men realise really how much you do (SU7, p.11)

Once women were actively involved, there was a sense that men's dominance remains:

I think its far harder for women (.) you know it does tend to be male dominated... very close to home it is very all males (SU2, p.8)

Conversely, discourse will discount the validity of particular claims that men are superior.

I think a woman's voice can be just as strong as a male's voice with an illness ... I don't think it should be a problem if it's the right person speaking (SU1, p.13)

However, sometimes women's implied inferiority was seemingly internalised and men's implied articulation left women feeling vulnerable:

when I am feeling(.) and it has happened when I've not been too good(.) when I've been there I felt very vulnerable in that setting because some of the men are very articulate...(SU4, p.30)

On occasion, the particular attributes socially constructed as feminine (such as nurturance and listening) were expressed as assets that aid the role of active service user:

I think they [service user representatives] need to be a good listener ...and have a lot of common sense...I think it can be very hard if it doesn't come natural to you... But if it feels natural (.) it can be very easy (SU2, p.2)

4.1.3 Constructing the organisation

This broad discourse spoke of different aspects of service user involvement and activism, including aspects of the organisation within which it takes place. This discourse spoke of people's perceptions of the extent or otherwise to which institutional factors either promoted or inhibited user involvement. Some of this was about relationships with staff and fellow service users. There was a sense that disempowerment and possibly token involvement ensued where structural arrangements by the organisation were seen to contain service user involvement. The consequence was variously discussed; service users were aware of opportunity to sit in consultation but acknowledged that real influence was beyond reach. Similarly the organisation was acknowledged as holding ultimate control, to engage in their best interests, to act on service user views when it would suit. Alternatively, the organisation enabled a contribution from service users to things like interview panels which impacted a sense of partnership working in the discourse. The irony was that where service users were in managerial control of a user involvement group responsibility was assumed and acted out.

Issues brought to the fore debates over the effectiveness, or meaningfulness of user involvement in changing practices and also issues of incorporation of user involvement within the system.

Professionals within the organisation were variously seen as gatekeepers of involvement and the caretakers for those service users involved:

I think my perspective is that the patient should be involved at all levels (.) because I think they are the ones that experience the service you know... and how it feels like to be it to be in such a big system of bureaucracy(.) and things like that... and I think they should be involved at all levels as much as possible ...and I think staff need to give them the time of the opportunity to do that(.) because I think there's only everyone can benefit from a patient involvement anyway (SU6, p.10)

historically there have been people who are around like psychology services(.) or people working around with a social model of disability... so I think they have tended to the allies to service users who have very much supported that voice (.) because I don't think we would have had the impact the users have had without those people really... (SU4, p.7)

There was a sense that this may lead to incorporation where the user activism was contained by policy and contracts:

I think perhaps over the last five years (.) the whole notion of user involvement has become particularly mainstream (.) which I think is a huge danger and I have major concerns about... it was to balance the kind of needs to have the involvement of service users at the heart of everything... I went to Holland last year(.) spent some time with the Dutch patients counselling movements who now have enshrined in statutory responsibilities in very similar way to that which is emerging now with our patients forums... and what that effectively did was it created a statute around service user involvement... but there's very very limited definition(.) and what it has done it is killed that ground swell stuff (SU4, p.4)

Seemingly, service users enthused about the organisation's efforts to include service users in decision-making circumstances, while accepting the organisation as accountable. For example here, in interview panels:

I think that is a really good idea (.) you could ask anything(.) and then you got to say which ones you thought would be good (.) and then the staff(.) the staff got to make the ultimate decision(.) which was fine(.) but you know they took into account what we were saying(.) because the patients are the ones that are going to have to be treated (SU5, p.9)

I know when people (.) when service users first became involved in interview panels they were being given questions to ask(.) but it was quickly seen...there are questions that they wouldn't have thought of asking(.) that the service user sees as very important (SU2, p.5)

This appeared in stark contrast to the location of the service user as a wholly disempowered partner. This discourse considered institutional constraints like staff time and lack of encouragement as having a direct effect on motivation and as impacting passivity:

clients don't necessarily want to get involved(.) there's not a lot of motivation for them (.) and they can't really see the benefits of getting involved (.) and I don't know if it's sold correctly and positively anyway... I'm not really sure about like (.) I think they don't feel it would be worth getting involved (.) so I think that it's a motivation thing from the clients... but I think the staff are so busy anyway that they probably find it hard... they don't have the time to sit down and say let's go through it all (.) to think about it and consult on it (.) and meaningful consultation you know (SU6, p.4)

I think if the service user can be a bit controversial they're not always going to be taken up on it... You know (.) for example e(.) before this place was built(.) I first saw the plans and I did say (.) they've tried that in other places and it's not worked(.) its not necessarily the best you know (SU2, p.5)

Disempowerment was variously associated with lack of effort to get involved:

I think if they knew that it would have an actual impact (.) on an actual service (.) and how the unit was run(.) then I think that would be positive and I think they do to a certain extent... I think they have some sort of impact (.) but I think when people have been in the system for a long time you know five or six years (.) they can't really see the need to get involved (.) they wouldn't see the benefits (.) because basically(.) in their respect(.) they see that the system is what keeps them there(.) so to sort of plan to get over that hurdle of (.) well you're detaining me and I don't want to be here I want to be out(.) to sort of get over that hurdle(.) and then get them involved in the services that is keeping them there I think that would be really difficult (SU6, p.7)

I don't know so much about being involved in the decisions around the ward in hospital (.) because they are mainly made by the ward managers (.) aren't they...But you are allowed to have a say in patient meetings and things...I didn't attend any last time (SU1, p.3)

There was a sense that containing involvement had to do with the organisation not taking risks and power / knowledge relationships between staff and service users:

I think if you really want to change services (.) you start doing some positive risk-taking (.) and you will allow people to take control of those services (.)you give people responsibility to take control of their own lives(.) you make them the experts in their own lives... because certainly in my experience of using mental health services has been(.) I think (.) if I hadn't worked in mental health services (.) and hadn't known better (.) I would have very quickly have become a victim of mental health services in that all the experts were around me (SU4, p.6)

Alternatively, there was something about having managerial control that had the effect of making people think practically, take responsibility and work together to implement ideas that constructs an opposite view of service user involvement to that where staff were minute takers:

some of the requests that was put forward at the [unit] how can (.)erm(.) would be impractical for the staff to implement (.)do you know(.) some of the requests that was brought forward (.) so it was you had to get the management side to the issues(.) before you could see it...but like with being more self-help(.) we are a sort of management and staff(.) we are all the same(.) if you know what I mean(.) we have to (.) when we think of anything we've got to implement it as well (SU3, p.4)

4.2 The Staff Group: Overview

Interviews with the staff group elicited four broad discourses. The first addressed service user's identity and the second, the concept of gender. The third and fourth discourse, respectively; considered how their own (staff) identity was constructed in relation to the service user and then to the construction of service user involvement, which for staff, took in a cluster of emotions that involvement brought out in people.

4.2.1 *The construction of service user identity*

This discourse was about how the staff constructed the identity of service users. It was a broad discourse that variably constructed service users as sick and disempowered (a group that lacks confidence), to being any member of the local community, and potentially sharing characteristics.

Interviews were replete with discourse identifying service user representatives within the organisation as somehow different from service users in general, as having more in common with the staff group, but still different from staff in some unspoken way.

Service users were referred to as 'patients' and 'service users' intermittently in this discourse. Broadly speaking, the descriptor became 'service user' when talk was about consultation or involvement at a higher level than their personal care planning. At times, the phrase '*them and us*' appeared in the discourse. For staff, '*them and us*' expressed staff understandings of the relationship from the service user perspective. Staff saw that it is service users who view them, the staff, in terms of a '*them and us*' scenario.

Staff at practitioner level invariably constructed the service user through contact in the health setting:

Some patients are (.) some patients aren't (.) some patients would quite happily sit there I think until they go home (.) they are not always as forward and some patients are (.) they come quite regularly can I have a word with you (.) can I have a chat with you (.) what can I do about this... whereas like I say other patients you don't really (.) unless you actually go to them you wouldn't perhaps see them... some people will refuse to see you anyway sometimes you go to a patient and you say would you like to have a chat and they say I've got nothing to talk to about (S11, p.2)

At practitioner level the service user was generally framed as lacking in control, powerless within the care relationship:

when patients are quite psychotic(.) they don't have any insight into their illness(.) they don't actually see that they are poorly(.) they don't actually see that they need to be in hospital so how would you get to them to see ...what they don't actually see is that they are poorly(.) does that make sense(.) I mean that we always try as much as possible do you know we're honest we always say to people are you're in hospital for such a thing (S11, p.4)

I think unfortunately there is still some (.) not complete(.) but some evidence of a them and us thing on the [unit] which again goes back to the fact that people are detained are under(.) against their own(.) you know(.) choice (S12, p.7)

Such lack of confidence coalesced with avoiding conflict and consultation:

we didn't have anybody coming forward to say oh my God it's awful being here(.) you know(.) and it wasn't the time because we were having right big problems on there but nobody actually came forward to say that... now I don't know whether that would have been any different if they had gone on the male ward(.) but it just seems strange really that(.) you know(.) but again I don't know I don't know if its fear of conflict or fear of speaking badly about people (S9, p.13)

One big issue I think (.) is we need to(.) you know(.) remember that people are from different social classes and different levels of confidence and intelligence and education... and you know(.) some people are very comfortable at speaking out but others aren't (S4, p.7)

Communication 'skill' was part of this discourse associated with confidence. Staff talked about service users needing support, and in that sense, distinction between the identities of service user and staff was constructed:

if you're looking at auditing services(.) and patient satisfaction and situations like that... I think an advocate is very useful a very useful tool to get a more balanced view (.) and patients would not feel perhaps so concerned that if you say something negative(.) it might have an impact on their on their continued care (S9, p.5)

even though we try and break down barriers of them and us... sometimes that's always with the patient(.) and if they have got somebody who they feel that they can talk to (.)who can speak on their behalf(.) then they feel more involved and they feel that they can get the point across better (S11, p.3)

