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Feathers and Thorns

The Politics of Participation in Mental Health Services

A Thesis submitted to the University of Kent at Canterbury
in the Subject of Mental Health for the Degree of Doctor of Philosophy

By

Tessa Parkes

January 2002

In loving memory of Philip Whitfield... a doctor who wrote poems.

To LT for your enduring love and support throughout this journey of life and labour.

Abstract

A key development in mental health service planning and delivery in the UK over the last fifteen years has been the introduction of user participation. Alongside this development has been the growth and expansion of the service user/survivor movement. Research in Canada and Australia has documented the 'unsettling relations' created by these demands for participation and power sharing. Research in the UK has also raised questions about the ability of user participation to create the cultural change some believe is required to prevent services from being disempowering.

Feathers and Thorns explores the 'unsettling relations' and the conflict and power dynamics of user participation in mental health services, in a UK context, to address the lack of systematic research in this area. The study uses qualitative methods to investigate user participation in two statutory mental health settings in England, between 1997 and 1999.

Feathers and Thorns found that the uncritical adoption of the consumerist approach has led to a 'business as usual' model of participation and a consequent lack of discernible organisational and cultural change. The influence of user groups within statutory mental health services rarely extends to setting agendas, with the 'rules of the game' of participation still firmly controlled by statutory partners. There was evidence of professional and organisational resistance, as user participation destabilised the roles of both users and professionals and boundaries became increasingly blurred. It is suggested that this destabilising of traditional roles provides evidence of a shift in power relations, despite continued organisational and professional resilience to change. Although user participation was considered to be an effective strategy to legitimate existing power relationships and give the illusion of change: there was evidence that user groups and individuals have also gained from these processes, particularly in terms of raised consciousness, increased activism and self-assurance.

Development has failed, principally because it has been taken out of the forum of human agency and has been presented, by ubiquitous technocrats, scientists and planners, as a system to be planned, managed and directed by the top and from the top as if it were the system and not the people that mattered (Carmen, 1996: 193).

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Acknowledgements

This thesis is in my name but it has been a shared journey.

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Introduction

Setting the Scene: The Rationale for Research on User Participation in Mental Health Services

Feather in their cap, thorn in their side. LG

A key development in health service planning and delivery in the UK over the last fifteen years has been the introduction, and use, of the concept of user involvement or participation. Increasingly, the language of consumerism and choice has infiltrated health and social policies since the 'market-place' changes of the 1980's transformed the role of the public sector from provider to 'enabler' (Barnes and Walker, 1996). The rhetoric of care changed, alongside the creation of mixed economies of welfare and the relocation of treatment and care environments from hospital settings to the community. With the election of the Labour government in 1997 and re-election in 2001, the welfare pluralism that was created in the 1980's and early 1990's appears set to continue, although the emphasis on market forces is faltering. Partnerships between the public, private and community and voluntary sectors is now the concept with most political currency (NHSE, 1997). The involvement of users and carers in the reforms of the 1980's and 1990's has given way, in part, to a preoccupation with 'community' involvement and empowerment, reflected in policy initiatives like Health Action Zones and Healthy Living Centres (Barnes, 1999; Hogg, 1999).

Alongside these developments in policy and practice has been the dramatic growth and expansion of the mental health user/survivor movement, which provides a radical challenge to, and critique of, psychiatric and mental health services. One of the demands of this movement is that mental health services should involve their users centrally, both in decisions about their individual treatment and care, and in wider decisions about the appropriate services to meet the expressed needs of service users.

Claims of empowering practice and partnership working have proliferated over the past decade; something reflected in the nursing, social work and psychiatric literature (Anderson, 1989; Ashworth, *et al.*, 1992; Braye and Preston-Shoot, 1993; Glenister, 1994; Gordon, Alexander and Dietzan, 1979; Kondrat, 1995). As Richardson (1983) states, participation, like motherhood, is clearly 'A Good Thing'. However an examination of the writings of service users and survivors over the same period suggests a somewhat different reality. Assertions of 'involving' and empowering practice are still contradicted by stories of user/survivor disempowerment that describe a very different reality; where user views and opinions hardly seem to matter and rights are undermined on a regular basis (Campbell, 1992; Copperman and McNamara, 1999; Williams and Keating, 1999).

The change in culture brought about by the emergence of the concept of user participation has also placed expectations on staff in health and social care agencies that are rarely openly discussed. Although many of the texts on user participation prioritise staff training and development as prerequisites for involving/empowering practice (Braye and Preston-Shoot, 1995; Stevenson and Parsloe, 1993), the reality has been a lack of training on user involvement and a lack of acknowledgement of negative staff reactions to change (Campbell, 1990). According to Barnes and Wistow (1994), professional defensiveness has been evident in activities that have aimed to empower mental health service users. Marsh and Fisher (1992) also write of a resistance towards working in partnership with service users from social workers, who viewed giving up their control of problem definition as de-skilling.

Considering the high profile nature of user participation as a policy initiative, there is little in-depth research on the challenges of this participation and any conflicts of interest experienced (Croft and Beresford, 1995). And, despite work on the barriers to user-professional collaboration (Campbell, 1990; Pyke *et al.,* 1991; Quarrington, 1991), little substantive theory has been developed on the basis of these findings. Work by Baistow (1995), Barnes (1999), Barnes and Shardlow (1997), Barnes *et al.,* (1999), Barnes and Warren (1999), Barnes and Bowl (2001), Croft and Beresford (1989, 1992, 1995), Church (1995), Wadsworth and Epstein (1998) and Williams and Lindley (1996); on the dynamics of user participation in mental health services, are significant exceptions. The literature that does attend to the struggles and tensions is primarily written by people who have used or survived the psychiatric system, and by professionals, ex-professionals or academics who work within a 'survivor frame' (Church, 1995).

Critics of service-driven, or what Cornwall (2000b) has termed 'business as usual' participation, argue that there is a tendency for providers and professionals to use the current preoccupation with user involvement to forward their own interests, agendas and careers (Baistow, 1995; Harrison and Mort, 1998; Jack, 1995; Shemmings and Shemmings, 1995). One writer who has concerned herself with the struggles and challenges of user/survivor participation is Church (1995), whose doctoral work in the early 1990's was on user involvement in the Ontario community mental health service system in Canada. Her work focused on the 'unsettling relations' between mental health professionals and psychiatric survivors, brought about by demands for user involvement:

> Many mental health professionals have become uncertain about how to work in this new climate. They are confused and often angry about the changes going on around them but rarely discuss these feelings publicly. There is an urgent need for their silence to be broken before it builds into a backlash, which swamps the inroads which consumers/survivors are beginning to make. I want to engage with this problem. I see the need to develop specific practices, which would enable consumers/survivors and mental health professionals to work together across difference (Church, 1995: 140).

This thesis *Feathers and Thorns,* has a similar focus to Church's work in aiming to explore the 'unsettling relations' that user participation has brought about: the tensions and struggles being faced by professionals and users/survivors alike. I have named this work *Feathers and Thorns* because of the relevance of an expression from one of the user respondents describing user participation in her organisation: 'feather in their cap, thorn in their side', to the findings of this research. It also adequately describes the difficult process I experienced attempting to create a collaborative piece of research within the constraints of a doctoral study.

This study seeks to determine whether the preoccupation with participation and empowerment is merely a rhetorical device to indicate that change has taken place when it has not, or whether a 'cultural revolution' (Barnes and Walker, 1996), has indeed taken place. Observing user involvement in Canadian policy development, Church and Reville (1988) cite Martlett who writes of the danger of co-option:

> ... a favourite practice of professionals and social activists... groups are subtly... directed and trained to operate in a manner that reflects professional values (date unknown, cited in Church and Reville, 1988: 25).

This thesis asks: are users and user groups able to demand changes in services and to demand their right to more power and control over their lives and of the services they depend on? Are user groups and individuals now more 'empowered' after a decade of being 'involved' in their mental health services? Or is the co-option, described by Martlett above, the prevalent dynamic?

Feathers and Thorns places discussions of user participation and empowerment within larger debates and policy changes, that influence the ability of users and survivors to become viewed as full active citizens with rights and choices. These debates hinge on notions of appropriate governance for the NHS and other public services, and concerns about the limits of representational democracy more generally. Links must also be made between changes in the power of people who use mental health services within and outside of these services. For example, the ability of changes within services to tackle the current preoccupation with mental distress/illness as 'dangerousness', following public concern arising from incidents such as the death of Jonathon Zito (DoH, 2000; Taylor and Gunn, 1999). This preoccupation and the threat of new restrictive legislation has created a paradoxical situation where users' views are sought, but then systematically ignored if they fly in the face of new government policy. Another example is the continued reliance upon bio-medical and technological solutions where distress is viewed as just another 'scientific problem'. This also militates against the idea that people should be able to name their own problems and determine their own solutions.

Positioning myself

Before continuing it is important to position myself within this work. This is necessary because of the specific interests and concerns that underlie and inform my research questions and methodological approaches. Hermeneutic thought proposes that everyone, including scientists and researchers, is inevitably caught up in the value biases of their culture, their personal histories, work place, academic training and historical position (Emerick, 1996). Being explicit about the influences of the researcher can help the reader to assess the validity of the claims being made. Where questions of position, voice and legitimacy are rightly asked, there is a need to be clear with others and yourself 'where you stand' (Heron, 1996) and give information about motive and loyalty. I therefore provide a brief account of my experiences as a worker in the psychiatric/mental health system that led to the development of the original research questions of this thesis.

When I entered psychiatric nursing as a student I was completely unprepared for the experience, and my first placement in a psychiatric ward was traumatic. I developed fears about psychiatry, mental health nursing and hospitals that have stayed with me since. After a few weeks on the ward I began to understand that the my initial assumptions about the treatment, care and knowledge underpinning psychiatric practice, were not based on the reality of which I was now part. I was astonished at many aspects of the care of the people on the ward and the reasons given for the 'treatments' that were meted out. On one level it was the unmasked reality of human crisis, of abuse and suffering that I found utterly traumatic, on another level, and one I found more difficult, was the way in which this distress was interpreted and worked with by staff. I spent only seven weeks on that ward but during that time I grew more and more aware of the disparities between the claims psychiatry was making about its ability to cope with human distress, and the blatant chaos of the everyday reality which I was experiencing.

My naive concerns and questions were met with curiosity or hostility depending on whom I spoke to. Lacking the experience, skills and support to deal with this environment, to make sense of it or be able to challenge it effectively, I began to withdraw emotionally. I lost interest in everything around me, withdrew from friends and family, smoked too much, ate rarely and slept badly. I became preoccupied with the ward and the people there, their distress and the lack of understanding they received from the staff.

Although this ward was particularly chaotic and terrifying, and as I later found out, a far cry from the experiences of the majority of the other students, I believe I learned an invaluable lesson about psychiatric nursing and its operation. In that extreme environment I witnessed what in many mental health environments is less obvious: the almost fanatical desire to control the expression of human pain and distress. This was a feature I found bizarre, and I was immediately hooked into a quest to work out why. I changed my career path from overseas development to mental health nursing and committed myself to understanding and trying to change the practices I had witnessed over those early weeks.

However, I remained at odds with the established version of 'nurse'; soaked in values that I did not share and did not wish to share. My preferred role of confidant and gentle helper so frequently got lost within the agendas of assessment procedures, medical treatment, restraint and containment of emotional chaos. People's struggles were often decontextualised from their lives, social circumstances, family and culture. The process of medicalising distress cut people off from finding their own patterns, seeking out their own meanings and finding their own solutions. Psychiatric professionals often intervened in ways that prevented those who came for help from using their own resources. They did so by mobilising powerful professional strengths; medication, invasive treatments, therapies, observation and control, while restricting the ability of patients to mobilise their own strengths. Psychiatrists and nurses seemed largely to devalue the process of the patient being involved, or indeed responsible for their own mental health and well being (Parkes, 1997).

These were not libertarian and supportive environments, but combinations of hierarchical, punitive and controlling structures that dominated all relationships within them. I struggled to work with the differences between my way of wanting to work and the dynamics of these settings; but eventually could no longer do so without losing my individuality and self-respect. I was tired of trying to explain myself and tired of trying to fit in to places with which I had no affinity, held together by structures in which I could not believe.

Becoming more aware of how psychiatry has oppressed people who enter its influence has helped me to acknowledge and face my part in that system. Becoming aware has also helped me to acknowledge how it hurt me. My experiences of abuse and oppression within the system as a worker were short-lived and minor compared to many users' experiences. I was able to walk away when the going got too tough. I see *myself* as a survivor of psychiatry too, though in a different way. I see that I could have lost my humanity and self-respect, my hope, energy and humour. Looking back to that time the memories have faded now and it is difficult to remember it all. Part of the powerlessness I felt, was my reaction to the enormity of human pain and suffering that one can witness as a 'helper' in this system, unable to make things better. But there were other causes of my powerlessness and I have now come to describe my experiences as a worker in the psychiatric system as inherently limiting and oppressive.

I left nursing after six months of working as an RMN staff nurse, with no job to go to. After a few months I began working as support worker and then team leader with Penumbra, a voluntary organisation providing supported accommodation for people who had spent a considerable amount of their lives in psychiatric institutions. This opportunity to put into practice my ideas of support helped me recover from my experience of front-line nursing and I also began to formulate some of the questions I address in this research. Some of these early questions were: What makes practice empowering? Why do so many professionals (including the CPN who only talks about taking medication to stop the voices) say they are empowering the tenants?[1] Why are we all claiming to be empowering? What is in it for us? Where are the tenants amid all this empowering practice? And what about abuse of power – where does that fit with all this talk of empowerment? So reluctantly, after a number of happy and challenging years in Penumbra, I left in order to set about answering these questions.

Research Aims and Questions

Based on the analysis of the literature on user participation in mental health services, described in Chapters one and two, and the explication of my position as a worker within this field, my central thesis is as follows: participation will not succeed as a strategy to improve services, or change relationships between service users and service providers, if it is disengaged from an understanding of power and its effects. Four main aims were devised to guide the research and generate the research questions. These were to:

- Document the practices of user participation within the psychiatric/mental health system from a critical perspective;
- Identify and describe the barriers to user involvement;
- Provide an account of the 'unsettling relations' (Church, 1995) of participation; and
- Develop our understanding of, and build on theories about, the experience of participation and any resulting changes in power relationships.

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[1] Tenant was the name given to people who lived in Penumbra houses.

The research questions that were developed from these aims can be categorised into three main groups. The first group is a collection of questions that are concerned with *describing the current policy and practice environment of user participation in the context studied.* These questions concerned the meanings, motives, conditions, incentives and obstacles surrounding collaborative activities between users and professionals/managers in statutory mental health settings. This first group of questions aimed to document the *personal views and experiences of different players, at different levels of practice, in different organisations.* The sub-questions identified for this first group were:

- What is the nature and extent of user participation in the context studied?
- What meaning does user participation have for different actors/stakeholders and is there any consensus across different interest groups?
- What are the motives for involving service users individually in their treatment and collectively in the delivery of mental health services?
- What conditions support participative practices?
- What rewards, incentives and opportunities does user participation present to individuals involved?
- What are the barriers or obstacles to participative practice in mental health services?

The aim of this first group of questions was to document the current policy and practice environment and context in order to use this as a baseline for further exploring some of the more complex relationships and tensions within participation.

The second group of research questions was concerned with mapping the tensions that exist in contexts of participatory activities, particularly in relation to power, as can be seen from the sub-questions below:

- What challenges does the sharing of power in mental health services pose to those professionals involved? For example, what examples of conflict can be seen?
- Can participation in mental health services be understood using the consensus model of involvement or does the conflict model offer a more accurate tool for analysis?
- Is there evidence of professional resistance to user participation and power sharing?
- If so, how is this resistance manifested in structures and processes?