Providing support fostered independence and confidence:

they won't go unless I go(.) I mean obviously someone else can take over (.) and I think because when things develop and they get more confident they will go (S4, p.7)

Alternatively, the caring relationship, even in its attempts to promote involvement, somehow sustained subservience, as service users were expected to behave and conform to routines, as a recipient of care:

patients that we get in(.) the kind of revolving door syndrome(.) you know the patients that are in and out in and out they know the system(.) they know the routine(.) nine times out of ten(.) they will have the same named nurse if that is what they want(.) because they have the choice to change(.) so they know who their named nurse is(.) they know when they are unsure that they know when they can come and talk to them... whereas I think what may be needs to be pushed a little bit more... is for people who are not known to services to come and(.) it's like we explain our admission(.) the details the team and how they work with the ward(.) and how the name nurse session works(.) things like that to be a little bit more encouraged (S11, p.9)

Disempowerment and containment was most conspicuous for service users detained under the Mental Health Act:

before they've even got to unit(.) because of the mental health act they've actually got no choice of coming to the unit(.) so straightaway they recognise some element of power and authority(.) because these people have made that decision about their care... when they come to the unit the first person they meet will be their named nurse(.) which will be often one of the senior nurses(.) so straight away again they are meeting somebody who is presented to them as somebody who's going to be coordinating their care or often in charge of their care (S12, p.3)

In this discourse, the service user was seen as perhaps knowingly withstanding health care, passive aggressively:

with the best will in the world you are not going to get 100% compliance(.) or you know the patients we can have (.) they'll agree to everything on the care plan and as soon as they get out of the gates it is bye bye (S7p6)

By stark contrast, there was a discourse whereby staff sympathised with service users,

Well my principle is that we are all service users... I am a service user you are a service user (S8p5)

...or showed empathy for the expectations on service users to contribute to meetings:

we tend to invite people to meetings and expect them to participate(.) when in fact(.) I go to some meetings (.) and I feel quite uncomfortable contributing(.) and I don't really feel confident to put my point of view across (S4, p.8)

Repeatedly, staff talked about the service user representative within the organisation, as different from service users in general, more like 'semi' professionals, enjoying status within the organisation.

there is a certain status with being a service user involved at strategic level(.) who sits on the interview panel for the Chief Exec'(.) and the executive directors (S6, p.8-9)

Service user representatives are talked about adversely, as losing sight of service user issues in the absence of genuine support:

it is around developing our skills(.) so that we can develop their skills for engagement at whatever level they wish to get involved... but we don't want them to become professionals like ourselves(.) or we lose the essence of what it is to be the service user(.) and that has happened that has happened over time (S6, p.5)

4.2.2 Staff identity in relation to service user involvement

In this second discourse the staff made sense of themselves, in their role as staff, in relation to service user involvement. Nursing culture seemingly hindered working alongside service users. Interviewees didn't associate themselves with this nursing culture, (suggesting political correctness in talk about working in partnership was dominant). However in the wider picture, culture was seen as significant inhibiting factor.

Most of the discourse related to practice issues, about professional judgement differing from the service user's requests, about a commitment to a duty of care.

Traditional mental health nursing care clashed with service user involvement:

sometimes older people like myself(.) do sort of tend to sit back and think(.) erm, is the tail wagging the dog (S7, p.1)

a lot of people are scared by patient and public involvement(.) because they feel somehow it's a slur on their professional ability to do the job... and I think we need to put on some sort of training course for staff (S4, p.18)

because of sort of prejudicial views(.) you know(.) that they know best because they are the professionals(.) so that in itself is a barrier(.) not everybody(.) you know(.) we might be being told that this is the way forward(.) we might be working as an organisation(.) from the top we might be supporting the system(.) but not everybody agrees with it (S9, p.7)

A defensive culture of staff protecting themselves contributed to disincentives to engage in user involvement activity:

mainly because professionals are quite erm protective really(.) they may feel that they stand to lose something by really involving service users... I think the arrogant attitude is that we know what's best for our patients... I've heard it said quoted by colleagues (S4, p.1)

I think it is probably cultural (.) because as I say we were always taught don't get involved(.) don't get too close to relatives(.) don't get too involved in family life(.) you know(.) don't(.) don't do anything like that(.) so I think there is something about that(.) because I know when I was trained you were criticised if you got too close (S4, p.17)

Generally, 'duty of care' framed the staff role identity. Staff talked about a conflict of interest with the service user:

there is obviously conflict of interest(.) their interest is that they want to go home (.)and our interest is that they need to be a lot better(.) because they could be a risk to themselves to others(.) there is a formal liability... so it does make it difficult because they kind of see us as the bad guys (S11, p.3-4)

Such conflict created an antagonism between staff and service user; staff not able to advocate:

this is where the whole issue around person-centred care comes in(.) you know(.) if a patient doesn't want to take medication(.) and you think that it will be in their interest to take it(.) how do you advocate for them (S9, p.6)

4.2.3 Gender, mental illness and service user involvement

Staff talked about gender, combining with service user identity, to produce a special kind of construct. Service user involvement was effortlessly gendered in the staff discourse. Women staff described a woman's service user involvement through social constructs of gender, patriarchy and life roles.

Women were a minority group in consultation exercises and seemingly lacked the confidence to place themselves in lead positions:

women would probably need a lot of coaching and confidence building(.) and stuff like that(.) I mean I would hope for a gender balance in all of this (.) but and it will be interesting to see what percentage of women to men (S8, p.13)

lead positions were assumed by males but I think they were probably voted in... but when I think about it(.) the males were like the lead spokespersons(.) the secretary was male (S8, p.14)

This lack of confidence in mental health settings was no different from women generally in other institutions in society. Broader social constructs, to do with gender socialisation, patriarchy, and supposedly essential feminine or masculine characteristics were talked about:

look at the big drive that we've had to have to increase women politicians(.) you know... they have to be positive discrimination(.) it had to be you know(.) that was a really big drive... and it is similar you know on a different level it's a similar situation... we're asking people to be political(.) which might not be in their sort of nature you know(.) commenting(.) looking at sort of actually having the confidence to be able to read something and comment on something(.) to be directly involved(.) to feel that perhaps your views would be valued you know(.) particularly people(.) women who suffer mental health problems (S9, p.14)

men in the mental health Forum right(.) erm(.) they are very motivated and articulate(.) enjoy being in the setting(.) they enjoy the officialdom of the meetings(.) because the meetings are quite manager and male dominated it reflects life I suppose the hierarchies society doesn't it (S10, p.3)

Similarly, in contrast to a male construct, women were seen to have greater abilities to nurture, to cope with emotions, to organise and to problem solve. These abilities were suggested as useful to how service user involvement manifests:

some women do take a stand(.) but they seem to do more in a nurturing supportive type way(.) rather than actually quite domineering and forthright and driving... the men once they get over the emotions can be very driving and very forthright where women are more supportive and nurturing(.) and will help organise things and give the point of view (S4, p.12)

Women were presented as quiet, problem solvers, organisers, who sought support from one another in privacy. Somehow women exclusively had intuition for other women's distress:

females need to have their own space...because they are more nurturing aren't they(.) they don't tend to give their problems out(.) they are problems solvers you know(.) they sort of have the nurturing role(.) and they think sort of to be this way is a breakdown of their nurturing role(.) but everybody needs to be nurtured and rather than being the nurturer they are the ones that need to be

nurtured... and I think women understand this better in women(.) because you know yourself(.) yes you can cope with it but sometimes all you needed was somebody to put their arms around you(.) you might not have said anything(.) but a woman would know instinctively and men don't (S7, p.13 -14)

There was a sense that helplessness lay behind men's difference, their dominance:

men can tend to be quite dominant and they want to be controlling(.) they want to help(.) and do something... the people that we have come across here sometimes often feel really helpless(.) and they feel that their helplessness is very very difficult... whereas women tend to do the organising(.) they concentrate on things(.) and you know they tend to get on and do things (S4, p.12)

Muted throughout the gendered discourse, group identity and solidarity was seemingly important, occasionally, it was presented as a core difference between men and women:

women like to come together(.) and I get the impression women like to support each other (S10, p.2)

...it was a discourse which constructed a socialisation of women moving into caring professions and taking on caring roles in service user involvement; and men to strategic positions, either as staff or service user representatives:

some of the female service users (.) or ex service users I know(.) and(.) and the ones that I can think about (.) actually came in as volunteers(.) or came in as paid staff to the organisation(.) rather than as service users involved in the voluntary capacity... they came and actually had a hands-on approach to working in care...rather than wanting to influence policy or strategy(.) and maybe that reflects a male/female split (S6, p.9)

maybe it's something about men are more likely to push themselves forward into these sorts of roles and positions... and I mean(.) I suppose it mirrors my experience of professional life(.) which is(.) you know(.) in a profession where the majority of staff are women... there seems to still be an imbalance of women in senior management positions in the National Health Service (S8, p.15)

the male service users who are involved with us(.) they start to change through their involvement... they start to wear the suit they start to wear the Tie(.) they start to carry the diary(.) and they start to look more like our own staff than they do themselves perhaps... whereas the one woman I can think of who is the service user(.) doesn't wear the suit(.) she doesn't carry the diary(.) and she is herself (S6, p.8)

There was an equal and opposite discourse acknowledging heterogeneity across service users, differences not necessarily pertaining to gender:

it's about getting everyone's view(.) and everyone's perspective on care(.) not just concentrating on a woman's because we think it's more important(.) or just concentrating on a man's(.) because we think it's going to be you know (S4, p.13)

As such, gender blindness was apparent; in effect gender may be disregarded:

I wouldn't know the gender balance in the [Trust] service user Forum (S8, p.14)

I couldn't tell you what the uptake of that was (.) an assumption is I would probably think(.) that women would take it up a bit more than men (S11, p.10)

it only dawned on me in preparation for this(.) but I can think of lots of instances that I'm aware of that that has happened... and yes(.) the males tend to take on this more service user representative role (S6, p.9)

4.2.4 Service user involvement and a cluster of emotions in the talk

The whole notion of involvement was central to the fourth discourse, ranging from successful to unsuccessful conceptions. Emotive talk emerged as staff made sense of user involvement. Poor user involvement was constructed through metaphors like 'tokenism' and 'parole'. How staff preferred to engage with service users brought about further available discourse, eliciting the barriers to engagement.

The scope of the impetus for service user involvement ranged from government directive to a sense of caring and this discourse was replete with narrative describing personal experiences of meaningful involvement where service users were listened to and where action followed requests.

Staff discussed involvement as an empowering experience, both for themselves, and the service user:

An example was on a ward the other day (.) and somebody did not want their medication and medication time (.) they wanted it at a different time(.) and it's such a small thing and yet if you get it changed they feel really positive(.) they're in control(.) and they are able to influence things in an illness where you have a lot of things taken away...you are able to feel positive about something I think that is a big plus (S1, p.11)

A very pragmatic issue of finance, and therefore management backing was reflected as facilitative:

I think sometimes managers are very separate from the clinical issues (.) which is why I think it has to be driven by clinical people... but I think the least managers can do is connect with those clinical issues (.) and can think(.) I've got a daughter at home (.) I can imagine what it is like for a kid to come into this sort of place and think what that experience for a child is like (.) and he can do something about it and can make sure that the money is allocated for that rather than this (S5, p.3)

...management support and partnership working over issues was more than empowering, the organisation benefits; service users were happier and complained less:

I am going to bring up with the other carers and see what their views are (.) and obviously I am going to discuss it with my management (.) and obviously as it is that (.) is a more open and honest environment(.) where he obviously feels part of the team because he is involved(.) whereas in the past it might have just resulted in a complaints letter to the Trust (S4, p.10)

Frequently, 'tick box' 'tokenism' described the most powerful construct of service user involvement. Notions of governance and bureaucracy punctuated this discourse. It exuded a frustration for the seemingly narrow approach taken to involve service users, at face value only.

it appears to me that it might be more for the convenience of the service planners(.) than it is for the ultimate benefit of the users of the service ...I do think you need to be very careful(.) and ask yourself every time you do(.) say what were you doing this for(.) and who is this going to benefit(.) or is it just about ticking that box(.) and feeling quite smug and comfortable that we have involved service users...you know it's not easy(.) it is really difficult(.) particularly and again(.) I use the learning disabilities example about service users (.)and I know your research is about mental health ... if you're going to do it properly(.) the amount of preparation(.) the amount of education you have to give to people so they can meaningfully become involved (.) otherwise it's just tokenistic (S13, p.3)

my view of service user involvement is that it has been very tokenistic (S8, p.1)

when you're looking at sort of service development as well(.) not wanting the degree of influence that maybe it a wider consultation would throw up(.) because that might mean change(.) that might mean we go against what our you know however many year plan is (S9, p.10)

we need to look at lots of different ways that we can involve people(.) you know not just stick to the same old ways of you know of basically ticking a box (S4, p.8)

'Tokenism' was used to make sense of the service user representative that spoke from within the organisation, within an incorporated model:

I think with the political thrust now that everyone must be involved (.) has brought us around to the situation that we are in at the moment (.) where things can still be considered tokenistic... can still be considered that we're doing it just to tick the box(.) but there does seem to be a feeling in my view anyway that there is a genuine acceptance this is the right way to go... the difficulty is in not just trying to create another arm of the NHS(.) or another arm of service(.) because there are so many people(.) sorry that's the wrong thing to say(.) not that there are so many people(.) but that the people who are sort of at the front of service user representation tends to be the same people (S9, p.1)

Staff questioned incorporation with the Trust as limiting genuine service user perspectives:

because it's such a small number of people that we are dealing with(.) that there can be this tendency(.) as I say(.) for them to develop as part of the organisation instead of something the runs alongside it (.) and is able to contribute to it from a different perspective (S9, p.7)

...particularly in our Borough(.) because we've not had a way of recruiting service users and facilitating their development (.)we tend to have tokens service users who come to every meeting and become professionalised to some degree (S8, p.2-3)

Consequently, consultation was easier; by virtue of this incorporation, the organisation was able to predict the service user's talk:

I think it makes the consultation easier you know (.) if you know you have got a group of people you know you can rely on (.) to give a view on things (.) and yet because of the way that the organisation has developed those people... that they have become almost part of the organisation then (.) it's almost like consulting with part of yourself (S9, p.1)

Generally, the Government and statutes were seen as the driving force behind service user involvement in healthcare practice, this was demonstrated in paperwork evidenced through the service user signature on a care plan:

I suppose from my point of view (.) I am more aware now that the patient needs to see (.) [the care plan] the patient needs to sign(.) so even now as I was saying(.) it is led by them(.) they will know what is on a care plan(.) we are actually more aware that they need to see the written thing (.) written down there rather than just talk about it (S11, p.12)

generally there has been a big Push more recently with the NHS plan(.) and with a lot of the National service frameworks(.) around services having to

consult with service users(.) when you're looking at sort of service planning and delivery (S9, p.1)

Elsewhere, mental health practice in particular, was talked about as avant-garde, motivated by morality:

really (.) prior to [policy] (.) it was considered good practice(.) and I think [service user involvement] had already been embraced by mental health long before some of the other NHS specialties (S6, p.1)

Choice, and the service user right to choose to be involved in care, was generally lost in the discourse, but occasional consideration of the right to opt out was given:

you know that our mantra at the moment is that service users should be involved in everything... okay no problem with that(.) but surely it should democratic right not to be involved in service planning for example... If I go into a bank I want to service from that bank (.) I don't want to come out armed with a questionnaire about how they can improve their services (.) I'm too busy to answer that. (S13, p.2)

However, such disengagement was incompatible with expected levels of consultation. In such situations, it seemed that refreshments were made available and interestingly, one view was that goodies became a form of bargaining power:

the only way that they get people to turn up is by bringing a load of goodies along... they don't pay them(.) but if they didn't turn up with pop and fruit and you know(.) they bring everybody a goodie bag along(.) you know(.) to encourage people to come along... and now you can look at that positively or you can look at that negatively... but if they didn't bring that along then people wouldn't be as willing to join in (.) and if they didn't join in then we wouldn't have(.) we wouldn't have sort of service users on the [unit] saying we want more activities (.) and we want this and want that (S10p9)

Consistently, service user involvement was an emotive issue for staff, frustration coalesced with the notion of a sea of barriers that existed; nursing culture, time, money and training:

someone has got to arrange the transport the sandwiches(.) and and no consultant is going to do that you know!...the devil is always in the detail. (S13, p.8)

there are different levels of importance...you know if you're commenting on the choice strategy or you're commenting on the mental health bill(.) then you're the in group and its being facilitated(.) and that is considered payment time... but say as a service manager(.) I decided I wanted to consult with the patients on the [name] unit as to how they feel their lot is basically (.) then I'm not going to get a red cent (S9, p.10)

very often we are asking them to take part in really high level of activity(.) that an NHS staff member might take 20 years before they can do it... but we want service users to turn up almost out of the blue and do this for us (S6, p.4)

Training was an issue for staff also:

it's not the empowered participants in terms of the community service users and carers that will be the most challenged here(.) I don't think... it's usually the staff (.) because of course these sorts of approaches do challenge the old system and culture (.) and the way things were done(.) so I think you've got to anticipate that a lot of planning to be done around the staff (S8, p.13)

don't forget the staff in all this patient and public involvement... we need to ask them what they think(.) and how they think as well(.) as well as asking patients and carers themselves(.) because I don't want to swing totally the other way so that the staff feel neglected (S4, p.18)

Speaking hypothetically, staff took time to discuss how they would like to see service users involved, as leaders, participants in creative processes:

I want to see the service users carers in time... community participants should be able to conduct a patient process mapping on their (.) you know (.) they lead it (S8, p.4)

you are not always looking for a radical view(.) you are looking for meaningful consultation(.) and you are looking for people who are willing to give their time(.) and are not going to be intimidated by the whole process(.) and that's where it becomes problematic then... because you get the same people wanting to do it(.) and I don't think we're doing it in creative enough ways (S9, p.2)

This final exert brought together the essence of much of the talk; a view of service user involvement as a socially constructed problem that wrestled with notions of difference and took in disempowerment, stigma, class systems, social problems and cultural issues, expressed as issues much greater than health care alone can resolve:

I think obviously you know (.) 20 years in the health service (.) and seeing particularly mental health services (.) particularly inpatient services (.) I have worked in the community as well (.) but I think from an inpatient point of view (.) the people who are in there tend to be the most disempowered groups that we have... you know(.) particularly if you're looking at people who are being held under the mental health act... so I think it's actually(.) from my point of view(.) it's recognising that people can be incapacitated but that can be fluctuating(.) therefore you can be much more creative about how much you share things with patients(.) how much you will allow them to develop their own understanding of the situation(.) and also(.) I have the experience of what is termed revolving door patients (.) patients who get better while in hospital and become very ill afterwards... now why is that(.) because when they leave hospital everything that they agree to do while they were in hospital was not

what they wanted to do(.) they agree to do that because that was going to get them out of hospital(.) and we've got to change that(.) we've got to change the whole way that we work with people... now if somebody doesn't want to take a depot injection when they're in hospital... they ain't going to take it when they go out(.) so (.) we need to think more creatively about how were actually going to encourage people to think about their own well-being ...and how they want to change things... society has changed in a considerable(.) considerable way(.) you know(.) people do routinely take non-prescribed drugs now(.) that's not good for people(.) but how do you change society... mental health is about society(.) so why should people with mental health be any different... that is just an example really... I mean they are different (.) because we know that it impacts (.) or that it can impact differently on their lives(.) but I think trying to make a special case that they(.) that people with mental health problems cannot fit into doing what everybody else does(.) and they therefore become very disadvantaged ... so I mean(.) you know(.) that's how things have shaped for me seeing how people(.) seeing how society has changed(.) but yet parts of mental health services want to remain very traditional... and they can't be(.) you know(.) we all have the right to say what happens to us and have some influence over it (S9, p.15)

CHAPTER 5: DISCUSSION AND CONCLUSIONS

5.1 Introduction

Applying discourse analysis means discussion does not stop with merely presenting or describing what people say. The analysis considers the potential consequences, functions or effects of the available discourse. That is, if a person sees things from a particular point of view, how might this affect what they actually do? Or, similarly, if a particular perspective is dominant, how might this open up or, conversely, constrain, the organisation or future development of service user involvement. Discussion aims to bring discourses together to enable a look at how talk influences and envelops social constructions of the phenomena, of the discourse.