The third and final group of research questions were concerned with documenting user group empowerment. I wanted to explore whether signs of resistance to professional or organisationally led user involvement could be detected and to assess whether user groups or individual service users were more empowered after a decade of being 'involved' in their mental health services:

- What has been gained by user groups and individuals in the process of user involvement?
- What strategies and tactics are used by user groups to demand power and create their own agendas for change?
- Is there evidence of capacity building within user groups?
- What factors impact on the ability of user groups to create change?

Chapter three will discuss the development of these questions and related methodological issues in more depth.

Limitations and language of the thesis

These research questions cover a broad range of issues and present an ambitious task for a single researcher. Limitations therefore had to be placed on the focus, methodology and location of the research to make the task feasible. The chosen focus was two statutory mental health Trusts in a metropolitan area in the UK. Although the research questions would have benefited from being applied across health, social services and the voluntary sector, this was not possible due to time and resource constraints. The research does not attempt to address carer issues or carer involvement since this is considered to be a separate topic. Although user consultation is sometimes included in discussions on participation, I will only be considering involvement that is more extensive than pure consultation. The methodological boundaries of the study will be discussed in more detail in Chapter three.

Language, like involvement, is a contested area in mental health. According to Church (1995) it is also a site of struggle. Compared with the disability movement there is no consensus among users and survivors about ideology and language (Beresford, 1997). This can lead to hesitancy in pieces of work like this, written from the perspective of an 'outsider' (Church, 1995), because of attempts to please everyone. Some people describe themselves as mental health service users, some as consumers, and some as survivors or psychiatric survivors. According to Beresford (1997), terms have sometimes been adopted uncritically by those from marginalised groups as symbols of a new determination to speak and act for themselves, without a full awareness of the ideological baggage that goes with them. However, for some people language is extremely important, and much time and deliberation is spent searching for appropriate language that sums up the identities and experiences of those who belong to the movement.

Because language in this area is changing and evolving within the movement itself, I shall be using a mixture of terms throughout this thesis to indicate this fluidity. I use the terms: 'user', 'survivor', 'service user' and 'patient' interchangeably, and where they seem most appropriate. The terms: 'user movement' and 'user/survivor movement' will also be used interchangeably as will: 'professionals', 'staff', 'clinicians', 'managers' and 'workers'. While recognising the differences that the words 'involvement' and 'participation' have for many people, because of the lack of a consensus on the 'right word', and because the literature and the respondents used these words interchangeably, I use these terms synonymously. Although the language of participation will be problematised, in Chapters one and two, there is also a need to demonstrate the commonality of these terms. I therefore use the terms 'user involvement' and 'user participation' to denote practices that attempt to improve public services or delivery of assistance, by the involvement of users in these services. Partnership is used to mean more than participation and involvement and therefore will be used when equal power relationships are aimed for or are discussed. Empowerment will only be used to denote increases in personal and/or collective power. When indicating the voice of the people who participated in this research as interviewees I use the terms: 'interviewees', 'participants' and 'respondents'. I generally use the term 'mental health services' rather than 'psychiatric services' which is often more accurate, because it is more common to do so. Lastly the words Mad and Black are capitalised to denote that they are used as political categories.

The most problematic task I faced in this thesis was that of making sense of power and participation using an eclectic range of theories, because of the different understandings these theories have about the nature of the social world and human beings. One of the main aims of the thesis was to make use of a range of theories, both in terms of understanding power and in the task of researching it. However, as described in the methodology chapter in detail, this aim brought many conceptual challenges with it. This was primarily caused by the use of social constructionist theory alongside more traditional, realist and structural approaches to understanding social practices, power and knowledge production. Burr (1995) explains, in her text on social constructionism, that many of the conceptual problems that constructionist thought poses, have still not even been adequately worked through by scholars that actively support these approaches. This is particularly the case with regard to the role of these ideas in helping to understand what it is to be human and how we understand personal and social change (Burr, 1995). Although it is not my intention to provide a comparison between these two approaches a brief word needs to be said here to explain what could be seen as inconsistencies of approach.

Two of the main areas where differences between the constructionist and realist/essentialist (for want of a better summary term) approaches to human nature and power led to contradiction, was in regard to the role of human agency versus cultural/discursive structures and whether or not human beings can be said to have 'natures' and therefore attitudes and personalities. According to social constructionist theory, attitudes and opinions are essentialist concepts pertaining to structures that reside inside a person as part of that person's make-up. For social constructionists, however, beliefs and opinions are manifestations of discourses or 'outcrops of representations of events upon the terrain of social life' (Burr, 1995: 50). In this analysis the things that people say and write are examples of discourses in action rather than products of different personalities. Indeed, according to writers such as Foucault (1972), nothing has any independent, essential existence outside of language. But if everything is an effect of language then traditional psychological concepts such as emotions or attitudes become redundant. The effect this has on the concept of human agency, according to Burr (1995), is thus:

> Our hopes, desires and intentions become the products of cultural and discursive structures, not the products of human agents (59).

Social constructionist thought proposes that the idea that human intention and action is at the root of social change is therefore an illusion. This problem is linked with another issue concerning the conceptualisation of reality and truth and the relativism that underpins constructionist thought. So given that there may be numerous discourses, all conflicting, surrounding any object or event, we are no longer left with any notion of truth: all we have is a variety of different discourses, each as valid as the other. Burr (1995) describes the difficulties that this poses for those that wish to say that some structures/processes/events have definite real effects, whether it be about the capitalist economy, ageism or child abuse.

These epistemological problems of truth, agency and social change are massive and attempting to resolve them is quite beyond the scope of this thesis. However, by talking about power and inequalities of power, as I do in a large proportion of this thesis, one becomes immersed in this conceptual minefield. My decision has been to use many theoretical frameworks in this research on the basis of the utility each one has for a study such as this. Different and sometimes contradictory theories of power resonated with my data. This led to examples in the findings where staff attitudes are described as barriers, drawing on realist understandings of human nature and human agency, at the same time as drawing on discursive ideas from social constructionism. In the literature review and in the methodology chapter I have therefore attempted to provide a summary of all the theories that I found useful, despite their conceptual contradictions.

Throughout this thesis, when describing participation and power, I shall describe organisations, institutions, agencies and services as having 'agency' in a similar way as individuals are ascribed agency or 'power to'. This is to recognise a view that proposes that organisations have power and can wield power, as individuals can; a theoretical position proposed by both Clegg (1989) and Menzies (1970). Although this perspective would be challenged by social constructionists, I have found these ideas helpful as interpretative tools. Another possible inconsistency is that power is understood as facilitative and productive rather than as 'zero-sum', drawing on the work of Foucault (1972, 1973, 1976) for example, however, when describing power relationships I also use terms such as 'power-sharing' and 'redistribution of power'. Despite their association with a zero-sum conception of power, these terms also have utility as 'common-sense' expressions and are often used when describing the need to address structural power inequalities. It is my hope that readers will see the value of the work in the way it combines different approaches to understanding the social world and knowledge production, rather than only seeing the inevitable contradictions and inconsistencies that are a result of engagement with a subject such as this. As Burr (1995) emphasises, the intellectual debates on these matters have not been concluded, and probably never will, and I have engaged with them in this spirit: seeking pragmatic approaches that fit well with my research data, rather than adopting a 'one size fits all' approach.

Guide to chapters

This introduction has briefly described the rationale for investigating the subject of user participation and power relationships in mental health services from a critical perspective. This rationale is based on concerns from the literature and my own concerns as a practitioner and advocate for change in this field. Further clarification of the methodologies used will follow in Chapter three, after a detailed review of the literature on user participation in mental health services and other theoretical reference points, (Chapters one and two) to explicate the rationale for further research in this area. Chapters four to six present the research findings and describe in detail the *feathers and thorns* of user involvement in the contexts studied. Chapter seven discusses the significance of the findings of this study in relation to other empirical work and theoretical frameworks and concludes with an explicit agenda for change and a discussion of the strengths and limitations of the research.

Chapter One

Research on User Participation in Practice

Chapters one and two introduce the reader to the main debates and issues concerning the theory and practice of user participation in health and welfare services in order to provide a theoretical consideration of the terrain within which my work is located. Chapter one describes empirical and theoretical work on user participation in practice, with Chapter two detailing the conceptual and theoretical underpinnings of the study; theories of participation, power, institutionalised practices, empowerment, change and pressure group activity. The aim of this literature review is to provide a coherent rationale for conducting a piece of research in this area and for seeking answers to the research questions I have identified. As stated in the introduction, although there has not been any research undertaken in the UK on all of the exact questions I have posed, there is a wide range of literature on participation in different contexts, and associated theoretical and empirical critiques, that I will draw upon to inform this work.

In this chapter, the first section provides background to the research context by detailing the drivers for change that resulted in the user participation agenda of the 1990's. The second section presents evidence of the operation of user participation in practice, by drawing on key empirical research.

Part One: Why Participation in Mental Health Services?

There have been various influences motivating the collaboration between service commissioners, planners and people who deliver mental health services, and the users of these services. Changes in government policy, the developing user movement and other drivers for change, are briefly detailed.

The 'market-place' reforms of the 1980's and 1990's

Driven by the policy rhetoric of market consumerism on the one hand, and the emergence of vocal self-advocacy groups on the other, user involvement and participation was placed firmly on the agenda of health and social care agencies from the beginning of the 1990's. The first formal entry of the consumerist ethos into the National Health Service in the UK, was the introduction of community health councils (HMSO, 1973). However, it was the 1980's and 1990's that heralded the most significant developments in consumerist thinking within health and other welfare services, with the growing concern with cost-effectiveness and efficiency. Another push towards the 'commodification of welfare', came from the Conservative government's interest in shifting the balance of power away from public services and professional bodies and towards the people that used these services. It addressed the concern about professionals having sole responsibility for care, the ability of bureaucracies to provide appropriate services, and the lack of accountability in within the NHS more generally (Lupton, Peckham and Taylor, 1998). It also implied recognition of the calls for change from patient/user/carer groups whose voices were growing in strength.

The intention of legislation throughout the 1980's and early 1990's was to recommend that the views of consumers be taken into account in all decision-making regarding the provision and delivery of health services (Department of Health, 1992). The consumerist model was seen as being able to hold services to account for their performance, using similar methods to those that had been used in other public services (Bleach and Ryan, 1995; Goodwin, 1997). Within this model service users were mobilised to complain, first and foremost, in order to spur providers into improving the quality and efficiency of their services. *The Citizen's Charter* (HMSO, 1991) and *The Patient's Charter* (HMSO, 1992), along with a plethora of local charters, reflected this attempt to shift power away from professionals. The implementation of care management in mental health was another attempt to put users and carers first (DHSS/SSI, 1991). The White Papers *Working for Patients* (Department of Health, 1989a) and *Caring for People* (Department of Health, 1989b), also constituted attempts to promote 'New Right' remedies for the ills of the welfare state, where salvation lay in 'rolling back the state' to enable the market to better deliver required services. *The National Health Service and Community Care Act* (1990) also imposed a requirement to consult with users and the public more generally in determining health and social care priorities.

The emphasis of this legislation was on greater diversity of provision, individual choice, competition between providers and more reliance on the personal resources of service users and carers. According to market theory, competition between different providers ensures the necessary discipline to improve services and achieve value for money (North, 1993). The consumer-driven reorientation of welfare services has been a consistent thread of reform from the Conservative era through to the policies of New Labour. The Labour administration has introduced other policy changes including the involvement of user representatives on the National Service Framework steering group for mental health, and an annual national survey of patient and user opinion (Barnes *et al.*, 1999). More will be said about some of the ambiguities and inconsistencies of the consumerist model of involvement, created through the internal market changes, in the next chapter.

Service user/survivor pressure for change

The user/survivor movement first started in the USA in the 1970's as the mental patients liberation movement; a political movement comprising of people who had experienced psychiatric treatment and hospitalisation. This movement was influenced by other social groups such as the women's movement and the Black civil rights movement that concerned themselves with issues of self-determination and self-definition. The mental patients liberation movement was concerned with the abuse and negative experiences suffered by people within psychiatric institutions. The user/survivor movement's two main goals are to develop self-help alternatives to medically based psychiatric treatment, and to secure full citizenship rights for people labelled 'mentally-ill' (Everett, 1994). The movement has developed its own philosophy, and operates a variety of self-help and mutual support programs in which ex-patients themselves control the services that are offered (Chamberlin, 1990). In Holland, the movement was early in developing Patient's Councils in state-run hospitals that are now required by law (Gell, 1987). Compared to the Dutch movement, which mainly sought to reform institutions, the US and Canadian movements concentrated on developing self-help alternatives to traditional psychiatry, including after-care and support services (Chamberlin, 1990; Church, 1995; O'Hagan, 1993; Shimrat, 1997).

Criticisms made by those in the user movements in the US, Canada and the UK, about psychiatric services, are many. Authors, both users/survivors and academic professionals, have highlighted problems including; the gross imbalances of power in services (Campbell, 1990; Chamberlin, 1990; Deegan, 1990; Johnstone, 1989; Potier, 1993), an over-reliance on drugs as treatment (Breggin, 1993: Faulkner, 1997; Rogers, Pilgrim and Lacey, 1993), the mis-diagnosis and mis-treatment of distress (Fernando, 1995; Penfold and Walker, 1984; Taylor, 1996; Williams *et al.*, 1993; Williams, 1999; Wilson and Francis, 1997) and the abusive culture of services (Copperman and McNamara, 1999; Crossmaker, 1991; Glenister, 1997; Nilbert *et al.*, 1989; Williams and Keating, 1999).

In Britain, the user movement started tentatively in the 1970's in small pockets throughout the country (Rogers and Pilgrim, 1991). The groups involved in campaigning at this time were the Campaign for Psychiatric Oppression (CAPO), the longest standing user group in Britain, and the British Network for Alternatives to Psychiatry. However according to Seegar (1995), users of psychiatric services have been challenging the authorities about their treatment for hundreds of years. Indeed, records show inmates of Bedlam petitioning Parliament about their conditions as long ago as 1620, and further signs of this movement can be seen in the formation of groups such as the Alleged Lunatics Friendly Society in 1845 (Seegar, 1995). It was not, however, until the mid-1980's that the movement began to grow significantly both locally and nationally, with the first Patient's Council being established in 1986. Survivors Speak Out (SSO) grew out of a conference held in 1986 and became the first national group representing the views of users/survivors. Three movements can be discerned as contributing to the development of user groups in healthcare services: theories of normalisation, increased self-determination among users, and the growth of advocacy (Lupton, Peckham and Taylor, 1998). The key themes behind all these movements are a concern with human and social rights, self-realisation, non-segregation, independence and control over one's life.

Many users and survivors in the mental health user movement view welfare services, including health and social care services designed originally to ensure social citizenship, as part of the problem; further reinforcing their exclusion (Beresford, 1997). It has been proposed by writers such as Emerick (1991), that the mental health service user movement can be understood as a 'new' social movement because of its radical agenda, social and cultural aims and an emphasis on self-advocacy, direct action and non-hierarchical forms of organising. Emerick (1990, 1991, 1996) has offered the most thorough analysis of the mental health service user/survivor movement, both in the USA and in Britain, to date. In the UK some users do not believe a user 'movement', as such, exists. This is because the views of people in user groups and the aims and approaches of these groups are so diverse and sometimes so divided; both about what needs to change and the ways of going about creating change. Some groups and individuals favour a 'medical' model approach or 'individual improvement' approach, while others view the medical establishment as a force for social control and emphasise separatism, radicalism and empowerment (Hatzidimitriadou, 1999). As Church and Reville note in their 1988 paper: how radical to be is a constant dilemma for many user and self-help groups (Church and Reville, 1988). Because the term 'user movement' is valid for many people and is used in the literature extensively, I will use it throughout the thesis to indicate the collective voice of users and user groups while bearing in mind these reservations. Due to the significance of the literature on new social movements and pressure group activity, to the findings of this thesis, a short summary of this literature will be included at the end of the next chapter.