In this study I have elicited and analysed a number of discourses from both staff and service users. This talk can be seen as the various ways in which these individuals or collectives make sense of or understand the notion of service user involvement in its different forms.

In this study discourses address staff and service user talk, drawing upon clear differences and common features. Outside of the artificialities of a research study, discourses express available constructs in the micro-social world of health services within which the two collectives co-exist. The discussion aims to do justice to the richness of the study findings within the word limit that constrains the thesis.

5.1.1 Aggregating service user and staff discourse

The discourses in Chapter 4 present how staff and service users make sense of issues (relevant to the core research question) in isolation. Identity, gender and the organisation around which the service user involvement takes place are described and interpreted.

I explored connections between the various discourses presented, to facilitate a meaningful discussion. On paper, this appeared something like a mapping exercise, and it is at this stage that the function of the talk was realised. For example, in the map, considering how staff talked about service user identity in one particular way

was linked to how service users made sense of identity. Other connections were developed through similar mapping exercises to build interpretations of how service user involvement was constructed through discourse. The discursive connections between the identified discourses in the findings of this study can be depicted diagrammatically (see appendix v). In keeping with discourse analysis methodology, this map is not to be seen as static, with talk belonging to any one individual. Varying constructs could co-exist within one individual's view, and there are some overarching features to the talk. Bringing together the various discursive notions from staff and service users presented a rich discussion. Mapping discourses facilitated this focus upon the construction of service user involvement within the context of the organisation. The construction of different forms of involvement evolved.

Three broad forms of user involvement are evident in this study; non- involvement from service users, talk that constructs an incorporated model led by representatives within the Trust, and the construction of independent user involvement either through non-statutory groups or by being involved in personal care planning.

The discussion follows in two parts. Both parts present an aggregate of what service users and staff have said and considers both the impact and function of the available talk and resonance with the wider discourse, such as that available in the background literature.

Part one looks at the sense made of service user involvement focusing on:

- Non-involvement from service users
- Representative service users in an incorporated model
- Independent service user involvement

The second part of the discussion looks at how gender coalesces with the three constructs presented.

This chapter concludes by highlighting the discursive barriers to effective user involvement that are made apparent from this study, and the ways in which women particularly may be affected.

5.2 Constructions of service user involvement

5.2.1 Non-involvement of service users

Service users may choose not to get actively involved, either in their care, or in the organisation of services. Staff and service users alike construct service users as dependent on the encouragement of staff in hospital. Elsewhere staff talk about service users disengaging from a relationship with mental health services on discharge. A number of discourses construct non-involvement or, similarly, may lead to non-involvement.

Mental health service use often devalues a person and brings with it a social stigma (Pilgrim and Rogers 2001, Read 2001, Secker et al 2001, Minett 2002, Tait and Lester 2005). In this study, some service users talk about a lack of confidence in themselves. Both staff and service users described service users as 'ill', which has notions of disability and may effect non-involvement (Secker et al 2001, Minett 2002). One service user expressed a view that the hospital would be insecure if service users were acting as hospital managers, similarly staff members talked about service users perhaps fearing speaking out, both discourses express service users as lacking confidence. Lack of confidence may develop into passivity consistent with disempowerment as discussed in the literature (Goffman 1961, Pilgrim and Rogers 2001). Despite the government directive to offer choice, it is well documented that mental health service users consider that they lack choice (Read 2001, Minett 2002, Rankin 2005).

A power dynamic emerges in the staff relationship with the patient/recipient of care. A relationship of respectively, dominance and disadvantage between staff and service users, framed by the global description 'them and us'. The medical model and traditional nursing, dominant in health care training and practice generally constructs service users as dependent, which therefore disempowers (Pilgrim and Rogers 2001, Read 2001). The staff culture based on traditional nursing is an expressed barrier to involvement in this study, and echoes the literature as possibly effecting non-involvement (DoH 1999). Service users respond to such pathologising and adopt a

passive relationship with staff. Cynicism heard in the discourse surrounding service user involvement may emerge because staff do not have the time to reflect and make sense of aspects of their relationship with service users. Similarly, the staff hierarchy may restrict practitioner level staff assuming the necessary autonomy to empower service users in day to day care.

Where some service users may simply disengage, others service users may actively show resistance to consultation when this is requested of them. Formal detention creates a special kind of disempowerment, feeding in to feelings of powerlessness and exacerbating the effects of the status as mentally ill (Pilgrim and Rogers 2001, Rankin 2005). Lack of motivation to get involved and a rejection of any real influence from involvement is talked about by service users. For the staff, this group is described variously as; non-compliant, manipulating; the most disempowered.

In this study, staff talk about a disquiet around the use of 'goodies' as a form of payment to achieve consultation. These 'goodies' are presented in stark contrast to routine care, which are not facilitated by attention to comfort and hospitality. Instead, there is some resonance with Foucault and the idea that resistance is at play (Foucault 1988). Staff draw upon a notion that without refreshments service users would not engage and therefore the implied condition that 'goodies' are available begets a form of power at the hands of the service user. It seems a power struggle is described. Staff talk about this situation as service users subverting the system. Elsewhere, however in the service user talk, payment is dismissed as a motivating factor for involvement. Altogether, it is a particularly interesting cameo with various alternative meanings open to discursive interpretation.

5.2.2 An incorporated model: service user representatives

Service user involvement at high levels within the decision making of the organisation can be based on an incorporated model in the role of 'representatives'. The incorporated model can have both positive and negative effects for service user involvement. Staff widely acknowledged the government as the positive driving force behind service user involvement, and mental health as a forerunner to other

specialties. Conversely, a sense of overwhelming barriers; a lack of support, nursing culture, staff confusion about what it means to involve service users and limited value ascribed to it all effectively detract from their capacity to change the situation within the organisation.

Central government requesting consultation but providing arbitrary funding is talked about as the norm in this study and elsewhere in the literature (Minett 2002). Random purposeless involvement is noted and involvement is effectively devalued; echoing the finding that a proportion of staff do not take service users seriously (MHF 2000). Staff use tokenism discursively to describe such incorporated involvement throughout this study.

It is hard to accommodate a sense of the service user as an activist for the User Movement. Service users within the incorporated model can struggle to define their role and position in the organisation, a barrier discussed by Read (2001), as a result of involvement being other people's agenda.

Staff construct a view of representatives variously as: semi-professional carrying a diary, which enables the staff and the organisation to claim that representatives are not representative of the group, as seen elsewhere in the literature (Barnes and Shardlow 1997, Hugo 2001, Read 2001, Secker et al 2001, Minett 2002). Furthermore, describing service user representatives as a clique enjoying the officialdom of the organisation, in effect undermines credibility and sincerity of the User Movement and its objectives. These discourses may be subconscious means to resist unadulterated user views emerging in the incorporated model.

Positive effects for the service user representative can emerge from an incorporated model. Seemingly, insider knowledge benefits service user confidence. Being listened to at organisational and strategic levels effectively breaks down barriers as echoed by Rankin (2005) and affords a respect for management in this study. The availability of support and resources facilitates service user opportunity (Read 2001, Minett 2002). In this study service users never volunteered financial reward as a

valuable or valued aspect of involvement. In contrast, money as a primary motivating factor for service user representatives was expressed as negative and unprincipled.

Doing good for the community and advocating for change to enhance the service user experience resonant with notions of citizenship is voiced by representatives in the incorporated model and also by service users who are involved independently. Group membership is variously described to strengthen service user confidence (Barnes and Shardlow 1997), as found in the literature, creating '*enthusiasm and commitment*' (Minett 2002 p53).

5.2.3 An independent model of involvement

Service users also talk about independently organised or motivated involvement. It can be involvement in the service user's own care or as part of a non-statutory mental health group. Such groups offer support and self-help and, may be involved in campaigning and in communicating with the Health Trust. Both service users and staff talk about mental health user groups as offering solidarity to mental health service users.

Involvement by service users taking opportunities to speak and to be heard, constructs personal growth, value and self-esteem. A sense of having a valuable occupation emerges. Such purposeful occupation benefits personal worth through having a greater social status. In this study, further involvement follows, having resonance with the literature (Barnes and Shardlow 1997).

Similarly, in this study, staff in an empowered position constructed successful user involvement stories. Facilitating service user wishes can be a rewarding and caring experience for staff.

5.3 Deconstructing gender

The discourse in this study, being from women only, constructs a particular sense of gender in relation to service user involvement. At times the sense made is hidden,

women are seemingly gender blind, at other times gender is talked about as having qualities that effect both involvement and non-involvement and a clear function that emerges from the discourses.

5.3.1 Women's non- involvement

By deconstructing gender it is possible to see how women staff allow women service users to remain passive, which is then a route to non-involvement or alternatively not listening to what women have got to say.

Gender socialisation limiting women's public life is endemic in the background literature (Greer 1969, Walby 1990, Lorber 1994, Giddens 2001) In this study, women talk about the possibility of oppression by gendered home life responsibilities. They draw upon having domestic roles, busier lives, and possibly more dependencies than men do. Alternatively, women develop a construct of escaping to home and responsibilities as a means to circumvent involvement with mental health services. As such, gender socialisation limits women's opportunities to develop confidence in public life. Constructing women as less confident than men; complaining less than men; out of fear, may concomitantly effect staff, by making them less likely to approach women for consultation type activity.

The Feminist debate that psychiatry influences a discourse of mental illness as the province of women, as overly emotional - *mad* (Busfield 1996, Chesler 1996), is talked about in this study also. A woman's sense of self becomes stigmatised, she becomes disabled by buying into such gendered constructs: of women as '*mad*'. Interestingly, women in the study, relate to the madness construct as more disabling than their gender. To group women as different from men with mental ill health did not make sense to service users. However, it may be what women are describing *is* the gendered construct of madness, a subconscious construct in society. This then leads to all the doubly binding effects that being a woman with mental health problems begets, echoing background literature (Jones and Cochrane 1981, Busfield 1982, Showalter 1987, Busfield 1996, Chesler 1996).

Subsequently, women service users may easily assume traditional (disempowered) patient/recipient relationships with staff, entering into a *revolving door* scenario with mental health services. Simultaneously, women staff draw upon a gendered construct of self; in the talk about being valued less than men within the organisation. Accepting this as an intrinsic element of the institution's social stratification echoes gender positions in life in general (Greer 1969, Lorber 1994). Where (women) staff are disempowered at practitioner levels, (not having the time, autonomy) this may correspond to service users not getting involved, something which is echoed in literature (Rinehart and Garner 1991).

Finally, women talk about a sense of solidarity as important. Currently, the organisation of service user involvement is not conducive to such informal, supportive functions. Lack of such preferred informality may be one route to non-involvement and lost opinion.

5.3.2 Women involved

The opportunity to be a part of a group is important to women service users in this study. Women service users involved as representatives or as part of an independent group talk about recognising other people's need for support, encouragement, education and providing a listening ear. The staff talk about women entering into involvement as volunteer carers or as paid staff. There is resonance here with broader sociological ideas that perhaps women socialised into specific gender roles are more sensitised to caring activities, and gain pleasure and value from familiar role activity (Giddens 2001). Seeing caring as a feminine act is a social construct in itself, not necessarily the province of women's involvement, but is clearly constructed here as part of the gendered discourse around involvement.

The dilemma then arises when women retain a sense of inferiority compared to men in service user group settings. Is a separate women's service user group needed or is this a form of marginalisation, buying into gendered constructs and limiting women's advancement?

5.4 Conclusions

Service user involvement is about wanting to make a difference; effecting social change. An important discursive barrier to social change and service user involvement is the construction of difference, influencing the construction of mad people and of women in society. These interpersonal and structural factors constrain people's ability to engage in transformative activity and assume full citizenship.

For mental health services to be transformed such that the complete range of inequalities are eradicated, would most likely depend on wider social change. Inequality is underpinned by the construction of difference. This study draws upon two such social constructions; mad versus sane and women- irrational versus men-rational. New discourses that support a healthier construction of what it is to have mental health problems that encourage the wider emancipation of women, which liberate constructions of masculinity and femininity are needed.

Progress for women mental health service users is more greatly impeded because, in most of its history, citizenship and equality have not focused on marginal groups. Unless women's position in wider society changes it is unrealistic to expect mental health service users to effect this change from such a relatively disempowered position as citizens.

Service user involvement may be best achieved in an independent model alert to the risks of incorporation and able to act with the type of creativity that facilitates empowered people (Campbell 1996, Pilgrim 2005, Pilgrim and Waldron 1998, Tait and Lester 2005). The dilemma for the User Movement is whether it can progress as a force for change without the active support of sympathetic professionals who have access to resources and power within the mental health system without the User Movement being incorporated to its own detriment (Campbell 1996, Pilgrim 2005).

CHAPTER 6: RECOMMENDATIONS

6.1 Summary

This study has made known the discourses people in the host organisation draw upon to construct user involvement. Some salient recommendations to the Trust emerge out of the given talk, that has a relevance to the wider health service.

Tait and Lester (2005 p.174) conclude their summary of user involvement by advocating the need for a consistent approach to including service users from mental health organisations:

‘Above all, meaningful user involvement that makes a difference cannot be a one off invention or a discrete programme of work. It must be a part of the fabric on mental health services that affects every aspect of mental health provision.’

Pilgrim (2005 p.12) highlights diversity within service user involvement models of practice, but advocates it as best positioned outside of the system of the service provider organisation to enable an independent voice:

‘All voices are listened to because the libertarianism typical of new social movements tolerates and encourages difference. One wing of this range has eschewed services and cooption, emphasising instead an oppositional agenda...On the other wing, the reformist position, with the support of professional allies, has offered itself up for cooption under the terms and conditions of user involvement in local services.’

The following recommendations are presented based on the findings of this study, understanding of the context in which the study was undertaken and from the findings and recommendations in the background literature.

6.1.1 Recommendations to Service users

- Supportive consultation groups, independent from the host organisation may help women service users to engage with confidence. Attention paid to fostering support and solidarity among members through team building activity, may encourage participation.

- Independent training and development of service users to enable involvement, to promote independence and confidence in involvement would be positive.

6.1.2 Recommendations to staff and the host organisation

- Creative ways of involving service users, need to be considered so that people can engage, and can have choices encouraging a discourse that involvement is a meaningful and purposeful activity. The Trust may wish to consider informal meetings in community settings; via the day centres, a back room of a playgroup, a local shop (suggested by one interviewee). By asking individuals what their preference for involvement would be.
- Staff workshops would be valuable for all staff; there needs to be attention to the dislocation between how staff see themselves and how they see service users. Progressive transformative change will need to be based upon breaking down constructed differences between the various people involved in mental health services and society in general.

Arguably, the whole of society needs to consider the wider determinants of socialisation, within the organisation, to look to empower staff and service users, and for the wider context, the whole of society needs to look to empower women.

6.1 Further work

Resonance with the background literature is apparent; however, the effect gendered constructions have on user involvement locally remains unclear simply because the study has not explored male discourse and cannot provide such comparison. It would be useful to conduct this study with men to hear how men make sense of mental health service user involvement.

It will be useful to discuss the study findings with various groups in different settings across the organisation, to get a sense of whether people recognise the available talk. This aspect of the study has not been undertaken at the time of submission of the thesis. I will share this study at the user forum that some of the participating service users were part of. In doing this, I hope to explore how people feel the study reflects the various ways of making sense of involvement. It would also be interesting to

explore if opinion has shifted or altered in any way since the data were collected, and how service users feel about the conclusions and recommendations the study makes.

Transformative action follows this thesis. As Willig (1999 p. 17) states:

'discourse analysis as a guide to reform depends on the willingness of policy makers, politicians and professionals to cooperate with recommendations.'

Remaining mindful of the possible need to compromise, in order to enable realistic changes, discussing the analytic interpretations within this study with Senior Management and Corporate Governance personnel is as important, if not more important, as the achievement of Masters by Research.

CHAPTER 7: REFLEXIVITY

7.1 Introduction

Throughout the research a reflective diary, which included records of feelings, analytical notes and ideas was kept to assist reflexivity. This chapter will describe the sense I make of my involvement in this study and my personal journey looking back from where I am at completion and reflecting back to before the research began. Reflection describes my personal position and beliefs, with particular emphasis on the relationship between staff and service users, my position as a former service user of psychiatric (in patient and out patient) services within a different institution, my position as a researcher; the relationship between interviewer and interviewee, and also gender.

7.1.1 A reflexive account of the relationship between staff and service users

I was aware of potential 'insider status' as a clinician in the Trust where the study was carried out (Conneeley 2002). However, as I mentioned earlier, I would question the extent to which disciplines like Occupational Therapists are fully fledged insiders in the psychiatric institution. This partial outsider status occurs since they are not ward based and also because their professional education is fundamentally grounded in developing skills and independence of people in our care. However, I accept that to a service user my position would probably be seen to be more insider than outsider.

7.1.2 A reflexive account on my position as a researcher; the relationship between interviewer and interviewee

I felt from the outset of the research that identifying myself solely as a researcher, without acknowledging my position as Occupational Therapist, was difficult given that this study was carried out in the institution where I work. When I presented myself I acknowledged the study being a piece of work for the research and audit department of the Trust. I made no reference to my clinical practice, identifying myself as a Research Assistant.

On occasion, interviewees would refer to Occupational Therapy. One service user acknowledged Occupational Therapy as a form of positive service user involvement.

This talk led me to reflect and draw parallel with clinical situations: Doctors will suggest the need for Occupational Therapy intervention regularly when I am present at clinical ward round, when I'm not there, Occupational Therapy can be easily overlooked. And so, when the interviewee talked about Occupational Therapy as a form of positive involvement, this did not appear to me a meaningful construct, whereas my supervisor interpreted this as unambiguous. I continued to experience a dilemma as a Researcher/ Practitioner at the back of my mind. As a research I am a novice- masquerading, where my practitioner role was well known. In my position as a novice, I worked hard to present myself as a confident researcher, and in my working hard I would wonder if the organisation staff, colleagues and service users, were able to see my occasional uncertainty of research skill.

I was mindful that interviewing women nursing staff, colleagues, clients, service user representatives and management could lead people to make assumptions about the study, lead them to construct their discourse towards a perceived 'political correctness' about service user involvement or simply create self-consciousness during the interview. However, during all interviews I observed participant discursiveness, animation, open body language and lack of evasiveness. The woman-to-woman experience, alluded to within feminist methodology (Oakley 1995), may also have contributed positively. All the interviews felt like honest dialogues and my observations support the integrity of the data.

From a sociological, feminist perspective, acknowledging personal involvement is inherent within social research because social research necessitates people coming together to admit others into their lives (Oakley 1995). I was aware of the part I played during interviews, thinking about the influences I may have on the interviewee and trying not to influence the conversation. I would respond sometimes with encouragement to a particular view in an attempt to give confidence to the interviewee to offer more depth to their construct. Whilst this encouragement aimed to build confidence I avoided being partisan in what I encouraged.

7.1.3 A reflexive account for my position as a former service user of psychiatric services

Undoubtedly, my experience as a former service user of psychiatric services when I was 18 years old inspires my interest to explore and identify the sense that service users make of their experience today. My undergraduate research aimed to explore relationships between staff and service users. Between October 1991 and December 1992 I spent nearly nine months in hospital, including one involuntary admission. I had experienced psychosis, catatonia, depersonalisation, severe anxiety, physical disability, and I was mute for a time. I was treated for anorexia nervosa on a mixed adult ward.