Other drivers for change

Some professionals have taken a critical stance to both the theory and practice of mental health and psychiatric care and have drawn attention to imbalances of power and the extent of abuse within the system. A series of exposés in the 1960's and 1970's of bad practice and abuse in psychiatric hospitals and hospitals responsible for the care of people with learning disabilities and older people (Robb, 1967), also contributed to calls for radical change. Public disquiet with what was seen to be the poor quality, paternalism and lack of responsiveness of public services, was furthered through the evidence of these exposés and subsequent inquiries. Organisations such as MIND, that brought together professionals, users and carers to campaign for change, have also been key players in advocating for reform; albeit with accusations from some quarters that their paternalism has also been part of the problem (Rogers and Pilgrim, 1991).

A number of professionals and academics, writing critically of psychiatry and related professions, have endorsed the demands for change from users/survivors. Accusations of abuse and neglect have not stopped with the advent of user participation however, and reports of serious abuses continue to come to light in health and social care services (Blom-Cooper, 1992; Brown, Stein and Turk, 1995; Cambridge, 1999; Lee-Treweek, 1994; Longcare, 1998; McCarthy and Thompson, 1997; Williams, 1995). Authors such as Cambridge (1999), Williams and Lindley (1996), and Williams and Keating (1999), continue to make the case for mainstream services to take into account the significance of power and powerlessness within health and social care provision. The literature on institutionalisation and professional practices is highly relevant to this research and is therefore dealt with in more detail in the next chapter.

Other examples of pressure on health and social care services to change should be noted before bringing this section to a close. Changes in ideological values and theories about madness and mental illness, largely informed by the anti-psychiatric thinking developed in the 1950's and 1960's, brought ideas of democratic and involving practices into services. This can be seen, for example, in the therapeutic community movement where patients/service users became central to the running of their services, and to their own and others' treatment and support (Jones, 1982; Kennard, 1998). These developments also became part of some professionals' practice, with ideas of 'working with' as opposed to 'doing for' people informed by normalisation and social role valorisation principals (Ramon, 1991; Wolfensburger, 1972, 1984). Professionals who wanted to work in more egalitarian ways were drawn to these models to guide their new roles and value base. These models placed importance on the rights of clients/users to be treated respectfully and to exercise independence (Barnes *et al.*, 1999).

Summary

This part of the chapter has briefly described some of the main drivers for change that created a more conducive climate for participatory activities. I have described the concerns with power abuse in health and social care settings and the 'quasi-market' reforms that have been important drivers in the move towards user participation in health care services. The user/survivor movement has also been briefly described in order to set in context discussions of citizenship and rights that feature in later chapters. That such a wide range of different and sometimes divergent forces should come together to demand change over the same period, is an unusual development that should in itself merit further exploration.

Part Two: Evidence of User Participation in Practice

The second part of this chapter is concerned with the experience of user participation in practice. Since this study aimed to explore how participation was working in practice and to detail the power relationships of participation, there was a need to examine work that has already been done in order to assess current evidence and to highlight gaps in current knowledge. This section focuses, therefore, on empirical research evidence in the main, leaving a more detailed discussion of the theoretical and conceptual issues and critiques of participation till the next chapter.

Catalysts and constraints

The pressure to involve users in their treatment and in service delivery and planning, from the drivers described above, has led to a situation where user participation is seen to be synonymous with good practice (Barnes and Bowl, 2001). Even a cursory glance at the professional literature for the disciplines of nursing and social work indicates how pervasive the claim to be empowering now is amongst professionals in health and social care services. An analysis of this literature in depth, however, indicates that descriptions of involvement and empowerment are fraught with theoretical ambiguity; with a notable lack of conceptual connection with power, powerlessness and disempowerment (Baistow, 1995). Indeed, Bowl (1996) reports from two research studies that there is still considerable confusion about the meaning and purpose of user involvement, with little evidence of power sharing and/or commitment of resources to enable change. Croft and Beresford's (1990) early national study on user involvement, found evidence of a commitment to involvement in practice as well as policy, even reporting that the principal of involvement was ingrained in the operation of some agencies. But, as Lupton and Hall (1993) contend, this evidence did not reflect disagreements about the extent to which user involvement was designed to enhance the degree of power and control held by users. Croft and Beresford's (1990) survey also found that nearly 90% of participatory initiatives set up by statutory and voluntary sector social services fell into the categories of consultative and market research approaches: there were few instances of involvement where service users had a direct input into decision-making.

Lupton and Hall's (1993) study concerned itself with the factors; both human and organisational, that encouraged the development of user involvement and those that operated to frustrate or inhibit its progress, in one local authority social services department. They found that although there was a general commitment to the principal of greater user involvement, there was considerable disagreement and uncertainty about the nature and extent of it in practice. Some of their respondents articulated the danger that, without a genuine commitment to empowerment, involvement could be 'an exercise in rhetoric' that left existing power relations between professionals and clients untouched (1993: 8). The constraints on user involvement, identified by Lupton and Hall's (1993) study, included the following:

- a lack of time and money;
- the need for better informed staff;
- a lack of appropriate information systems by which to identify need and monitor services;
- a lack of flexibility in the organisational administrative infrastructure;
- a lack of detailed guidance on how to do it;
- difficulties of tokenism; and
- a lack of representativeness.

Attitudinal resistance was also identified as a factor, with the 'doing to people' mentality still well entrenched. Lupton and Hall's (1993) study identified the main benefit of user involvement to be an improved quality of service provision that met people's needs more effectively and flexibly, resulting in increased job satisfaction for staff. Some of the benefits for users, according to staff respondents, were a greater sense of control, more choice and ownership, a greater sense of dignity and self-worth, and more accessible services.

Research by Ellis (1993) and Lindow and Morris (1994) on user involvement in needs assessment and community care planning, indicates the level of difficulty staff had with engaging in genuine and open dialogue with users. In Quarrington's (1991) Canadian study, on the establishment of a self-help group on a ward for people with chronic mental health problems, the responses of nurses to increased patient assertiveness and autonomy were recorded. Early on in the establishment of the group, nurses were said to have 'scoffed at' the patients' hopes for the future; having difficulty looking 'beyond the labels, stereotypes and diagnoses' (Quarrington, 1991: 27). Nurses also expressed feeling threatened by the growing autonomy of the patient group (Quarrington, 1991: 27). However, similarly to Lupton and Hall's study (1993), one of the most interesting aspects of this study was the reported increase of satisfaction the nurses had in their work after attempts to increase patient participation.

In another Canadian study, Pyke *et al.* (1991) describe three types of barriers to power sharing between nurses and patients; attitudinal barriers where professionals believed they should always be in control, the skill barriers of patients where they felt intimidated by professionals and lacking in confidence and practical barriers such as a lack of clerical and financial support for patients. This study suggested that nurses began to view the power relations between themselves and patients more critically once they had questioned the traditional passive role of patients. In both Quarrington's (1991) and Pyke *et al.'s* (1991) studies, nurses were initially sceptical of patient participation in services and were reluctant to share power and develop closer relationships with patients.

Beresford *et al.* (2000) name three kinds of barriers inhibiting the effectiveness of user participation in influencing the quality of services; the communication difficulties between users and providers if they are to engage with each other on a basis of equality, the nature of the competing discourses, and the values each party brings to the debate. Imbalances of power between users and professionals, and the disempowerment experienced by many service users, means that it takes time and resources to build confidence, to decide what users want and how they want to make themselves heard. According to Beresford *et al.* (2000), these imbalances of power also increase the likelihood that agendas will be set by professionals, and that the style of working and the language used will be professionally led.

Taking a wider view on participative practice, Hopton (1995) has argued that neither critiques by users nor professionals has had any effect on what he describes as the 'occupational culture of nursing'; which he cites as one of the main barriers to user participation in practice. He suggests that nurses are affected by a form of 'false consciousness': 'they believe they share the concerns of service users and struggle alongside them against the power of psychiatry' (1995: 52). This statement links to a point made by Marsh and Fisher (1992), in their empirical study on partnership practice in social work, where social work professionals said when asked about involving users that they: 'Do all that already'; a phenomenon the researchers described as the 'DATA' effect (1992: 37). This study found that although professionals saw themselves as having a commitment to working with users, their practice showed little evidence of this.

Although writers such as Gilliatt, Fenwick and Alford (2000) suggest that service users are gradually being enlisted as responsible partners in delivering the services they receive, there is evidence suggesting that while there is potential for substantial local change in response to concerted efforts from users and professionals alike, there has been little change at a national level (Barker and Peck, 1996). Indeed, Croft and Beresford (1995) emphasise the drawbacks of participation in practice; describing the ways in which many service users have been caught up in a heavily political world that is stressful and unfriendly, with organisations and agencies preaching involvement and empowerment but continuing to act in painful and excluding ways. They assert that health and social services are still administration rather than user centred, and user involvement in many cases, has become 'bureaucratised' (Croft and Beresford, 1995), with the activities user groups are involved in often far removed from their personal experience of service use.

Consequently, according to Beresford and Campbell (1994), most arrangements for user participation in services are linked with administrative rather than political structures, as this is where most of the forums are located. These authors argue that because power does not lie in administrative structures, this has ensured little relocation of power and therefore little change. Beresford (1997) also argues that because participation in the health and social care services has been constructed in terms of services and in the interests of the service system, gains for service users have been severely limited. It seems apparent, in fact, that users can pay a substantial personal cost for their involvement, especially in the early stages, as Church and Reville stated as early as 1988 and writers such as Barnes and Wistow (1994) have also identified. McGrath (1989) identified some of the difficulties with the joint planning exercises of the 1980's as the co-option of individuals into statutory organisations, disillusionment over the lack of progress made and concern about the tokenistic nature of much participation. This overloading of users' energies is also a common finding in work on partnership in the community and voluntary sectors (Taylor, 2000a). I shall now discuss some of the reasons why this lack of change may be happening, according to evidence gathered from empirical research on the power dynamics of participation and on defensive professional cultures.

Professional defensiveness, insecurity and role ambiguity as particular constraints on participation in practice

One of the main constraints on user participation suggested in the literature is that of professional defensiveness. According to research by Church (1995, 1996) and Wadsworth and Epstein (1998), this defensiveness arises because of a perceived threat to professional roles and responsibilities. The resulting role insecurity and ambiguity appears to have a significant impact on the ability of staff to engage in participatory activities with users. It is important to detail some of the literature that deals with this particular constraint, because of the relevance of this material to my later analysis. Although there are obvious parallels to work on institutionalisation and professional practices, which will be covered in detail in the next chapter, it was seen to be most fitting to cover some of this literature here when discussing research on the constraints to user participation.

Professional defensiveness can arise from the role ambiguity, conflict and insecurity brought about by user participation, as Church's work (1995) on the 'unsettling relations' of user participation in Canada graphically details:

> Professionals confronted with "consumer" knowledge repertoires become upset; their personal as well as professional identities are called into question. The disruption is expressed emotionally, with feelings ranging from discomfort to frustration to tears. There is anger which is out of proportion to the situation; there is silence when there should be speech (1995: 2).

She describes the way that survivors 'broke the rules' of taken-for-granted established meeting behaviour during the legislation consultation process initiated by the Ontario government and the resulting public hearings that took place. As well as attempts to 'shift the agenda' of the consultation, the survivor community broke the rules over the 'right' or 'proper' way to behave. By getting angry in the hearings and meetings, they were accused of 'bad behaviour', 'improper behaviour', 'grilling people', of being 'intimidating' and 'confrontational' and were asked to be more reasonable (Church, 1995). Some participants in the consultation believed that control was being exercised over what was appropriate to say and not to say, and the reasonable channels to go through. Church draws on the work of Lyman (1981) who writes about the ways that dominant groups teach their subordinates codes of behaviour, such as 'politeness' or 'reason' which subdues anger into non-political forms of action.

Blaming users for their displays of anger was also a finding of Barnes and Wistow's (1994) research on staff responses to user participation. Barnes and Wistow (1994) also note that professionals admit to being surprised by the level of anger and hostility displayed by service users who feel abused by professional actions or inaction. Church (1995, 1996) argues that, despite varying degrees of agreement in principal, professionals have shown tendencies to produce justifications for a lack of progress, rather than engaging with the challenge. Statements like 'we're too short staffed' repeated over a number of years, can sound like hollow excuses. As Croft and Beresford (1993) have argued, taking action to involve users requires a willingness to change attitudes and practice, not merely increases in staff numbers. Campbell's (1990) work on professional reactions to increased user control is of relevance here. He describes three common professional reactions to increased user involvement and power; hostility, apathy and support, in descending order of frequency. Indeed, Stevenson and Parsloe (1993) maintain that professional resistance is to be expected when user involvement occurs, because of fears from professionals that: 'once embarked on empowerment there can be no end, no resting point in the process. And they are right' (1993: 55).

Another reason why professionals may resist the challenge is the fear of loss of role. Wadsworth and Epstein's (1998) account of their action research study in Victoria, Australia adds a fascinating and rich dimension to discussions of staff insecurity. Their work attempted to establish dialogue between staff and users/consumers in a large psychiatric hospital. They found that a major stumbling block to progress was defensive regimes, detected in silences and stand-offs, which characterised staff responses to consumer feedback. They describe the difficulty staff had in talking about what the authors term 'the undiscussables': the emotional responses of fear, anxiety, frustration, and feelings of being treated badly by users.

The staff in Wadsworth and Epstein's study were described as being 'dismayed at their own disempowerment within the services structure' (1998: 359); unable to hear consumers without first being heard themselves. The silences were conceptualised as being part of a reluctance to speak about, and thereby dismantle, the carefully constructed 'difference' and 'othering' discourses on which the professional power and authority to provide 'care' was based. The line between 'them' and 'us' seemed to have a necessary role in protecting staff from opening their 'closed-loop' thinking that protected them from their deep-seated anxiety:

> Consumers, therefore, in some ways continued not to be heard both because staff's own repressed, self-repressed, and repressing emotional responses block their hearing and because the carefully constructed objectifying professional mental health discourse has as little place for active, sensible, valuable input from patients as it has for staff who can admit to not knowing all the answers all the time for all of the consumers... (Wadsworth and Epstein, 1998: 359-360).

Wadsworth and Epstein (1998) call the process of consumer/user demands being met with disempowered, 'emotionally-blocked' staff, as 'closed-loop' thinking; drawing upon Argyris' (1993) work on barriers to organisational change. Here 'closed-loop thinking' has a similar meaning to the term 'self-fulfilling prophecy', also used by Argyris (1993), to mean the cyclical reinforcement of negative ideation. Wadsworth and Epstein (1998) believed that this 'closed-loop' thinking interfered with the ability of staff and users/consumers to make connections with each other on a human to human level.

Wadsworth and Epstein's (1998) study suggests that the staff found it very difficult to meet consumers/users on territory in which it was safe and enabling for them. This led to stand-offs and stalemates, where both staff and consumers/users felt trapped, frustrated and angry. Consequently the organisation was unable to make the much needed change to equalise power relationships. Wadsworth and Epstein also draw on Menzies' (1970) work to describe the self-protective defences used by mental health hospital staff. Wadsworth and Epstein (1998) state that in meetings they observed, staff were literally swallowing the words they wanted to say:

> We found they often either could not or did not want to speak about certain topics – even ones that seemed on the surface relatively unproblematic or obvious to us. They might gloss over something, move on quickly to something else, cut the conversation short, or otherwise indicate we'd strayed into uncertain, unpleasant or difficult waters. We learned that many staff dealt with stress and their emotional responses in private, at their own cost, and in tightly knit and closed circles of trusted colleagues or friends (1998: 367).

Wadsworth and Epstein (1998) named these silences, and instances where staff felt constrained to speak, as 'cork in the mouth' responses and as the 'undiscussables' (1998: 368-369).

Church's (1995, 1996) and Wadsworth and Epstein's (1998) work on the unsettling relations of user participation, highlights the role ambiguity and uncertainty played out in current environments that advocate participative practice. This section has demonstrated that all is not as straightforward as the rhetoric of user involvement may have us believe, indicating the importance of further detailed work on the 'unsettling relations' of participation in UK mental health services.

Participation in the context of inequality

When discussing participation it is necessary to consider literature that details the impact on mental health service users and survivors of disadvantage and internalised oppression, due to their previous experiences of services and structural positions of powerlessness. Many people, especially disadvantaged people living in distressing conditions, are not used to exercising power in their lives. Williams and Lindley (1996) have identified ambivalence and conflict as being part of the collaboration process when members of powerful groups attempt to work with members of oppressed groups in some way. They draw on theory from inequitable inter-group relations to describe the risks of attempting true collaboration within contexts of inequality and previous power abuses. In these situations, members of the least powerful group may be sceptical of the willingness of powerful members to genuinely put others' interests before their own; rather than continue to act in their own best interests. Williams and Lindley (1996), in their work on collaboration with users, refer to the powerful dynamics supporting the status quo as mechanisms used to 'keep people down'. Some examples of this being; professionals controlling the agenda, talking in jargon, ensuring that users are an obvious minority and the questioning of user representativeness.

Hastings, MacArthur and MacGregor (1996), from their work on community involvement in regeneration initiatives, suggest that overt conflict may be a sign that partnership is actually working, and consequently that smooth working relationships in partnership environments may in fact reflect weak community partners:

> While the existence of turbulent relationships is no guarantee that a partnership is healthy, the absence of conflict should serve as a warning that all may not be well (Hastings, MacArthur and MacGregor 1996: 25).

Hastings, MacArthur and MacGregor (1996) stress that how the service or agency responds to community or user anger is critical. In order for communities (users) and agencies (services) to move beyond entrenched positions, they suggest the need for community (user) views to be listened to and accepted by agencies; recommending that conflict should be expected in participatory situations. Barnes *et al.* (1999) identified conflict or 'internal feuding' *within* user groups, in their study of user groups and participation. This expression of personal hostility has also been found to be present in relationships between community groups and local government in joint-working environments: a factor that can interrupt the progress of partnerships in fundamental ways (Taylor and Seymour, 2000). Taylor (1999b) writes of the fragmentation that can be born of exclusion, particularly exclusion through poverty:

> Communities which are defined by their exclusion from the opportunities in mainstream society are not natural sites for cohesion and co-operation (1999: 13).

Taylor (1999a) also argues that the common expectation that excluded communities should bring a united view to the table is both unrealistic and unhelpful, and in her view working with difference and diversity should be viewed as a requirement of working with marginalised groups.

Another danger to increased genuine participation of users in service systems, in the context of power inequalities, is that of co-option. Co-option has been described as a likely outcome where user groups are lacking in power. Barnes (1999) cites the work of Jenson and Froestad (1988) on client organisations in Norway, which proposes that due to the poverty of resources and the lack of self-confidence resulting from clients' dependency on services, client organisations are particularly susceptible to co-option by professional groups and other political organisations. The risk of consumers being co-opted in support of provider interests is also raised by Baistow (1995) in her critical analysis of the motivations of 'empowering' professionals. Baistow argues that use of the term empowerment is 'largely linguistic and rhetorical, relying on taken-for-granted meanings that need more careful scrutiny' (1995: 34-35). She suggests that although the focus on empowerment within public services, and within society more generally, seems to imply greater freedom for citizens, it may in fact be increasing the role of government in our lives. She highlights the emphasis on personal rather than collective empowerment, and the current moral imperative for citizens to be empowered and in control of their lives. Those who are not empowered, she argues, now require help to become empowered: a task that health and welfare professionals are more than happy to undertake.

Baistow (1995) describes this process as the 'colonisation of ordinary life' by professionals, with an associated transfer of power away from the citizen, towards professionals and the state. In this analysis, although there may be potential for empowerment, new kinds of regulatory possibilities are opened up by professionals extending their roles into new areas of expertise. If empowerment is becoming, or has become, central to professional legitimacy as Baistow suggests, what implications does this then have for the goal of increasing the power capacity of previously disempowered service users? Her view is that because professionals have positioned themselves as those who decide *who* should be empowered and *how* a good deal of power ultimately remains with them.

In a similar vein, Harrison and Mort (1998) have considered the role of public consultation and involvement in the NHS, and propose that co-option is a likely outcome of these policies and practices. This is because of the tendency of managers to 'play the user card' in order to support a particular position or strategy. They refer to the:

> ...use of user group opinion to buttress one or other manager's or professional's or their institution's preferred course of action as against that of a colleague's or other institution's (1998: 66).

They describe public health managers as perceiving user groups as merely one of a number of competing interest groups they must consult, but not however, to the detriment of other stakeholder views. When user and provider views coincided this was unproblematic, but when their views differed, managers found easy routes to undermine user views through accusations of unrepresentativeness or poor organisation (Harrison and Mort, 1998). Despite the positive responses of health managers and professionals that the researchers spoke to, all were careful to leave themselves with ways of dismissing the outcomes of user participation if it did not support their own goals. Harrison and Mort's conclusion was that:

> Practices of public consultation and user involvement may therefore function as means by which some of the critiques of democracy as currently practised may be deflected (1998: 67).

According to Harrison and Mort's research there is a growing participation movement, or what they have less euphemistically described as a growing consultation *industry*. However, they note the overwhelming tendency for user involvement, as well as consultation, to stop at the 'giving advice' stage, rather than result in joint decision-making; and to be invoked to support existing interests, stressing the legitimating function of this practice. Building up the legitimacy of user groups as commentators could therefore be seen to be in the interests of service providers. Research undertaken by Barnes *et al.,* (1999) suggests that being associated with the user voice provides legitimacy and a strengthened political position for officials. These authors draw attention to the danger of exploitation of users and user groups if alliances are not based on a partnership of equals.

Another major way that the user voice is marginalised in contexts of inequality, according to the literature, is through accusations of the user voice as unrepresentative. Beresford and Campbell (1994) argue that representation has become an excuse for resisting people's efforts to become involved and to side-step requirements to listen to them. Lindow (1991) has also written about the preoccupation with representativeness as a way of undermining the validity of user views. Indeed, issues of representation and representativeness are central in debates about user participation. Croft and Beresford's (1990) work *From Paternalism to Participation* surveyed user involvement in the statutory and voluntary social services for the first time and found that the single problem with which agencies most often identified was the unrepresentativeness of those who became involved. As Croft and Beresford (1990) point out, this use of representativeness to undermine the user voice has not been limited to welfare services: other liberation and collective movements have been similarly accused.

Barnes (1999), in her research on the self-organisation of disabled people's and mental health user groups, also encountered accusations that users were unrepresentative when organised collectively. She argues that 'representative' meant 'unorganised' and 'unrepresentative' meant 'organised', because of a confusion between the legitimacy of interest and identity groups:

> Organising within user movements can create the conditions in which it is possible for people to act as genuine 'representatives' of communities of identity, but it can also be used to undermine the legitimacy of such representations by constructing them as expressions of self-interest in the context of pressure group activity (1999: 79).

According to Barnes (1999) interest group politics, where powerful lobbies try to influence policy for their own gain when already in a powerful position needs ought to be differentiated from action taken by groups of powerless, marginalised people, who wish to gain basic human and civil rights.

As Taylor (1999a) emphasises in her work on the involvement of marginalised communities, individuals who actively participate are not typical; some people are more comfortable attending committees than others. This tendency may be associated with the gender, class, 'race' and age of community members. In her research on voluntary and community sector partnerships with statutory agencies, voluntary sector respondents argued that partnerships were set up to encourage 'the usual suspects' since statutory agencies preferred to consult with people who spoke their language and played by their rules. However, Beresford and Campbell (1994) suggest that the main reason service users are viewed as unrepresentative by providers, is because the *experience of being involved* changes people:

> ...getting involved may not only lead to change, but also change *us*. We become different. We become 'unrepresentative' in ways some service providers do not want. We become confident, experienced, informed and effective. At the same time, because getting involved is not something that most people are encouraged or have the chance to do, the mere fact of being involved may be seen as making us unrepresentative (1994: 317).

Taking issue with the implication that the fault lies with the service users who are 'involved', Beresford and Campbell (1994) accuse service providers of double standards and of a failure to address issues of representation effectively themselves. Some examples include the lack of broad-based user involvement in health and social care services as a whole, and the involvement of isolated individuals rather than people who are members of user-controlled groups or organisations. Beresford and Campbell propose that interpretations of representation are based on competing conceptions of involvement, hence the confusion and conflict:

> While policy-makers and service providers tend to use the term to mean 'typical', and call into question our 'typicality', what the word more often means for disabled people and service users is having our perspective, views, interests, demands and rights fully respected in discussion, forums and decision-making. Thus concern with the typicality of individuals is confused with the representation of collectivities (1994: 320).

The thorny issue of representation arises in the findings of the thesis and shall be discussed again there.

Summary

Although there has been considerable growth in initiatives for user participation in the planning and delivery of services, questions are now being asked about the extent to which this participation has enhanced the degree of power and control held by users; with some critics insisting that participation is happening without any equivalent redistribution of power (Baistow, 1995; Beresford *et al.,* 2000; Croft and Beresford, 1995). Parallels can be made between this criticism and criticisms made in the past by other oppressed groups who have been offered limited opportunities to get involved in decisions that concern them (Arnstein, 1969). Other constraints to genuine involvement were identified, such as professional defensiveness and insecurity, the use of participation as a 'strategy for legitimation of the status quo', the 'occupational culture of nursing', the structural powerlessness of users, a focus on changing administrative rather than political structures, and lack of time, money, training and guidance.

The literature described here is central to the subject of this thesis: participation and relations of power/powerlessness. What it has demonstrated is the extent to which participation in the context of power inequalities poses particular concerns for genuine partnership and joint working between users and professionals. Key ideas about the characteristics of participation in contexts of inequality have included commentaries on the ambivalence and conflict that occurs in these environments, in part due to the previous power abuses that have been experienced by those on the receiving end of services. Conflict can be understood as a sign that participation is working, despite its uncomfortable dynamics, because of the way participation challenges the status quo. It has been recognised that internal conflict within marginalised groups can also be prevalent for many different reasons, particularly as a consequence of experiences of exclusion.

I have described the powerful mechanisms used to 'keep people down', to support the status quo and resist change, such as the accusation that user voices are unrepresentative and therefore easy to dismiss. Co-option is one such mechanism, sometimes difficult to discern because of its tendency to present itself as the consensus: the 'reasonable' route to change. This is similar to the tokenism which will be described in the next chapter using Arnstein's (1969) theory of participation. An example of co-option and tokenism in the recent literature, is Harrison and Mort's (1998) work on involvement in health services as a 'strategy of legitimation of the status quo', and the devices used to construct user demands as just one more interest group whose needs need to be accommodated. The pluralistic view of power, that this activity depends upon, will be explored in more detail in the next chapter. Suffice it to say here that this way of understanding power and influence, rather conveniently it could be argued, does not imply the kind of radical changes to the status quo that other theories and models such as Lukes' (1974) or Foucault's (1972, 1973, 1976) do.

Concluding Comments

In terms of research approaches, most of the studies that have taken place in this area (Barnes *et al.,* 1999; Church, 1995; Lupton and Hall, 1993; Marsh and Fisher, 1992; Wadsworth and Epstein, 1998) have addressed the subject of user participation from a qualitative perspective; giving precedence to the personal views of professionals/managers and service users. This use of qualitative methodologies seems well placed because it enables a full picture to be developed of some of the difficulties faced by both organisations/staff and user groups working in this new terrain. Qualitative research methodologies therefore appear to be best equipped to investigate user participation since they acknowledge the different positions and vantage points held and give due regard to the socially constructed nature of social phenomena such as this. Chapter three will describe the decisions made regarding my choice of qualitative methodologies for this research.

This chapter aims to outline some of the main research on the experience of user participation in mental health services in order to explain the rationale for undertaking research on this subject. The main conclusion to be drawn from the literature in this chapter is the extent of the tensions and conflicting interests that seem to be inherent in examples of participation in action. The evidence set out here demonstrates the increasing amount of literature documenting concerns about the conceptualisation and practice of participation. However there have been few studies that have detailed the way that these conflicts of interest are actually being managed in practice. In the early 1990's, Lupton and Hall (1993) wrote of the dearth of research on the ways in which 'these contrasting and potentially conflicting tendencies are being played out in specific situations' (1990: 6). Baistow (1995) draws attention, similarly, to a lack of research on users' experiences and views of empowerment. And, most recently, Barnes and Bowl (2001) have also commented on the lack of research on the UK experience of user participation in mental health services to date. These authors state that research evidence remains speculative, with little detail provided on the success or otherwise of service user interventions.

Neither has there been any detailed research explicating the barriers and obstacles, or the risks and rewards, of user participation. Two studies that have provided accounts of the unsettling relations that participation can bring about, are those of Church (1995) and Wadsworth and Epstein (1998). These studies documented user-professional relations in Canada and Australia respectively, yet detailed systematic work of this nature has not been undertaken in the UK as yet. *Feathers and Thorns* aims to provide an account of the 'unsettling relations' of user participation in mental health services in this country, to address the lack of attention this subject has received. I agree with Everett (1994), that if the user/survivor movement is to make power visible: 'a clear understanding of the mechanisms and the uses of power becomes essential to the change process' (1994: 61). The aim of this study is, therefore, to help make the mechanisms and uses of power in participation, visible to those working for change. The next chapter will present an analysis of some of the theoretical and conceptual problems surrounding participation, drawing on work from urban regeneration, community and overseas development, as well as health and social care. It will also elaborate on the ways in which this literature informed the development of the research questions addressed in this thesis.

Chapter Two

Relevant Theoretical and Conceptual Frameworks

From the research evidence presented in the last chapter it is clear that there are significant barriers and disincentives to partnership and collaboration that need to be more closely examined in order to understand why progress has not been faster and more widespread. This chapter continues to draw on recent research and literature to provide a theoretical critique of participation; describing some of the main debates, tensions, and conflicts inherent in attempts to 'do' user and community participation. I outline the two broad approaches to participation that are identified in the literature; the consumerist and the democratic approaches, in order to account for the many meanings public participation has in state services. Where relevant and applicable, the critique will draw upon literature wider than the health and social care field, with the aim of providing a more comprehensive picture of the power dynamics and 'politics' of participation. I then discuss theories of power and one of the main effects of power in mental health services: institutionalisation and professional practices. This is important in order to justify my central thesis; that participation will not succeed as a strategy to improve services or change relationships between service users and service providers, if it is disengaged from an understanding of power and its effects. Theories of change, empowerment and social movements will also be discussed along with the relevance of these concepts to the framing of my research questions and research design.

Part One: Theorising Participation

Consumerism or Citizenship? Different Approaches to Public Participation

The concept of participation is not limited to health and social service policy and provisioning. During the 1960's and 1970's there was a growing demand from citizens to be involved in the decision-making processes which effected their lives. Participation is also a key and oft used concept in overseas development and UK urban regeneration work, and has acquired a variety of meanings and sparked a wide range of initiatives and practices across these arenas. Across health and social care, urban regeneration and overseas development, there is widespread confusion about the scope and purpose of 'participation'. Hogg (1999) questions whether it means the enabling of citizens to take part in decisions, or whether it functions to 'legitimate' and validate decisions made by purchasers and providers of services on behalf of the public.

According to Croft and Beresford (1992) it is useful to view participation in its historical and political context in order to be clearer as to the motivations and purposes that may lie behind it.