I believe that very few people, certainly where I work, know about my experience. Even now I feel unsure of the interpretation people will place on me, of me, given my experience of mental illness. The stigma of mental illness remains strong, is deeply debilitating; highly anxiety provoking, and yet a dichotomy exists because there is a great sense of achievement, strength and love that comes from surviving mental illness and being supported to reach recovery. During the research process, I felt a 'pull' to disclose my understanding of the position of having experienced mental illness. For interviews, I would reflect on interviewees strength of 'self' in their willingness to be included in this study as service users. And even at the writing of this study I struggled to go beyond the stigma attached to mental illness, to disclose this personal position.

My memory of my own experience is vague. However, I generally consider I was very well supported and received unconditional positive regard from my position as a service user, and it influenced my choice of occupation. Where my position may bear upon the analytic interpretation presented surrounds the stigma of mental illness, the lack of confidence that comes from the experience of being a service user in hospital, and a person who has experienced acute severe mental illness.

7.1.4 A reflexive account on gender in this study

In terms of reflecting on gender, I have reflected on my position researching women consistently through the study. More specifically, I have questioned whether this

study makes me a feminist? Or whether through the process of focusing this study on women's experience I have become sensitised to feminist ideology? Does this make me a feminist?

The honest answer is that I do not know. I consider I have taken a feminist standpoint throughout this study, and as a result of this study I have an increased awareness to the social constructionism of gender, gendered discourse and the (also debilitating) effect this has throughout the world. However, I do not feel that interpretation in the analysis has suffered any (problematic) bias from my being a woman, conducting this research with women from a feminist standpoint, because it is clearly stated that the absence of men's discourse means that this study cannot confirm that the identified constructs relate only to women.

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Centre Number:
Study Number
Participant Information Number for this trial:

CONSENT FORM

Title of Project
Women's Voices: An analysis of views on service user involvement in mental health care.

Name of Researcher
Jennifer Casson, Occupational Therapist / Research Associate

Name and number of independent person
******* , Assistant Borough Director**
Tel:

Please initial box

1. I confirm that I have read and understand the information sheet dated..... for the above study. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected. ☐
3. I agree to take part in the above study. ☐

_____ Name of Participant	_____ Date	_____ Signature
_____ Name of Person taking consent (if different from researcher)	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

- 1 for participant; 1 for researcher;
- 1 to be kept with hospital notes (patient participant specific)

Women's voices:
An analysis of views on service user involvement in mental health care.

Information to Participants

Researcher: Jenny Casson

Date of provision of this information:

You are being invited to take part in a research study. Before you decide it is important for you that you understand why the research is being done and what it will involve. Please take time to read the following information carefully, share your thoughts with others if you wish. I am available to discuss it with you if there is anything you are unclear about, or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this information.

Background

Our service users are increasingly being seen as important partners in service planning and delivery of care. Effective working partnerships are seen as crucial for a successful, modern health service. Research that focuses on 'what' is important for users, as regards their involvement, is often lacking within the policy.

What is the purpose of the study?

The Y Trust recognises that service user involvement is very important to us and this research aims to explore people's views and perspectives about women involved in service planning & delivery of care so that we can address the issues and improve partnerships in the future.

Who will be doing the research?

I am a Research Associate at Y Trust. I am undertaking this Research study for X Directorate, and will be supervised by The University of Central Lancashire.

Why have I been asked?

I want to talk to people like you because your views and perspectives matter to this study. All the people being asked to take part have been suggested to me as relevant interviewees that can add to the overall information I gather.

Do I have to take part?

It is up to you whether or not you choose to take part. If you are happy to be interviewed I will ask you to sign a consent form saying you agree. You can withdraw from the study later, at any time if you wish. Taking part or choosing not to has no effect on your care at Y Trust.

What happens if I do take part?

If you do agree to take part, I would like to interview you for about 1 hour. I have a list of themes and questions I would like to cover in the interview but ultimately your views and perspectives are what matter to me and I would be happy for you to discuss as you wish around the themes and questions.

If you agree, I will be audio taping the interview. You can ask for the tape to be stopped at any point for you to listen to what you have said.

I will then have the interview typed in code and destroy the tape recording. Once the interview is typed you will be completely anonymous and unidentifiable.

I will maintain confidentiality at all times, and all data will be held secure. No people involved in this research will be identified in the reporting.

What happens to the results of the study?

It is hoped that the results will contribute to local initiative in the future and shed light on issues relating to service user involvement, therefore facilitating ways forward for the organisation.

Just a few further points, the ideas that emerge from the interviews will be written into a report for 'The University of Central Lancashire'. I hope to achieve a Masters level qualification. Please be assured that no people involved in this research will be identified in the reporting.

If you would like to receive a copy of the report I will need a postal address, and I will obtain this when we meet for interview.

What happens now?

You can contact me over the next day for further information if you wish. I will return on ____/____/____ to confirm or otherwise your choice to be interviewed and the consent form to be signed if you agree.

Contacts for further information:

Jenny Casson, Research Associate / Occupational Therapist
Address: _____ Tel: _____
Mick McKeown, Principal Lecturer
The Dept. of Nursing, The University of Central Lancashire
Tel: _____

Thanks again for taking the time to read this information.

Women's voices:
An analysis of views on service user involvement in mental health care.

Information to Staff

Researcher: Jenny Casson

Date of provision of this information:

You are being invited to take part in a research study. Before you decide whether to participate I would like to address the rationale and the process. Please take time to read the following information carefully, discuss with others if you wish. I am happy to clarify any detail further. Take time to decide whether or not you wish to take part.

Thank you for taking the time to read this information.

Background

Our service users are increasingly being seen as important partners in service planning and delivery of care. Patient and public involvement is high on the political and policy agenda. Effective working partnerships are seen as crucial for a successful, modern health service. Mental Health policy increasingly emphasises the necessity to involve service users in aspects of service planning, practice and evaluation (Department of Health, Sainsbury Centre for Mental Health, National Institute Mental Health England). Research with a focus on 'what' is important for users as regards their involvement is often lacking within the policy.

What is the purpose of the study?

Our organisation recognises the importance of service user involvement in the *new* NHS, and acknowledges the need to look at issues for women in mental health. This research aims to explore views and perspectives about women involved in service planning & delivery of care so that we can address the issues and improve partnerships in the future.

Who will be doing the research?

I am undertaking this Research study for The Learning Foundation, as Research Associate based at Y Trust. A Principal Lecturer from The University of Central Lancashire will supervise me; he has research experience in service user involvement.

Why have I been asked?

All the people being asked to take part have been suggested to me as relevant interviewees that can add to the overall information I gather.

Do I have to take part?

Participation is entirely of your choosing. If you are happy to be interviewed I will ask you to sign a consent form saying you agree. You can withdraw from the study later, at any time if you wish. Taking part or choosing not to has no effect on your position within Y Trust.

What happens if I do take part?

If you do agree to take part, I would like to interview you for about 1 hour. I have a list of themes and questions to facilitate discussion but I would be happy for you to expand around the themes and questions, according to what you feel are meaningful and pertinent issues.

If you agree, I will be audio taping the interview. You can ask for the tape to be stopped at any point for you to listen to what you have said. I would delete any part of interview material if necessary. The interview will then be typed and the tape recording will be destroyed. Once the interview is typed you will be completely anonymous and unidentifiable.

I will maintain confidentiality at all times, and all data will be held secure. No people involved in this research will be identified in the reporting.

What happens to the results of the study?

It is hoped that the results will contribute to local initiative in the future shed light on issues relating to service user involvement, therefore facilitating ways forward for the organisation.

The ideas that emerge from the interviews will be written into a report for 'The University of Central Lancashire'. I hope to achieve a Masters level qualification. Please be assured that no people involved in this research will be identified in the reporting.

If you would like to receive a copy of the report I will need a postal address, and I will obtain this when we meet for interview.

What happens now?

You can contact me over the next day for further information if you wish. I will return on ____/____/____ to confirm or otherwise your choice to be interviewed and the consent form to be signed if you agree.

Contacts for further information:

Jenny Casson, Research Associate / Occupational Therapist

Address: Tel:

Mick McKeown, Principal Lecturer

The Dept. of Nursing, The University of Central Lancashire

Tel:

Thanks again for taking the time to read this information.

Women's Voices:
An analysis of views on service user involvement in mental health care.

Interview Schedule

Interviews will attempt to elicit information in the following areas:

- The overall principle of service user involvement and government drive for participation in delivery and planning of care.
- Involvement of service – users within the organisation to date, satisfaction / dissatisfaction / helpfulness
- Training needs for service users, views about training needs specific to women
The current service user representatives experience of training for the role.
Received and considered important.
- Support mechanisms and resources available for service users, views about needs specific to women
The current service user representatives experience of support and resources available for the role. Received and considered important.
- Perceived differences emerging from a person's gender relating to service user involvement
- The barriers to service user involvement and how they impact:
from the organisation
from the individual (self & others)
Perceptions of the origin of barriers to service user involvement.
- Awareness of levers to service user involvement:
from the organisation
from the individual (self & others)
Views and perspectives of how these levers help
- Perceived benefits and outcomes from service user involvement:
for the organisation
for the individual (self & others)
- Perceived costs arising out of service user involvement:
for the organisation
for the individual (self & others)
- How personal views are arrived at

Breakdown of the data generated

Total words generated: 110,871 words over 20 interviews

Person Location	Transcript Number	Word count
Patient and Public Involvement Lead	S1	3106
Unqualified assistant		
Hospital Chaplain	S3	5608
Ward Manager Older Persons Services	S4	9259
Systemic Family Therapist	S5	7729
Service Manager	S6	3919
Care Programme Approach Manager	S7	7789
Service Manger Older Persons Services	S8	7590
Service Manager Acute Services	S9	6847
Service user Involvement Co-ordinator	S10	6379
Staff Nurse Female Acute	S11	5010
Occupational Therapist Secure Services	S12	3988
Borough Director	S13	4618

Total staff words (12 interviews):

71,842
Average 5,987 / person

Person Location	Transcript Number	Word count
Acute Adult service user	SU1	2762
Service user representative	SU2	3043
Service user	SU3	5670
North West User Network	SU4	13257
Adult Secure Services	SU5	2314
Service user Advocate	SU6	4144
Service user	SU7	6103
Service user	SU8	1746

Total Service user words (8 interviews):

39,039
Average 4,880 / person

Transcript Staff Interview, an excerpt

Interviewer: *italic text*

Interviewee: ***bold italic text***

(Introduction / repeat protocol / discuss format)

What is your understanding of service user involvement and where it is coming from?