One of the reasons for the ambiguity of participation as a concept, suggested by Lupton, Peckham and Taylor (1998), is that it can be seen as both a means to an end and an end in itself. The belief that participation and involvement can be empowering for individuals has been asserted by Bacharach (1975) for example. However, as Lupton, Peckham and Taylor (1998) point out, an understanding of involvement as individual self-discovery and empowerment can obscure its connection with wider social and political processes. This belief in participation as a basic social need can also be seen to be operating from a consensus model of power; assuming that participation will be a positive and rewarding experience, rather than one characterised by power conflicts and resistance. As the findings of this thesis describe, user participation is commonly experienced as uncomfortable and stressful for all involved: a challenge to those that see involvement as a form of self-actualisation. However, as the findings emphasise, self-actualisation can indeed be a consequence of involvement, though not necessarily in the straightforward way that those such as Bacharach (1975) have implied.

One of the theories put forward for the lack of progress in mental health services, with regard to user involvement, is that conflicting ideologies and societal expectations underpin the different demands for user participation and involvement (Croft and Beresford, 1990, 1993). Penfold and Walker (1984) describe ideology as

> ...the socially produced construction of ideas and explanations: a set of procedures and practices that both accounts for and organises the social system (1984: 35).

As described in the last chapter, one of the drivers for involvement came from policy makers who wished to increase the efficiency and economy of services. Another driver for increased involvement came from the users demanding greater control over the services that they use, and greater control over their lives as a whole. The way in which participation can mean all things to all people, has been described by Richardson (1983):

> The ambiguity attached to participation has helped to foster its own cause. Because so many hopes have been linked with it, so many different expectations about what it will achieve, it has been embraced by spokesmen of highly varying political hues. Consumers have advocated participation in order to achieve their particular ends and the service providers have similarly welcomed it in order to serve theirs. The very uncertainty of its impact has enabled a common rallying call (99).

According to Croft and Beresford (1995), competing discourses underlie these different drivers, hopes and expectations for change. They suggest that the public services discourse on participation is concerned with policy and services, management, efficiency, effectiveness and economy: with a focus on refining and adjusting services rather than on substantive change. Service user or survivor discourses, in comparison, give precedence to people's lives as a whole, with support, choices, restrictions, opportunities and wider issues such as inclusion, equality, autonomy and rights high on the agenda (Croft and Beresford, 1995). These different discourses and political imperatives can be summarised, suggest Croft and Beresford (1993), as the consumerist model and the democratic model of involvement. Table 2.1 illustrates their views on the different purpose, concerns and outcomes of these two models.

Table 2.1. Models of Involvement

	Democratic	**Consumerist**
Purpose	To bring about change	To gain information and authority
Desired Outcomes	Services as a means to an end not an end in themselves	Better managed services and value for money
Main Concerns	People's desires, rights and choices	Resources and service provision
Focus	Advocacy and having say in change	Partnership and extraction of needs

(From Labyrinth Training and Consultancy, 1992 Cited in Croft and Beresford, 1993: 21)

The term 'consumer' describes people in terms of their relationship with a product or service, where the power lies with the service and the service providers rather than with the recipient. It implies choice between products; something that does not often exist in health and social services. The market reform legislation of the 1980's and early 1990's reflects this focus on the empowered consumer. The report by the Audit Commission (1992), for example, represented a landmark in health policy legislation by stating:

> The first aim is to empower the service users and their carers (1992: 11).

However, as Barnes and Walker (1996) point out, neither the *NHS and Community Care Act* (1990), nor the White Paper *Caring for People* (1986b), gave any concrete proposals for user participation or empowerment. According to Jack (1995), user control has never actually been on offer, with legislation ensuring the retention of professional expert status and professional control of both problem definition and resource allocation. User choices, in practice, continue to be mediated through professionals like care managers: a fact that undermines the choice of the individual, one of the professed main principles of consumerism. It has also been argued that a consumerist approach can bias service responses to those who already benefit disproportionately, relative to their need for health care. Similarly, Barnes and Wistow (1992) criticise the appropriateness of the 'supermarket' style of consumerism, or 'consumerism by proxy' model, because vulnerable people are rarely in a position to 'shop around' or opt out, as the rhetoric of the model of consumerism assumes.

Taking a closer look at the language of individual choice and individual rights of the consumerist model exposes a vocabulary of market research rather than political renewal. Walsh (1994) suggests that *The Citizen's Charter* and *The Patient's Charter* are associated with procedural conceptions of rights; concerned with information, complaint and redress, rather than enhancing the capacity of services to affect outcomes. Applying the concept of rights to health care services is fundamentally problematic in many ways, not least because rights in the NHS are largely symbolic and difficult to enforce. Hogg (1999) has highlighted the fact that there is no tradition of user participation or democratic accountability in the NHS: something that has not changed with the market-based reforms. Trust boards and health authorities are still governed by non-elected members, although social services have a different model by virtue of having a mandate for action through local government. In fact, a study by Strong and Robinson (1990) of the implementation of general management reforms in the NHS, concluded that the reforms had militated against increased user/consumer participation: the reforms were more concerned with implementing national agendas than with developing priorities with communities. According to Lupton, Peckham and Taylor (1998), the introduction of the internal market actually eroded the existing opportunities for institutionalised public involvement by abolishing the old regional structure and boards and the practice of local authority nominations to health authority boards.

In comparison, the democratic approach aims to empower people by giving them a voice in organisations and services and offering a different model of rights: a bottom-up rather than a top-down approach (Croft and Beresford, 1993). It advocates change in the distribution of power through its concern with people as citizens. Not only do these models of involvement denote differences in the kind of involvement offered and expected, they contain different assumptions about the nature of power, empowerment and civil rights. Because of their belief that the reforms of health and social care services are based on a simplistic market analogy, Beresford and Croft (1993) argue that the conception of user participation within the consumerist model is therefore inherently restricted. Beresford (1997) states that the quasi-market reforms have not been associated with a broader analysis of political debates about democracy or the participatory processes that the welfare service user movements have called for.

The participation of users in health and social care services therefore brings about conflict between different ideologies in a number of ways. There is a conflict between 'expert' psychiatric perspectives and lay perspectives, for example. The increasing professionalism in health services in the 1960's and 1970's, noted by Lupton, Peckham and Taylor (1998), has seen the attempt of a number of occupational groups to seek control over the definition of health and social problems and their solutions; as well as decisions over eligibility. These multiple claims to specialised knowledge and expertise can be seen as countering lay involvement in health care services because of the assumed passivity of service users this professional expertise implies. Williamson's (1992) work on consumer influence in the NHS emphasises this problem by describing the overt and covert resistance of the professional culture to lay participation.

Due to the inequalities of power that underpin different models and approaches to user involvement, the task of disentangling the contradiction from the consensus becomes vitally important. Croft and Beresford (1992) suggest that the threat to professional power from user and lay participation is managed, in part, through deliberate manipulation of the ambiguity of participation in professional discourse. For them, recognising the 'two faces' of participation helps to understand the rhetorical nature of much of its presence. They believe that the lack of a common understanding or definition of participation, leads to a confusion about the ultimate intentions of services to change; as the top-down professional/policy approach meets pressure for change from the grassroots. This confusion can seriously inhibit progress towards real transformations in relationships between service users and professionals, and in services themselves, as Barnes and Walker describe:

> ...the limited goal of consumer consultation is sometimes mistaken for empowerment, or regarded as a sufficient expression of citizen participation (1996: 380).

So although the consumerist strategy has given voice to, and legitimated, some of the criticisms held by users of health and social services (Barnes and Walker, 1996), few of these criticisms have been adequately answered by the consumerist reforms: even a decade later professional power seems largely unaffected. The systems that aimed to permit greater consumer choice have in practice been restricted by the clinical autonomy held by the medical profession, and by the practice of other professionals such as social workers (Shemmings and Shemmings, 1995). Notions of the rational and informed consumer ignore the formal and informal systems of control that systematically shift power away from the service user. In mental health services, notions of consumerism are challenged not only by 'professional accountability', but also by the power vested in professionals through mental health legislation.

Indeed, some critics suggest that the claims from professionals that they are empowering service users, say more about the need of professionals to protect their own interests, than those of their clients/users (Jack, 1995). Croft and Beresford (1995), Jack (1995), and Shemmings and Shemmings (1995) for example, all state that the drive towards user participation and involvement can be seen as a reaction to the lack of credibility and the insecurity and uncertainty, that health and social care professionals are suffering at present. Professionals claiming to be empowering users are, in these authors' view, attempting to legitimise their own positions and secure their own professional autonomy. According to Jack (1995), user involvement, without control over outcomes, serves only to domesticate the term in favour of professional interests: colonising yet another activity to which they have no claim. The new professional ethos of involvement and empowerment even legitimises the need for professional empowerment and autonomy as a precursor to user empowerment (Baistow, 1995). Similarly, Barker and Peck (1987) describe the way that professionals and workers have incorporated the language of involvement and advocacy into their vocabularies, alongside traditional vocabularies of 'illness' and 'therapy'. They believe that workers fail to differentiate between the various terms and use them interchangeably because they have a consensual view of the world; one that assumes compatibility between new vocabulary and old, when the concepts can in fact be seen to be in conflict.

Although participation has traditionally been viewed as separate from political activity and political participation, there is now a move to view participation within social and public services as connected to political forms of participation through the notion of 'good governance' and citizenship (Cornwall and Gaventa, 2000). This push towards a consideration of citizen participation in policy formation and implementation is part of a search for new, more direct forms of governance, whereby citizens may influence governments and hold them accountable (Cornwall and Gaventa, 2000). In this search, participation becomes more than just a social right: it becomes a political right as Lister (1998) describes:

> ... (the) right of participation in decision-making in social, economic, cultural and political life should be included in the nexus of basic human rights... Citizenship as participation can be seen as representing an expression of human agency in the political arena, broadly defined; citizenship as rights enables people to act as agents (1998: 228).

Similarly, Barnes and Shardlow (1997) argue that traditional models of representative democracy are no longer sufficient to achieve accountability in ways that can contribute to a learning society because they offer few opportunities for discourse. One danger is that the beneficiary model of involvement would simply become an interest group approach: 'one amongst a number of self-interested stakeholders lobbying a pluralistic system' (Barnes, 1999, 79-80). However, the dialogue that some user groups have started to enter into with service purchasers and providers, in order to develop mechanisms to hold these services to account, is significant. According to Barnes and Shardlow (1997), users becoming involved in user groups can provide experiences that may become the springboard for active participation in environments beyond the service system. They state that user groups working to change services may in fact have a wider impact through direct participation in collective purposes. This expression of active citizenship challenges assumptions about the capacity of service users which goes well beyond the welfare service system. The political goals of the user/survivor movement: participation, inclusion, equal opportunities and autonomy (Campbell, 1996), give an emphasis to civil and human rights and hence draw heavily upon the concept of citizenship.

Barnes (1999) suggests that collective action amongst service users can provide a means through which citizenship can be expressed, in three different ways:

- Seeking to achieve social rights associated with the status of citizenship;
- Providing a forum from which excluded individuals can contribute to the *practice* of citizenship; and
- Enhancing the *accountability* of public services to their citizen users (1999: 82).

According to Barnes, (1999), through a concern with rights and social justice and through activities of advocacy and campaigning, user groups and their members are seeking to achieve the *status* of citizenship. Through their activities they are contributing to the *practice* of citizenship, becoming 'makers and shapers' as well as 'users and choosers' (Cornwall and Gaventa, 2000). It is proposed by Barnes (1999) and Cornwall and Gaventa (2000) that this wider contribution brings significant further benefits to user group members themselves as citizens, and to wider society, through the practice of a more deliberative process of democratic involvement and agency. Consequently, Barnes and Walker (1996) emphasise that empowerment should be understood as enabling people to participate within wider arenas than merely health and welfare organisations. Participation within wider structures of civil society may, therefore, denote empowerment because of the previous exclusion of many vulnerable or disabled people from these arenas.

However, as Barnes and Shardlow (1997) emphasise, the status of citizen is a disputed one in the UK because of the lack of a formal constitution. The three types of citizen rights first defined by Marshall (1950) are legal or civil rights, political rights, and social and economic rights. The operation of mental health law, and being deemed 'mentally incapacitated', can severely limit one's civil and political rights. The debilitating nature of mental health problems may also prevent 'the practice of citizenship' (Prior, Stewart and Walsh, 1995 cited in Barnes and Shardlow, 1997), through interpersonal and structural factors such as lack of confidence and self-esteem, social exclusion and poverty. Barnes and Prior (2000) propose that public service users have a dual identity as both consumers and citizens. As citizens, users have a voice in decision-making about services as well as their consumption. However, attempts have been made, according to Barnes and Prior (2000), to collapse citizenship into consumerism. These authors discuss the need to build public trust as a requirement for more effective partnerships between users and providers of welfare services; highlighting the importance of dialogue, competence, participation, openness, accountability and negotiation. The model of public trust they propose could be seen to have much in common with models of participative democracy. An emphasis on democratisation, decentralisation, learning from user groups and creating social capital are suggested as a means of creating more supportive environments for participatory decision-making. Participation in this context is seen as beneficial to a democratic society and decentralisation is seen as a mechanism to offer increased participatory and democratic frameworks.

Forms of Participation: Influence or Power?

As Lupton, Peckham and Taylor (1998) argue, one of the main justifications for user involvement is that it enables people to influence the decisions that affect their lives. However, they emphasise the capacity for people to be involved without having influence, as well as having influence without involvement. Work concerning the influence of 'active minorities' (Maass and Clark III, 1984; Moscovici, Mugny & Avermaet, 1985), also suggests that social power and social influence are not the same thing. This work builds on empirical evidence that suggests that even apparently powerless minorities can be remarkably influential if they consistently advocate on behalf of their cause. Consistency is key, since this is the characteristic that gives a minority the image of being more confident, and sometimes more competent than the majority (Maass and Clark III, 1984).

Hirschman's (1970) work is often drawn upon to make sense of the ways groups seek influence. Barnes and Shardlow (1997) build on his work by suggesting three ways that user groups may seek influence:

- by working in partnership with officials (modified loyalty);
- by acting as pressure groups (modified voice) or; by
- entering the market as providers or purchasers (exit) (1997: 290).

The community care reforms introduced by the 1990 Act included a mixture of loyalty, exit and voice mechanisms (Means and Smith, 1994). There is considerable debate about the strengths and weaknesses of exit versus voice models of empowerment. According to Means and Smith (1994), voice is crucial for those who wish to remain within a service, while changing the nature of the relationship. For them, exit emphasises the importance of being able to leave a service and move to another provider and is seen to be associated with the 'new right' consumer/market model approach to empowerment, whereas voice is associated with the 'new left' democratic approach to empowerment.

This differentiation is not a simple one, as Means and Smith (1994) point out. They argue that neither of these concepts operates in mutually exclusive ways. The limitations of 'exit' as a mechanism for user empowerment, even a decade after quasi-markets were set up in health and social care, is evident since choice is still so limited and controlled. Exit approaches therefore appear to have a very unsophisticated view of power, particularly in the case of non-voluntary mental health services. Voice approaches concern the ability to make views known about desirable changes within services used. But both of these approaches have been described as insufficient by those who advocate a rights based approach to empowerment, because of their meaninglessness to people on low incomes, and a lack of acknowledgement of the power imbalances between users and services. A push for legally enforced rather than procedural rights is promoted by those advocating a rights-based approach, however there is the obvious problem of enforcing social rights. But, for some the idea of rights in the public sector provides a new way forward. If rights can work, if they are clear and enforceable, then this would clearly be a more direct way of empowering the citizen then either the market, bureaucratic regulation or democratic accountability (Plant, 1992 cited in Means and Smith, 1994).

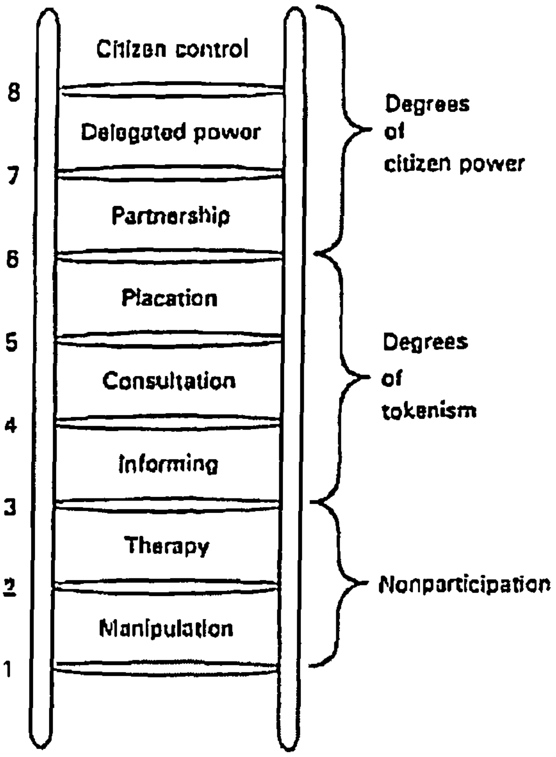
Means and Smith (1994) also recognise that groups adopt different strategies to 'influence' depending on the circumstances presented. Partnership and joint working are examples of the first method of influence: 'loyalty'. The activities of individual advocacy, lobbying and campaigning using the media, are examples of groups expressing the dimension of 'voice'. And groups involved in developing and running alternatives to statutory provision could be said to be exercising the third point: right to 'exit'. Barnes *et al.* (1999) build on the above and add one other dimension to the model: that of 'rewriting the rules'. This describes attempts to change the assumptions upon which the present system operates by 'changing the rules of the game'. Rewriting the rules can mean direct action, user-led research, or developing alternative models of emotional distress (Barnes *et al.,* 1999). These activities could be seen as having an ideological orientation, commensurate with other new social movements that view influence as presence (Phillips, 1995).

So if participation is to mean more than tokenism, citizens and public service users/consumers need to be able to exercise real power as well as influence. According to Drake (1992), this involves the fulfilment of three pre-conditions:

- that consumers must have the capacity actually to exercise power;
- that consumers must occupy roles in which power can be exercised (they must have authority); and
- that their role must be situated within links and networks such that the exercise of power is effective (that it achieves its purpose) (1992: 271).

Here, Drake is drawing on Arnstein's (1969) work on citizen participation. Arnstein's work on citizen participation in urban planning was concerned with identifying *how* people participate and at *what stages*. She offers a typology that has been widely utilised to help to distinguish tokenistic forms of participation from genuine citizen power. Arnstein's work is useful in detailing the different stages and forms of participation, and in giving a sense of the 'continuum' on which alternative approaches can be placed. Arnstein's ladder of participation is reproduced below in Figure 2.1.

Figure 2.1. Arnstein's Ladder of Participation



Source: Arnstein (1969: 217).

The ladder represents steps away from participation as manipulation, towards participation as full citizen control. The first two rungs of the ladder; that of manipulation and therapy, are examples of non-participation[2]. The next three rungs of the ladder; informing, consultation and placation, are described as degrees of tokenism. And the last three rungs; partnership, delegated power and citizen control, are perceived to be degrees of citizen power, thereby making the link between participation and citizenship.

Another typology helpful in the analysis of participation in practice is that devised by Cornwall (2000a) in her work on beneficiary participation in overseas poverty reduction. Cornwall develops White's (1996) typology, reproduced below in Table 2.2, that identifies some of the contrasting practices that manifest as 'participatory approaches'.

Table 2.2. Cornwall's adaptation of White's typology of participatory approaches

Form	**What 'participation means to the implementing agency**	**What 'participation' means for those on the receiving end**	**What 'participation' is for**
Nominal	Legitimation to show they are doing something	Inclusion to retain some access to potential benefits	Display
Instrumental	Efficiency to limit funders' input, draw on community contributions and make projects more cost effective	Cost of time spent on project related labour and other activities	As a means of achieving cost effectiveness and local facilities
Representative	Sustainability to avoid creating dependency	Leverage to influence the shape the project takes and its management	To give people a voice in determining their own development
Transformative	Empowerment to strengthen people's capabilities to take decisions and act for themselves	Empowerment to be able to decide and act for themselves	Both as a means and an end, a continuing dynamic

Source: Cornwall (2000: 9) adapted from White, (1996: 7-9).

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[2] I believe that some exceptions to this typology can be made; for example some feminist therapies *are* concerned with power and empowerment.

This typology can be used to locate the differing motives and meanings of participation for those implementing the participation and those on the receiving end. It also helps to clarify the desired outcome of different forms of participation. What is interesting about the typology is the suggestion that even when participation is used for legitimation and display by implementers, it can still have some usefulness for those on the receiving end. Another interesting facet is the way the meanings for both 'sides' gradually converge the lower down the table one goes. It is important to note that White (1996) does not see these four forms as static, believing that participation changes over time and may therefore move between the four forms. This typology by Cornwall and White and Arnstein's ladder will both be used in the analysis of the data in this study to identify the forms and levels of participation and assess the extent of participation in the contexts studied.

The Limits of Representative Involvement

Richardson (1983) identifies two forms of democratic participation; direct and indirect. Direct participation brings people into contact with decision-makers at a personal level and covers a range of types of involvement from citizen's juries to advisory panels. Indirect participation includes the other mechanisms by which people attempt to exert influence on decision-making and policy development, such as voting or pressure group activity. These different forms of participation can be linked back to different ideas about democracy; the classical Greek model of democracy where citizens meet their governors face to face to debate issues of government, and the modern day representative form of democracy, where these opportunities for debate are mediated (Lupton, Peckham and Taylor, 1998).

Lupton, Peckham and Taylor (1998) point out another form of participation, that of mediated participation, that acknowledges the rarity of direct participation and the fact that citizen's views will almost always be mediated through the representation of others. These authors suggest that most consumerism in the health service involves different forms of mediated representation rather than direct participation. They describe five forms of mediated representation; elected representation, professional representation or advocacy, provider representation within managed markets, statistical representation and Barnes *et al's.* (1995) notion of 'typical' representation. In this last form people are selected as representatives because they are typical of the interest group they are part of, according to the interest group itself (Lupton, Peckham and Taylor, 1998). User involvement in mental health services seems best described by this form; with users involved in full decision-making processes while avoiding the problem of a few people speaking on behalf of many (Lupton, Peckham and Taylor, 1998).

Work by Jeffrey (1997) has indicated the complexity of representative democracy as a model for engaging citizens in decisions. She examined the use of the representative model in local government structures and concluded by challenging the assumption that representative participation involved any devotion of power. She argues that a top-down approach to establishing participatory structures, through the replication of traditional council committees, creates a number of fundamental problems and limitations for participatory work. For a start, assumptions are made that participatory means face-to-face committee meetings: the logic being that if empowerment means taking real decisions, and real decisions are taken in committees, then people must attend committees in order to share power (Jeffrey, 1997). However Jeffrey proposes that any structure that limits membership, as committee processes do, risks replicating a representative system with all the problems of accountability that this brings. She argues that participation through the representative model can create a community elite that is disengaged from those it represents 'on the ground'. The community elite is then, in her opinion, in danger of becoming 'gatekeepers' or 'pseudo-councillors' and thus of blocking wider community participation in decision-making.

Another danger of merely including citizens/community members/users in certain committees has been suggested in the literature on policy networks. Marsh and Rhodes (1992) suggest that power holders will increasingly circumvent formal structures where representation of wider interests are situated; giving the impression of shared decision-making but in effect making more of the important decisions behind closed doors of informal alliances. This point links with criticisms of community involvement made by Taylor (1999a) that describe most attempts to involve communities in regeneration activities as 'window dressing'. Jeffrey (1997) and Hastings, MacArthur and MacGregor (1996) also raise this flaw in the logic of the representative model by emphasising that formal structures are only part of the process of decision-making; with informal and 'behind the scenes' relationships being often more important. According to Hastings, MacArthur and MacGregor (1996), bargaining and negotiation by interest groups and networks commonly takes place outside of committee structures: so although the committee makes the final decisions the community members are left out of wider debates. The absence of community members from these informal relationships leaves them with little role to play in formal meetings, a fact that seriously limits their influence (Hastings, MacArthur and MacGregor, 1996). There is an obvious danger, therefore, that the process of community members becoming involved in the formal council structures only increases the likelihood that power holders do the debating and decision-making outside of the formal structures, in order to retain control.

At a more general level, Stewart and Taylor (1995), from their work on community involvement, have warned that participation commonly involves the incorporation of the user voice into existing circuits of power. Atkinson (1999) describes this incorporation as inevitable, based on his work on partnership in urban regeneration. He suggests that partnership will merely reinforce existing relations of control and domination by discursively setting limits of what is possible and constructing the demands that can be made. He claims that more powerful organisations can use a combination of political and bureaucratic authority to control a less powerful organisation's objectives:

> Where organisations are created to fulfil new tasks... their objectives will in part be determined by the hierarchically constituted inter-organisational context within which they operate. More powerful organisations will set the context within which new organisations function (Atkinson, 1999: 62).

These authors argue that the limits of the debate or the 'rules of the game' can be circumscribed by discourses and practices that frame the goals, needs and language of participation. This comment by Atkinson (1999) about organisations set up to fulfil new tasks may well have explanatory power when it comes to analysing the role and function of user groups in this thesis.

Lastly, the work of Maloney, Jordan and McLaughlin (1994) is relevant here. They describe user groups as 'peripheral insiders' if they are included in policy consultation mechanisms but still viewed by the power holders as marginal. Consultation with these groups, in their analysis, is largely a cosmetic exercise where, for the power holders, more problems result from ignoring the marginal insiders than extending them courteous recognition. The notion of 'peripheral insider' may be a useful one for my research, despite it being developed in relation to community rather than user participation.

What this work on the power dynamics of participation suggests, is that participation in formal decision-making structures does not necessarily mean that community members are actually any closer to being influential than if they remained outside of the formal structures. Although a few community members witness decisions being made, the *processes* by which the decisions are made, and their involvement in these processes, is still largely illusive. This work draws on theories of power proposed by those such as Lukes (1974) where power operates through cultural processes and social structures, rather than the pluralist or single-dimensional model where power struggles operate in more visible and open ways. It also elaborates by example, Lupton, Peckham and Taylor's (1998) suggestion that forms of public participation may be established which give the appearance of people having influence but are actually used as a means of social control by containing criticism and unrest thus preventing challenges to the status quo. Tudor (1996) states, for example, that user involvement in mental health services may be a way of perpetuating the professional-led system by incorporating a limited and controllable amount of client/user input:

> While professional allies may open up some services and resources to a limited extent in seeking to empower clients they are doing no more than perpetuating a system in which professionals can choose what to dispense, including power (133-134).

Barnes and Bowl (2001) make a similar point, suggesting that power is embedded in the rules that govern processes through which user input is both sought and managed. They propose that one result of this use of power is an incorporation that lessens the momentum for genuine change by diverting the user/survivor movement away from its oppositional role.

Summary

In this section I have highlighted some of the literature that provides a critique of participation both as a concept and as an activity. I have described the different political imperatives behind calls for user involvement and participation; namely the consumerist and the democratic models of involvement. The conflicts between these different ideological positions are masked, according to Mullender and Ward, (1991), by the ever proliferating claims of involvement that act as a social aerosol 'covering up the disturbing smell of conflict and conceptual division' (1). Arnstein's ladder of participation and Cornwall/White's typology of participatory approaches were used to demonstrate the potential for some forms of participation to be used only for legitimisation and display, and to involve manipulation and tokenism. I have presented literature that questions the notion of the empowered consumer and details the limitations of the consumerist model of participation, which has yet to make a significant impact on professional power. The consumerist model of user participation thus appears to present sizeable constraints on all Hirschman's (1970) mechanisms of influence: loyalty, voice and exit. Work that attempts to unpack the power dynamics of participation has also been described in order to provide a backdrop to the next section that will go into theories of power in more depth.

These critiques were helpful in framing my research questions because of the way they draw attention to the complexity of power relations within both the theory and practice of participation. I developed my questions bearing in mind the debates detailed here, particularly in relation to the different models of participation, participation as influence or power and the links between participation and citizenship.

Part Two: Other Relevant Theoretical and Conceptual Frameworks

Theories of power, of social change, and of empowerment and social movements will be defined and discussed in turn in this section along with an explication of the relevance of these concepts to the framing of my research questions and research design. Literature on institutionalisation and professional practices will also be discussed because of the significance of this work for the research findings.

Theories of Power and Powerlessness

This section aims to consider some of the different ways that power and powerlessness have been theorised and assess the utility of some of these theoretical concepts for this particular study. If any conclusion is to be made from the literature on power it is that making sense of power as a concept can be an illusory and challenging task. As stated in the introduction of this thesis, there is no one underlying concept that informs this discussion: different theories of power contain different assumptions about the nature of personhood and human agency, depending on their epistemological underpinnings. According to Lloyd and Thacker (1997), orthodox accounts of power viewed it 'as a property, of groups, individuals, classes – that is of agents – or as the property of structures' (15). Clegg (1989) also identifies the dominant pattern of usage as that of 'power over', the episodic/agency or sovereign concept of power. In this analysis power is seen as absent except when obviously exercised. He also asserts the lack of a single authoritative concept of power and suggests that the episodic concept of power has functioned largely as if it were this single authoritative concept. However, since the development of post-structural and post-modern ideas in the 1960's and 1970's, power has increasingly been viewed as something to be understood in relation to social and cultural practices and discourse. This shift in thinking is often associated with thinkers such as Foucault (1972, 1973, 1976), however many contributors have aided this revolution in how concepts such as power are now understood.

According to Hugman (1991), there are two main approaches that can be discerned in contemporary discussions about power. The first approach can be described as 'power as an element of social action', and the second as 'power as an aspect of social relationships'. Although this is a somewhat simplistic categorisation in an area as contested and diverse as this, I believe it is useful for the purposes of a brief summary such as this. The aim of this sectionis not to present all the diverging conceptual debates about power and its relationship to truth, knowledge, human agency etc. It merely aims to describe two of the main approaches to understanding power, and indicate how these may be useful for this piece of research. In view of this I shall be using the work of Foucault (1972, 1973, 1976) and social constructionist ideas that view power as an element of social relationships and discourse, and I shall also be drawing on theories that view power as an element of social action, using the work of Bachrach and Baratz (1962) and Lukes (1974). Lastly I briefly describe the concept of ideology and its relevance for the study.

Power as an Element of Social Action

I shall start by describing the work of Lukes (1974) whose theories Hugman (1991) places within the 'power as an element of social action' approach to power. Lukes' seminal work on power (1974) developed what he termed the 'third dimension of power'; where powerful groups influence, shape and determine less powerful groups' wants and needs. Lukes (1974) begins his analysis by suggesting that previous discussions about power had been too linear and behavioural in their focus. He refers to work that viewed power as episodic, causal, intentional and mechanistic, such as the ruling elite model of power. This was premised on a belief in sovereign power first articulated in the philosophy of Hobbes (Clegg, 1989). Lukes (1974) defines what he calls the first and second dimensions of power thus:

1. situations of observable decision-making, focused on key issues over which there is overt conflict concerning the subjective interests of the individuals or groups involved;
2. situations of 'non-decision-making' in which only some potential issues become explicit, where there is covert as well as overt conflict concerning the subjective interests of individuals or groups (25).

He adds to these formulations a third dimension that, he proposes, radically transforms the way power can be understood. This third dimension is summarised by Lukes as:

3. situations in which the social agenda is established (that is, potential and explicit issues are created), in which there is actual (overt and covert) and also latent conflict over both objective and subjective interests of individuals or groups (1974: 25).

For Lukes this third dimension provides the most sophisticated tool to understanding social power, because of the way it distinguishes between coercion, authority and influence as forms of power. He sees the third dimension as encapsulating and extending the other two approaches because it continues to allow the questions that these dimensions raise to be asked as well as enabling more subtle questions to be raised (Hugman, 1991). Lukes proposes that power is socially structured since it does not depend on the capacities of individuals, although it may be seen in the practices of individuals;

> A may exercise power over B by getting him to do what he does not want to do, but
> he also exercises power over him by influencing, shaping or determining his very

> wants. Indeed, is not the supreme exercise of power to get another or others to have the desires you want them to have (Lukes, 1974: 23).