I think there is a real drive (.) not just through the Department of Health but on a much more wider scale from public and private industry as well too... its almost like involving customers (.) or clients (.) or service users(.) or whatever you wish to call them(.) but certainly it is one of our key priorities in health in the NHS(.) but even more specifically so it seems in mental health... and they were certainly key drivers from the National Service Frameworks for mental health which stipulated specific deliverables for user involvement(.) but really prior to that(.) it was considered good practice and I think it had already been embraced by mental health long before some of the other NHS specialties...

So are you talking about (.) there is a sort of drive from government and from the organisation (.) is that the background to service user involvement then...

I think it sets the framework (.) but I think she has also come from practitioners and service users as feeling more empowered anyway... I think as well it has come from some of the professional training that has changed greatly for all professions probably over the last 20 years in that there is much more of a focus on empowerment and rather than treating people(.) working with people towards recovery(.) so I think it is reflected in the training as well...

Right (.) it is interesting you talk about it coming from practitioners... can you expand on that?

When you say it is interesting (.) I think it has become part of the culture (.) my main experience has been in mental health anyway(.) but it seems that there is almost a culture around ensuring that service users have rights... well they had rights anyway but ensuring they are able to exercise those rights more(.) and I think service user involvement has come from that... we were actively seeking positive and negative feedback from them now so that we can improve... it just cuts across so many things (.) like clinical governance and standards you know(.) professional codes of ethics(.) it cuts across everything so that it is an integral part of what a practitioner does...

Talking about seeking people's views (.) do you consider people need help?

I do (.) I think it's more than seeking though (.) I think it's about seeking and valuing (.) because we are not paying lip-service and maybe in the early days we were because it was new to us... but I think we genuinely value what our service users are telling us now (.) and it does influence the way that we are developing our services... sorry what was that question...

No no you have answered it...

Has that answered it...

Yes(.) yes(.) the other thing we were talking about is the contention with what we actually call this group of people...

I know...

Erm (.) you mentioned quite a few different ways of describing them (.) do you have any preference (.) or any thoughts around how we should be describing this group of people...

Oooahhh gosh... it's difficult (.) ermm(.) you know we as service users ourselves(.) we allow ourselves to be labelled to whatever service we are in... if we are in acute hospital receiving some kind of medical intervention(.) we consider ourselves a patient(.) if we go to our GP(.) we think about ourselves as a patient(.) and yet that term is not really acceptable in mental health(.) erm (.) I don't know I don't have the answer to it... even when you ask service users and they don't know what to call themselves... it's nice to think of them as partners really...

...mmm...

...but there are times that you can't use that reference... maybe(.) in the way that you are collaborating over a care plan that needs to be signed can we use it(.) as partner(.) I don't know (.) I think we can use different names for the levels you know (.) the type of involvement they have got at that time (.) but I think they are the best people to ask I really don't know...

So is it you think (.) we should be calling perhaps service users (.) service users when they are involved in that sort of higher level of planning services(.) looking at services and structures... and perhaps call them patients when we are talking about their own care and care plan...

Mmm erm (.) yeah I suppose (.) what we can't lose sight of when they are involved in strategy (.) or interviews (.) or whatever(.) at that stage they are actually a stakeholder(.) but what we need to appreciate is the perspective that they are bringing is a service user perspective(.) but the role that they are engaged in at that time is as a stakeholder... but I mean if we have someone from the voluntary sector they are a stakeholder(.) but they are bringing a voluntary sector perspective and we mustn't lose that in the name we give them...

It does seem like a much more anonymous term (.) stakeholder (.) as you say they could be from the voluntary sector or service user (.) no one would know the background of the status...

And I think it is important sometimes that we do know their status (.) so that we can take their views on board...

Right...

The term service user seems okay to me at this moment (.) but I'm sure it will change over time (.) as it may be (.) I don't know (.) quite have some negative connotations (.) I think I think it's up to the individual (.) so long as we understand it is the service user perspective or something within that context that they are bringing when they get involved...

I understand (.) that it is about seeing that term as a positive term (.) and something that does have value... there is the argument that using this about drug use...

Yeah...

...but that is something quite different...

Yeah (.) absolutely...

So(.) going back again to say that some people might have problem expressing their views(.) do you know of particular initiatives looking to service user involvement...

I'm not sure that there is particular initiatives (.) I know of one or two (.) but I think it's around the approach (.) or the ways that individuals engage to get their views...initiatives (.) I know our learning foundation is looking at training programmes (.) and has actually got up and running at the moment (.) which enables people to participate at various levels of the organisation (.) from a service user perspective... erm(.) I'm not sure anything is being done centrally from the Department of Health (.) although there is guidance available from the Department of Health and on various web sites as well about the models of engagement for service users... but I think it often comes down to more local initiatives (.) about how you engage people (.) and obtain their views (.) looking at the whole wide spectrum of doing that (.) which isn't necessarily attending meetings (.) there are different ways of doing it and it comes down to approach(.) it comes down to the context of the environment that you set to with people(.) and it comes down to the facilitators skills as well(.) to be able to obtain the perspective that they need to influence whatever they are doing ...but I don't think we have grasped it as a national agenda (.)we haven't really given it clear thought(.) how to engage these people(.) because very often we are asking them to take part in really high level of activity that an NHS staff member might take 20 years before they can do it(.) but we want service users to turn up almost out of the blue and do this for us... So I don't think we have grasped (.) you know a (.) erm grasped how to do it properly yet...

It is interesting in the beginning (.) you talked about key directives from specific NHS documents (.) national documents from the Department of Health(.) but they have not given us the understanding about the skills(.) the... as you said how to do it... Do you say that needs to happen nationally (.) or do you think we should be doing that locally...

I think there is a potential for rolling it out nationally (.) to develop practitioners skills so that they can develop the skills of service users to do it... you see this is really difficult it's a bit of a(.) erm conflict really(.) if you skilled people up(.) do they become professional service users and maybe stop perhaps speaking straight from the heart(.) which is something that we really don't want to lose... at the same time we want them to have the confidence to be able to do that so is it about... (pause) I definitely think there is more that we should do... we almost don't want a national training programme (.) it is around developing our skills (.) so that we can develop their skills for engagement at whatever level they wish to get involved (.) but we don't want them to become professionals like ourselves (.) or we lose the essence of what it is to be the service user(.) and that has happened that has happened over time...

Do you think there is a time limit to that role of speaking (.) as a service user...

No I don't think (.) no (.) I don't think there should be a time limit (.) but it needs to be reflective... if the service user is a service user for life there should be no time limit on their engagement with us... if you know their recovery is really successful after 10 years and they are not really service users (.) they have disengaged with services for (.) you know however long (.) and it's not really reflective of what is taking place (softly) erm (.) what was I going to say about this now(.) erm(.) what I think we need to do is expand the pool of people(.) or expand the opportunity for people to get involved (.) using different ways of engaging them(.) may be by phone(.) may be by visiting them(.) may be electronically may be by letter (.)erm I think there is different ways that we can expand the resource(.) which I think is more important than putting a time limit on people...

Another thing you are very clear about (.) is that we need to be skilling up practitioners to seek out and support this confidence with service users... in my head I have the word advocacy (.) can you tell me about advocacy...

Yes (.) advocacy from my perception(.) are there to support people to express a need or a request (.) or whatever it is that they wish to express(.) they don't apply their own bias to what the client is saying... they are there to ensure that the message is heard or problem is solved or whatever(.) but it is a very very objective role...

Is that different from the way you would hope practitioners develop then...

Yeah (.) I would like practitioners to help people erm (.) to develop skills to engage(.) which is very different from what an advocate does... I believe we are looking at these people to perhaps do it without an advocate (.) so that you know(.) it is increasing their independence(.) increasing their confidence to express themselves(.) and really I mean erm advocates can play a key role at whatever level with people... but we are looking at developing people skills(.) so that they are no longer dependent on other people to do it for them...

Right (.) right(.) and then taking it a stage on(.) to them being in this stakeholder position you talk about... what sort of skills(.) what sort of person would you be looking for(.) for a role like that...

It depends how you want to engage them(.) if you want someone to attend meetings (.) then they need to be able to speak the needs of the common language that other stakeholders speak... they need to understand the context (.) the framework(.) they need to understand a certain amount about policy(.) it's pretty high-level stuff they need then to be able to articulate... they need to be able to concentrate(.) and they need to be able to have the social skills to engage at that level(.) they need stress management skills(.) it can be highly stressful to be involved at that level(.) you do have frustrations particularly about perhaps no funding (.) or things developing in a way that you would prefer them not to develop(.) or lots of reasons(.) and it's quite high-pressure(.) it's quite difficult to speak up in front of a room of may be(.) 20 or 30 people(.) and you may be the only service user there(.) and the rest are all professionals wearing suits(.) or carrying briefcases and diaries(.) you've got to be able to have the confidence to do that... you've also(.) I suppose got to have the skills to be representative of other service users (.) may be skills around convening meetings with other service users(.) chairing meetings(.) taking minutes(.) its being able to articulate their views as well(.) not just your own... so there are a whole host of skills and actually(.) most graduates of the NHS haven't got those skills...

...mmm

...So, it takes a long time to acquire them...

...mmm

So they are the kind of things that we need to be able to help them develop...

Mmmm (.) you mention the word representative (.) do you feel that we need representatives across different service user groups...

Yeah absolutely (.) and there is some areas where we really haven't done a very good job yet (.) i.e. young people and perhaps older people as well (.) and learning disabilities... I think adult mental health is really the trail blazer for service user involvement (.) but in those other areas we really haven't cracked it at all(.) but it may not be by these other people attending meetings... I think there are other ways to do it(.) but it needs a more creative approach perhaps...