In other words, according to Lukes, power works through the ideas of consensus or by *setting the terms of the argument.* He distinguishes between force and coercion, as examples of power related to observable conflicts of interest, and manipulation of bias as a form of power relating to conflicts of interest that are much more latent and covert. Thus he views the notion of 'power to' as just as central to an understanding of power, as the notion of 'power over'. Because power is socially and culturally located it can therefore have the appearance of consensus whereby individuals are unaware of the fact that they are exercising it or having it exercised over them. The 'third dimension of power' involves specifying the means by which power influences, shapes and determines possibilities and strategies of challenge, in situations of latent conflict. It focuses on the means by which social legitimacy is developed around dominant groups and instilled as beliefs or roles in dominated groups. It involves locating the power processes, meanings and patterns that get 'B to act and believe in a manner in which B otherwise might not, to A's benefit and B's detriment' (Gaventa, 1980: 15-16).

One of the ways these ideas relate to questions about professional power is the role that the third dimension of power has in making the operation of power seem 'normal' and 'natural'. It may make it difficult to discern power in action so that both patients/users and professionals are unaware that they are having power exercised over them or exercising power. A lack of overt conflict between professionals and patients/users may therefore be a function of power in action (Hugman, 1991). Hugman (1991) suggests that any apparent consensus between professionals and users of their services should therefore be taken as the object of inquiry, as much as any observed conflict. This point has implications for this study that concerns itself in part with the power dynamics of user participation in mental health services. Using Lukes' (1974) third dimension of power it becomes necessary to view consensus relationships, as well as conflict relationships with interest. A key question that will be helpful in relation to the data from my study is 'how do/es professionals/organisations/policy/practice *influence, shape and determine* the nature of user participation in the contexts studied and the demands that are made'.

What Lukes (1974) describes as the second dimension of power, a theory proposed by Bachrach and Baratz (1962), is important to mention before moving on; because of its relevance to this study. This second face/dimension of power was developed prior to Lukes' work and was also presented as a critique of the causal, episodic interpretation of power. After Lukes' work this dimension was described as the second dimension of power and concerns the concept of non-decision-making power in which: 'A devotes his energies to creating or reinforcing social and political values and institutional practices that limit the scope of the political process to public consideration of only those issues which are comparatively innocuous to A' (Bachrach and Baratz, 1962: 948). In other words, B is hindered in raising issues which may be detrimental to A's preferences. Non-decision-making can, according to Clegg (1989), involve the powerful not listening or not hearing demands articulated by the less powerful. If demands *do* get onto the political agenda they may be: 'effectively sequestered via endless committees, enquiries, or co-option' (1989: 77).

A further variation of non-decision-making can occur through the *mobilisation of bias*, or the process of *organising in and out* of certain issues (Bachrach and Baratz, 1962). Suppression of certain kinds of conflict, and exploitation of other kinds, is part of all forms of political organisation, according to Clegg (1989). One example of non-decision-making is the *rule of anticipated reaction.* This describes a scenario where B anticipates A's likely opposition and consequently does not raise an issue because of this. A's power, therefore, extends to formulating the issues to be discussed or seen as important. White (1996) has described a similar process in her work on participation in poverty reduction work overseas. She suggests that poor people's experience of participation and powerlessness can 'act back' on the construction of their interests because of inequitable power relations in wider society. In White's (1996) view, just because people do not express other interests, does not mean that they do not have them; it means that they do not have the confidence that they can be achieved. Because much of the power of mental health professionals can be seen as being wielded through social and cultural practices that involve the creation of consensus relationships (Hugman, 1991); the concept of non-decision-making will be a key concept for this study.

Power as an element of Social Relationships

This next section will outline the 'power as an aspect of social relationships' theory, according to Hugman's analysis by drawing on social constructionism theory and Foucault's (1972, 1973, 1976) work in particular (1991). Burr (1995) suggests that power is often thought of as the extent of a person's access to sought-after resources such as money, rewarding jobs or leisure time, and the extent to which a person has the capacity to impact on their world and on the lives of other people. So some groups, in this analysis, will have more power than other groups, often on the basis of divisions of class, 'race', age or gender. The social constructionist approach to power proposes, however, that although structural inequalities in society, such as 'race', gender, class and age are real; they are created and sustained by language and discourse which impacts on social structure and social practices. The social constructionist approach to discerning power and its associated ideological practices is therefore to investigate language and discourse.

Language is viewed as the medium for the power relations of the social world to be communicated and reproduced, through its role in 'naming' experience and reality (Fairclough, 1989). Fairclough (1989) emphasises that power exists in various modalities: 'including the concrete and unmistakable modality of physical force' (3), and is therefore not purely a matter of language. He highlights the danger of focusing purely on one aspect of power relations and the temptation to reduce our understanding to that aspect alone. He therefore makes the distinction between the exercise of power through *coercion* of various kinds and the exercise of power through the *manufacture of consent* or acquiescence to it. The manufacture of consent is achieved through ideology (Fairclough, 1989). He proposes that power relations depend on both of these types of power in varying proportions. Fairclough's work (1989) on language and power explores the relationships between language use and unequal relations of power from a critical standpoint. He argues that this exploration can help to build an awareness of how language contributes to the domination of some groups by others. He sees this as crucial to the process of consciousness raising: the first step to resistance and struggle against this 'natural' power order. He believes that language indicates what counts as knowledge, placing people within texts as subjects and objects, as 'knowers' and 'known' and establishing relationships between them.

This critical approach to language has been informed most directly by Foucault (1972, 1973, 1976) who suggested that power operates through networks and discourses 'circulating through the social body' (Smart, 1985), rather than through individual and collective agency. Foucault does not therefore view power as being located with particular individuals, structures or institutions such as the State; instead he sees it as embracing everything and coming from everywhere (Lloyd and Thacker, 1997). He conceives power as being deployed through strategies, tactics and techniques. The questions Foucault posed of power were different from the questions posed by other theorists about power. Rather than asking 'what is power and where does it come from?' he asks instead 'how is power exercised and by what means?' and 'what are the effects of power' (Smart, 1985).

Foucault (1972, 1973, 1976) wrote of the close relationship between knowledge and power, highlighting the development of discourses that attempted to define certain forms of reason and knowledge as having a greater truth status than others. Science and medicine were two of these 'objective' reality discourses and were accorded a higher status than other 'local', 'popular' or 'indigenous' knowledges. These ideas, when applied to the science of psychiatry, go some way towards explaining why the objective discourses of case-studies, assessments, diagnostic labelling and problem-solving, are so predominant; and why the personal, relational and temporal aspects of the experience of being in crisis have been lost. Discourse is, therefore, about more than just language, it is about the interplay between language and social relationships; 'in which some groups are able to achieve dominance for their interests in the way in which the world is defined and acted upon' (Hugman, 1991: 37). This can be through establishing, for example, dimensions of normal communications, content of discussions, the creation of 'scripts' and general conversational 'rules'.

Discourses are embedded in power relations and therefore have political effects (Burr, 1995). Social constructionist theory proposes that discourse wields power through creating representations of people that serve to support power inequalities, while passing such inequalities off as 'natural' or 'fair'. For Foucault, the particular common-sense view of the world that prevails in a culture is bound up with power, because of discursive formations that make possible certain truths and knowledges, and hence make possible certain kinds of agents and structures (Lloyd and Thackery, 1997). For him, knowledge is power over others or, more specifically, the power to *define* others. Power lies in the ability to define people as belonging to certain groups; such as the 'mad', the 'sick', the 'old', or the 'queer', as opposed to other groups which are represented as the norm; the sane, the healthy, the young and the heterosexual. So, in this analysis, power is not possessed by individuals, but is located instead in *discursive acts* and is exercised by drawing on discourses which present our actions as acceptable; given the knowledges prevalent in society (Burr, 1995).

Rather than understanding power as a repressive force, Foucault viewed power as most effective when it was 'productive'; creating new knowledges that contributed to the control of society and its members through what he called 'disciplinary power'. He therefore proposed a shift away from notions of a sovereign power, whereby the sovereign controlled the people by the power to punish, control or kill them. In his view disciplinary power encourages the development of self-regulation and self-monitoring, through the 'psychologisation' and 'medicalisation' of everyday life which then becomes a target for expert intervention (Burr, 1995). This form of power is efficient because people enter into the process willingly, a fact that Foucault saw as an essential aspect of the operation of power: 'Power is tolerable only on condition that it mask a substantial part of itself. Its success is proportional to its ability to hide its own mechanisms' (Foucault, 1976: 86). This view of power differs substantially from the idea that power is in evidence when a person forces someone else to do what he or she wants them to do: quite the opposite in fact, when power has to resort to violence or force this is seen as indicative of a *lack* of power (Burr, 1995).

Linking to the idea of power as productive, Foucault proposed that power and resistance are two sides of the same coin; where the power in one discourse is only apparent from the resistance implicit in the other (Burr, 1995). In other words, power and resistance always operate together. Drawing upon Foucault's ideas about resistance, Burr (1995) emphasises the importance of viewing discourses as potentially contestable and vulnerable to being challenged by others. According to Burr (1995) there are weak points where other discourses can present real challenges and where resistance is possible:

> Given that there are always a number of discourses surrounding an event, each offering an alternative view, each bringing with it different possibilities for action, it follows that the dominant or prevailing discourse ('knowledge' or 'common-sense') is continually subject to contestation and resistance (1995: 64).

I now wish to briefly attend to the matter of ideology, because of its relevance to these discussions. The ideas of both the 'power as social action' and 'power as social relationships' schools (Hugman, 1991) appear to link to the work of Gramsci and his doctrine of 'hegemony' (1971). Hegemony describes the process by which ideas that are in the interests of a ruling or dominant group become translated into a certain version of reality. This version then becomes the 'true', 'natural' or dominant explanation for a majority of people through its ability to make sense of everyday reality and hence become 'common-sense', as Ng (1980) writes:

> A major source of power for dominant groups is simply the routine operation of social institutions (14).

Social theorists such as van Dijk (1998) have argued that ideologies and hegemony form the central means by which power relations are maintained and reproduced. Originally Marx and later Althusser, Gramsci and Foucault, contributed to the understanding of how systems of domination work in contemporary society. Augoustinos and Walker (1995) suggest that ideology contributes to the classifications that exist to explain all aspects of social life and the process of stereotyping, as part of this categorisation, is central in rationalising the social arrangements that exist in society. They do this by contributing to the legitimisation of the 'dominant political, social and economic inter-group relations within a society' (Augoustinos and Walker, 1995). Justifications for the positions of different social groups are often ideological in nature, as Williams and Watson (1988) explain:

> Inequitable relationships are most effectively maintained by ideologies that obscure the existence of inequality, and mask the continuous and pervasive conflict of interests between the groups concerned... This is possible because dominance is invariably associated with the power to define ideology... (297).

As Augoustinos and Walker (1995) argue, a blind focus on the power of ideology can obscure the abilities of individuals to step outside and be reflexive towards ideas that have others interests at heart. However, they remind at the same time of the danger of underestimating the power of some of these legitimising and unifying representations and discourses.

This work on ideology raises the very real possibility that discourses of empowerment and participation within the mental health system may also serve ideological functions. For example by masking conflicts of interests between service users and providers through the re-naming of inter-group relationships as ones of partnership and reciprocity. Gaventa's (1980) work on power also adds another dimension to this idea by describing a consequence of hegemony as 'quiescence'; where subordinate groups continue to acquiesce even when the basis of power of the dominant group has diminished. The ideas of ideology and hegemony will be used in this study as powerful devices to pose questions about the degree to which power is exerted through the use of legitimising and unifying representations and discourses and through its ability to make sense of everyday reality.

Although the different schools of thought regarding the phenomenon of power (power as an element of social action and power as an aspect of social relationships) can be seen as emphasising somewhat contradictory principals in terms of its nature and operation, there are some ways in which they both appear to agree. I suggest that the main area of agreement is the idea that social relations are held in place by social and cultural practices that obscure the operation of power relationships in society. Both Lukes and Foucault agree that power is most effective when it is operating unnoticed through the creation of the 'normal' and 'natural' order; through hegemonic practices. The fundamental difference appears to be the idea of discourse being far more flexible and relative than Lukes' third dimension, because of the way that discourse offers opportunities for all groups and individuals rather than just dominant groups to use power. As Barr (1995) emphasises, even those in marginalised groups can draw on discourses that offer them a degree of power. And this is the key to social change using social constructionist theories of power; the resistance of dominant discourses through the use of alternative ones that construct reality in alternative ways.

I used the idea of resistance and the use of alternative discourses in the construction of the research questions by emphasising the potential for power to be operationalised by user groups through their resistance of dominant (professional/institutional) discourses of participation. I also use these ideas in discussing the implications of the research data. For Salaman (1979), the power of subordinate groups can be seen in their capacity for resistance. Scott (1990) in his study *Domination and the Arts of Resistance*, suggests that resistance by 'subordinates' can be seen in performances of deference and consent while they attempt to discern the intentions of the power holders. Scott's argument is concerned with interpreting the political conduct of subordinate groups. He suggests that public performances of deference and loyalty are important in the etiquette of power relations, because of the ability to manipulate appearances for one's own ends and to create the appearance of unanimity. The politics of resistance he argues, can involve circumspect actions such as 'acting a mask', the use of disguise and deception, evasion and foot dragging, rather than irrevocable acts of public defiance.

Using Foucault's ideas about power means showing an interest in techniques embodied in institutions, rather than being concerned with centralised and legitimate forms of power. It means addressing the exercise of power through its field of application and its effects, rather than with questions of possession or individual intention (Smart, 1985). And lastly, it means focusing on the way in which subjects are constituted as effects of objectifying powers, rather than being concerned with the motivations or interests of groups and individuals (Smart, 1985). As Smart (1985) points out, an analysis of power using Foucault would also proceed from a micro rather than a macro level: 'in order to reveal the particular histories, techniques, and tactics of power' (79). These ideas informed my research focus and research questions by reinforcing my concern to focus on examples of participation in action and on the ways in which professionals and users constructed themselves as subjects within this activity. Another perspective Foucault's ideas give the research described here is a concern with the notion of identity. For Foucault, the issue of subjection was intimately connected to the political struggles associated with 'identities' and subjectivity. I have therefore been concerned to investigate the way in which identity is used to subjugate and liberate in practices of participation.

Foucault's ideas emphasise the operation of power through professional practices that construct not only the content of interactions with clients but also the relationships with clients, the rules that govern interactions and relationships, and the role each party plays. Clegg (1989) also writes of power as relational rather than institutional:

> Power may consist in the networking of relations, in the way in which moves in the game implicate others as allies or adversaries in one's interpretation of what the game is (Clegg, 1989:38).

This focus on rules and roles is also helpful for this investigation of user participation. This is because of the way these ideas focus attention on whether participatory practices replicate dominant understandings of the 'professional' and the 'client/patient/user', or whether they present opportunities to resist these and present alternative understandings of the client, their role and relationships and interactions with care-givers. Hugman (1991) draws attention, for example, to the way in which professional discourse constructs patients as 'difficult' and 'uncooperative', through general conversational rules. He therefore questions whether the term 'cooperation' only describes situations where service user actions are in agreement with the expectations of professionals. These ideas have utility when focusing on the politics of participation, as I shall be doing here, because of the potential for participation to be merely another focus for the control of the client.

In these two sections on the two main theories of power: power as an element of social action and power as an aspect of social relationships, I have indicated the utility of different understandings of power for this study. I shall now examine the related area of theories of power and social change.