Transcript Service user Interview, an excerpt

Interviewer: *italic text*

Interviewee: ***bold italic text***

... So can you tell me what you understand of service user involvement?

Well I understand it be that you get involved in your own care package(.) and you give feedback into things that you would like to see happening or changed or that is what I see it as...

Right (.) so when you say feedback do you mean feedback into the way your package of care is...

Yeah yeah I used to go to the [hospital unit] and there used to be the patients committee meeting that we used to have, and they used to bring up points or any issues that you had or anything that you didn't understand about your care package(.) or if you had any questions by your medication and stuff and we could all talk at that and then we used to have a representative and that would get fed back into the system...

Do you think it was helpful?

Yes it was, but we used to have a member of staff who would sit on the committee and she would sometimes I thought that that was...the things couldn't be said quite openly what they would have been said if there wasn't a member of staff sat there but they had a member of staff sat there because (.) well in case of anybody taking ill or(.)and also if there was any disagreements or anything so was a bit more formal, so it had its pluses and it had its minus is that there was a member of staff there...

Why do you think people couldn't speak out in that group with member of staff there...

Well I was thinking, that if they had a particular issue with the CPN (.) that if they had voiced out anything that it could have got back to that particular CPN whereas if it was just (.) or if they could have brought out the issue and it couldn't have been identified to which CPN if you understand what I mean...

Hmmm (.) why would that be important...that people weren't identified...

Hmmm (.) I think they just thought that if it was identified that they were making a complaint their treatment would have been affected... it might have been completely unfounded fears (.) but I know sometimes that they would bring up issues that they knew were directed to one person but they would bring it up sideways as if it was they weren't involved do know what I'm saying...

...Yeah...

...I suppose they were scared of repercussions...

..Right (.) and is that on an individual basis do you mean...

Yeah (.) yeah on an individual basis that's right...

Have you been involved in any other groups that haven't had staff in them... Is there a difference...

Erm (.) we've got (.) I'm involved with the self-help group at the moment the mood swings self-help group (.) it's a totally voluntary group it's not run by the hospital or the [hospital unit] or anything it's just totally voluntary group erm (.) I've not been involved with any other groups within like the hospital situation or the National Health Service situation (.) that is the only groups what I have been involved in...

Mmm, can you tell me a bit more about how the mood swings group works...

Well it (.) we meet every month and we tend to get a guest speaker erm...on like how they have coped with depression or manic depression (.) they have had Art Therapy(.) they've done different things each month(.) and at the moment we're trying to get it going so that there are social activities so that we can just have like a day trip somewhere(.) or just a few hours out somewhere, it's just helping people identify coping mechanisms and things like that(.) helping each other like giving each other information about if you've had a similar situation how have you have dealt with it...

Right (.) why is going to that group helpful...

Erm (.) it makes you feel like it's not just yourself that's got this problem or felt this particular way (.) it makes you realise that there is other people and that they have dealt with it positive(.) you know and got themselves going in a positive way rather than just feeling isolated(.) dwelling on it making yourself feel worse(.) it just teaches you it gives you open inspiration to do things differently...

Do you see that group as service user involvement in care...

(Pause) mmm yeah it is service users because you get a lot of people from the hospital that has been like in (.) for treatment coming too(.) being referred to the group(.) and when they have been discharged and things(.) they advertise within the hospital on the wards you know for people to come so to an extent it is service user involvement it's like self-care like self help ...

...right yeah yeah...

...you know you know ongoing treatment(.) once they've got past like(.) the diagnosis the medication the hospitalisation stage(.) then they can come onto such as our group(.) so they know it's not(.) you know(.) because when you first been diagnosed as having something wrong with you(.) you think you don't know anybody else you only know a few people and it's like you feel so alone(.) so it's

good to have something to carry on to because like when I went to the [hospital unit], the group then wasn't going as such and the only thing that you was passed onto from the [hospital unit] ...

...right...

... for different reasons it doesn't suit everybody to go to that place

who decides what is going to happen at the groups you mentioned the two groups you've been involved in who decides what happens...

Erm, That's usually put to erm, like they have a Committee and it's usually put to(.) you get a general feeling(.) of like a questionnaire type situation where we will get feedback you know is this what you want...

So, are the most popular things what everyone wants...

Yeah yeah

...what gets done in the group...

yeah...

Is that the way it was sort of decided what happened in the [hospital unit] group(.) or was that different...

No no(.) because what used to happen in the [hospital unit] was(.) they would write minutes of the meeting and it would be put to the management(.) then there would be talks with the management(.) and a decision would come from that(.) whereas the self-help group is like all the members users come up with a decision between themselves...

Mmm (.) have you got any idea of which one is more productive...

...mmm (.) I would say they would probably be about the same(.) because like some of the requests that was put forward at the [hospital unit] (.) how can (pause) erm(.) would be impractical for the staff to implement, do you know some of the requests that was brought forward(.) so it was you had to get the management side to the issues before you could see it(.) but like with being more self-help we are a sort of management and staff(.) we are all the same(.) if you know what I mean(.) we have to when we think of anything we've got to implement it is well(.) do know what I'm trying to say, yeah(.) so you won't get like to erm what's the word not impossible things asked but impractical things asked know people think about it more first before they put their suggestion forward(.) because we have got to think of the practical side of it as well(.)we are implementing it...

Right right so that is very different then?...

Yeah

...do you think there is a difference between sort of(.) service user involvement with management and service user involvement from the sort of voluntary...

Oh definitely(.) yeah because(.) I think people where the management tend to think that erm(.) that they can ask for anything(.) and they can't understand why it is harder for them to understand why things are impractical whether it is forums time what ever reasons(.) they tend to think that because it is within an official(.) like the National Health Service that they should be given these things automatically...

Right...

...do you understand what I'm saying... I'm not saying everybody is the same but you know...

How do you think you've come to understand that about not asking for everything...

I think it's because I have been involved with committee works and things when I was working years ago(.) and it's just like experience gets you to understand that you know you've got to look at it from both sides, you know(.) whereas some people I think who have never had any involvement might think(.) while I can just suggest this and they should be able to do it for us(.) and then they can't understand if it's not explained to them in proper layman's terms(.) they can't understand that is not practical...

Right...

So...

Do you think people should think should think about the practical side of it whether it can move forward from an idea before they put ideas forward...

I think in an ideal world that would be right(.) I think some people when they are ill as well(.) especially they can't rationalise(.) it depends how the service user is at that time(.) if you know what I mean (pause) is rationalise the right word I'm trying to say ... Yeah...

Do you think we should be involving service users when they are poorly(.) in asking them their opinions and views...

Yeah I do (.) yeah(.) because erm(.) when you're really poorly sometimes nobody is asking you anything(.) it's more isolating really(.) you feel like when I went to the [hospital unit] when I was first going(.) there was all these things going on and it was quite a while before I was involved(.) I just felt like the outsider and maybe you couldn't have given any constructive input (.) but at least you would have-you would have felt part of (.) (pause) (.) the system you know(.) and being involved even though perhaps you couldn't have said given anything(.) it would have been nice to have been just involved...

Discussion map of the aggregate talk:

Notes written in italic refer to women's position specifically

Non-involvement	Involved Incorporated	Involved Independently
Talked about: (1) In hospital (2) Discharged from hospital	Talked about: (1) In the hospital as a selective group for representation at high level	Talked about: (1) Self-help group (2) Through mental health voluntary organisation group (3) Personal, through care planning
Issues and impact: Lack of confidence (<i>women 's socialisation</i>) Lack of knowledge Bio-medical dominance in training and practice (<i>Women staff are socialised as less empowered than men equivalents in nursing practice – service users need access to empowered staff</i>) Paternal relationship between service user and practitioner <i>Being seen as having less confidence and therefore consciously approached less for consultation type activity</i> Staff culture not conducive to empowerment and staff positioning themselves positively in relation to service users Disempowerment / receiver of care - them & us Service users don't see it as their position to complain – don't acknowledge choice as available <i>Staff perceive women service users as being polite and grateful – less likely to ask for views?</i> Formal detention / less motivation / disempowerment	Issues and impact: Negative: Service users struggle to define themselves Service users imitate staff to make a better impression – role modelling Staff don't identify service user rep. as sharing global service user identity Lack of value for the rep. input don't take service users seriously Service user rep is contained by the organisation Involvement is decided by / on Trust terms Trust can predict the service user comment or influence it No direct change as a result of service user involvement Consumerism Positive: A service user is present at trust board level meetings (<i>women socialisation means women are less in such positions</i>) Resources provide things like refreshments - create comfort environment for consultation	Issues and impact: Negative: Without the resources of the organisation The organisation staff are not always aware of involvement opportunities – not promoted well in the institution Staff feel threatened by empowered service users Staff culture of fear for autonomy of service users Positive: Solidarity (<i>being part of a solid group</i>) Confidence is encouraged Autonomy is inherent- Conducive to a sense of being an individual (not part of a homogenous group) People become more resourceful Responsibility for self others and the organisation develops Engaging in activities that support others & further impacts personal confidence and self worth (<i>Gendered qualities – caring etc</i>) Citizenship

<p>Stripped of choices – reject consultation (interesting cameo of refreshments) / disengage in the community</p> <p>Token approach / exclusive and non-inclusive / non-creative to accommodate user needs (<i>women - Seeking solidarity</i>)</p> <p>Lack of interest</p> <p>Lack of value / reward / discomfort (refreshments)</p> <p><i>Home life responsibilities – pressures / socialised into home as against public life</i></p> <p><i>Citizenship and equality has not focussed on marginal groups women wait to receive equality</i></p>	<p>Service users appreciate having their voice considered in participation (interviews)</p> <p>Service users have the opportunity to gain knowledge</p> <p><i>(Gendered qualities – caring etc)</i></p> <p>Status of the service user is impacted positively - personal worth and confidence</p>	<p>Staff feel empowered by encouraging service users</p>
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