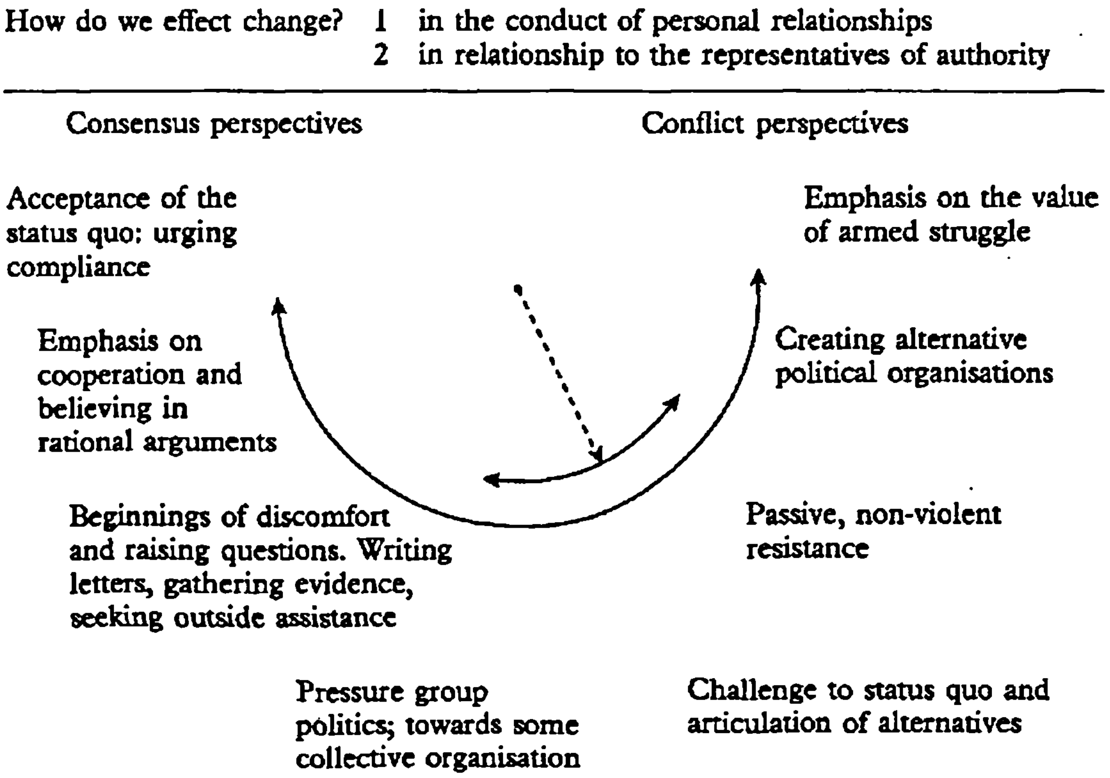
Theories of Power and Social Change

Most writers on the subject of power and social change, such as Ng (1980), follow Dahrendorf (1959, cited in Orford, 1992) in distinguishing between two forms of power in society: *consensus* and *conflict.* The consensus view, associated with Talcott Parsons, assumes that power differentials are functional; with those wielding power doing so for the most part, benignly so as to enable society to function smoothly and bring about changes that are to everyone's benefit (Ng, 1980). This understanding has been called the 'well-meaning' face of power (Orford, 1992). The writing of C. Wright Mills can be viewed in contrast to this with its emphasis on society being in a constant state of conflict, where power is seen as being wielded by dominant groups over others. The consensus model of power legitimises authority as a source of power, whereas the conflict model emphasises inequalities in society. As Ng (1980) points out, it is in the interests of the dominant in society to emphasise legitimation and the benign uses of power, whilst the powerless are more likely to call attention to the coercive nature of power differentials. Ng argues in his book *The Social Psychology of Power* (1980), that power is almost always ambivalent:

> Power in its organised form, such as the political state, is inherently ambivalent because it always contains an element of antagonism or conflict as well as an element of integrational harmony (85).

The consumerist model of involvement, described earlier in this chapter, can be viewed as proceeding on the basis of a consensus model of change rather than a conflict model of change (Ng, 1980; Rees, 1991). Rees (1991) elaborates on the differences between these models of change, in Figure 2.2 reproduced overleaf.

Figure 2.2. Rees' Model on Effecting Change - Attitudes and Actions



Source: Rees 1991: 84.

In this model Rees (1991) gives examples of different activity that can be placed around this circle of perspectives. An emphasis on co-operation; on rational argument and acceptance of the status quo, is viewed as indicative of a consensual model of change, whereas the articulation of alternatives; challenges to the status quo and organised resistance, are examples that indicate conflict perspectives of change. Rose (1990), writing on new social movements, has warned of the dangers of viewing the consensus and conflict models of change as mutually exclusive however, recommending that both can be used interchangeably depending on environmental circumstances. He asserts that the strategy or model used will largely depend on the way in which the dominant group or groups react to the demands of the social movement: for example, they may repress, ignore or wish to work with the movement. In Rose's analysis the model of change is rarely a matter of choice for movements or activists, but is determined by the social context that is fluid and changeable. These theories of consensus or conflict will be used along with the other theories of power described above to interrogate the research data. These theories may be helpful in separating out the different interests that Croft and Beresford (1993, 1995) describe as permeating both the theory and the practice of participation in health and social care services.

Institutionalisation and Professional Practices

The rationale for including a section on institutional and professional practices comes from the literature described in the last chapter on professional resistance to change, and the implicit and explicit challenges to the traditional role of the health or welfare professional that user participation presents. There is evidence to suggest that many of the attempts to create participation between users of health and welfare services and professionals have been thwarted by a lack of willingness on behalf of professionals to accept that anything needs to change, and therefore to make any such changes. Work on participation in the context of inequality can help to clarify some of the reasons why collaboration and joint working can be so problematic. It is therefore necessary to look more closely at some of the features of professional practices in institutional contexts in order to expand upon this analysis. The findings of this research have also shown that these factors play a significant part in limiting the success of user involvement in practice in statutory psychiatric/mental health settings. It is therefore necessary to consider these findings in the light of work that has already been done on this subject. Although much of this work could be considered to be documenting the extreme end of the continuum of institutional practices; that of abuse and violence towards patients/users, I believe that this work holds insights when trying to understand other settings where abuses of power may be more insidious.

Traditional approaches to the sociology of the professions propose that professions can be distinguished from other occupational groups by their personal service to others, rather than being purely self-orientated (Gillespie, 1997). However, writers such as Turner (1995) have highlighted the monopolistic practices and promotion of self-interest of the professions and consequently undermined these theories for their uncritical analysis. According to Turner (1995) professionalisation can be seen as an occupational strategy to maintain certain privileges and rewards. Freidson (1970) has been particularly critical of the medical profession for their monopolistic and dominating practice in the provision of health services, accusing them of being immersed in the creation of individual and professional wealth and the exploitation of those who need medical care. A feminist critique has also been levelled at the philanthropic view of professions that has focused on the gendered division of labour and treatment of women within professional groups (Gillespie, 1997). The medicalisation of everyday life by professions such as medicine has also been criticised by writers such as Illich (1977) in his descriptions of 'iatrogenic practices'. The depiction of the clinical, social and structural iatrogenesis, that Illich (1977) refers to in *The Limits of Medicine,* signified a damning attack on the notion of professional altruism.

According to Turner (1995), not only is the hospital a crucial institution within modern systems of health case but it is also symbolic of the social power of the medical profession and represents the institutionalisation of specialised medical knowledge. Due to structural and functional changes brought about by the transformation of medical knowledge, Turner (1995) suggests that modern hospitals now resemble bureaucratic collections of workshops that have an alienating effect on their patients: an alienation that impacts on the patient's capacity for recovery as well as their emotional wellbeing. Foucault (1973) described the hospital as a place of confinement and restraint; a focal point for the regulation and surveillance of the population through its disciplinary gaze. Consequently the emergence of the hospital has been largely bound up with the growth of medical dominance and professional power.

Alongside this growing scepticism about the beneficence of the medical profession and those allied with it such as nursing, and concern about expanding medical power, has been an increased awareness of the existence of abuse and inequalities in services. Evidence of abuse, discrimination and violence in health, social care and welfare services, has now been documented by service users, researchers and government inquires alike. As highlighted in the last chapter on drivers for change in mental health services, authors such as Cambridge (1999), Williams and Lindley (1996) and Williams and Keating (1999) continue to make the case for mainstream services to take into account the significance of power and powerlessness within service provision. They argue that failure to do so is largely responsible for difficulties in achieving the changes identified as needing to take place in the culture of services. Williams and Lindley (1996) draw attention to evidence exposing the failure of services to take account of the relationship between a person's mental health and the reality of living in a divided and inequitable society. Cambridge (1999) has asserted that difficulties managing the market of social care have contributed to the isolation of services post-market reform. He also suggests that the creation of dependency relationships, through the institutionalisation of vulnerable people and the professionalisation of care more generally, can produce environments prone to endangering those within them. Writing on the abuse of people with learning disabilities, Cambridge (1999) cites economic determinants to abuse as being manifested in the institutionalisation of capital and labour within services:

> The abuse of people with learning disabilities in all it's horrible forms will never be eradicated in a society which institutionalises human and other capital in services, and where dependency relationships themselves become a means of economic production. The professionalisation of care also risks hierarchies of power and status, which provide opportunities to misuse and abuse power between those that use services and those who help produce them (Cambridge, 1999: 303).

Institutions, whether in congregate mental illness or mental handicap hospitals, community services or family units, can create their own particular cultures of abuse. Cultures of abuse, according to Cambridge (1999) and Wardhaugh and Wilding (1993), can be characterised by the following; an isolated and inward-looking approach, staff intimidation, low levels of staff competence, low pay and poor working conditions, hierarchical structures, an absence of clear lines and mechanisms of accountability, and ineffective distant management. Wardhaugh and Wilding (1993) describe the corruption of care as involving the neutralisation of moral concerns, the routinisation of care work, and the powerlessness of certain client groups. Considerations of staff power and powerlessness are relevant here, as broader society and service management systems reflect structural inequalities like sexism and racism:

> If power corrupts, so too does powerlessness... While staff have near absolute power over many clients, they are in many other respects powerless. They are taken for granted by the organisation, seldom regarded as its heroes, given little support, not consulted about the organisation of their work (Wardhaugh and Wilding, 1993: 12).

Wardhaugh and Wilding state that the very nature of modern forms of bureaucratic organisation contributes towards the corruption of care by invoking the 'silencing of moral obligations' and the creation of moral distance: 'The crucial issue may be that staff are simultaneously powerless and powerful and this creates a dangerous ambivalence' (1993:12). This ambivalence connects to a number of the findings in this study, presented in later chapters, where environmental features of the corruption of care are discussed.

Martin (1984) summarised the ingredients of institutionalised abuse as individual callousness and brutality, low standards and morale, weak and ineffective leadership, pilfering by staff, vindictiveness towards complainants, and the failure of management to concern itself with abuse. Glenister (1997), in a discussion about the role of the mental health nurse; describes the brutality and intimidation expressed towards patients/users by mental health nurses, as cloaked in denial. He states:

> Violence appears to be an integral aspect of psychiatric services, which must be acknowledged, at some level, by both victim and perpetrator. (...) The subsequent history of psychiatric services indicates that managerial supervision is not sufficient to ensure violence is eliminated. A more challenging view is that violence is inescapable in institutions associated with coercion and control (45).

According to the research of Main *et al.* (1991) and Lucksted and Coursey (1995), patients/users are more aware of the power staff have to control patients than the staff. The bureaucratic and hierarchical structure of hospitals and nursing, even outside institutional settings, militates against the flexibility required for patient-centred care. O'Hagan (1993) suggests that these bureaucratic structures prevent users from being able to make decisions, as many of the decisions are made much further up the hierarchy, a point Glenister (1997) emphasises:

> Administrative rationality ensures little opportunity for the expression of human experience, which might challenge categorisation and control (51).

Some of these commentators are describing aspects of institutionalisation, a term first used by academics such as Barton (1959) and Goffman (1961) to describe processes by which institutions regulate and disempower those within them. In *Asylums* (1961) Goffman offered a damning sociological critique of the isolation and dehumanisation of the mental patient in large institutions. He describes the conditions of life demanded by these total institutions, and the effect on the inmates that resided within them, thus: '...in our society they are forcing houses for changing persons; each is a natural experiment on what can be done to the self' (1961: 22). Goffman believed that mental institutions, like prisons and concentration camps, are institutions where all spheres of normal activity are cut off from wider society. Patients/inmates are controlled in these places by being stripped of their identities, possessions and former roles, through rituals of dispossession. Staff that manage this dispossession are separated from the patients through having access to power and information, and through social distance.

Contemporary national and international literature agrees that the mental health/psychiatric system is still dominated by routines and regimes similar to those of the old institutions (Brandon, 1991; Breggin, 1993; Coleman, 1998; Shimrat, 1997). From work by Goffman (1961) on institutionalisation in the 1960's, through to recent commentaries from professionals such as Shaw (2001) on the hopelessness of nurses on acute psychiatric wards; reasons for staff developing 'survival mechanisms' that help them to emotionally withdraw from users/patients, have been suggested.

Lipsky (1980), in his work *Street-Level Bureaucracy* on the institutionalisation of public services, also provides many insights into the institutional practices of front-line staff. His work centres around the belief that street-level bureaucracies like schools, benefit offices and mental health services, have nothing to lose by failing to satisfy clients, since clients cannot avoid or withdraw from these services. In his analysis, the fact that clients are non-voluntary has significant implications for the users and providers of these public services because of the reduced quality of the interactions between workers and clients. Significantly, Lipsky argues that the costs sustained by the non-voluntary person in the interaction will be higher:

> Street-level bureaucrats can impose costs of personal abuse, neglectful treatment, or inconvenience without necessarily paying the normal penalty of having the other

> party retaliate (...) neglect and abuse of patients is a function of the non-voluntary nature of the association of clients with patients, and not strictly of bureaucracy or class discrepancies (1980: 56).

Lipsky (1980) describes street-level bureaucrats' (or public service workers') work as alienated, primarily because workers are required to deny the basic humanity of others:

> To the extent that street-level bureaucrats are alienated in their work, they will be more willing to accept organisational restructuring and less concerned with protecting clients' interests and their own connection with clients (1980: 79).

This point links well with work described earlier on the corruption of care by Wardhaugh and Wilding (1993) which also addresses the link between neglectful and abusive treatment and the pressures of particular kinds of work. With clients for whom society has little regard, low value is put on working with those people and consequently on the people that carry out this work. These care environments are therefore challenging and under-resourced with an emphasis on survival and getting by. According to Wardhaugh and Wilding (1993), this creates a dangerous situation for two reasons:, firstly, because of the emphasis on control, order and an institutional rather than an individual approach; and secondly, because questions will not be asked by management as long as the situation is kept under control. Wardhaugh and Wilding also make reference to the fact that staff with the most difficult jobs are the ones who are least trained, least supported and worst paid. Lack of resources thereby exacerbates the way the moral legitimacy of the work: 'is undermined by the gap which separates the rhetoric of policy from the sharp reality of practice' (Wardhaugh and Wilding, 1993: 16).

Lipsky (1980) continues this analysis by describing what he calls the tensions between staff capabilities and organisational objectives; whereby workers rationalise the discrepancy between service ideals and service provision. He calls this the 'modification of the conception of work'. He views worker's attempts to redefine the nature of the job, or the nature of clients, as coping responses to job stress; they modify their objectives to better match their ability to perform. He believes that front-line workers rationalise the ambiguities and contradictions in their work by developing their own private perception of their work:

> Possessing a simpler conception of the job than the one theoretically prevailing in reality, street-level bureaucrats are able to fashion an apparently more consistent approach to their work (1980: 145).

These private conceptions of work are sometimes shared by the organisations staff work for, but sometimes they are not. Taking limitations as fixed rather than problematic is another mechanism Lipsky (1980) describes. He argues that this discourages innovation, encourages mediocrity and is done to avoid confrontation with work failures. According to Lipsky, patterns of practice developed by individual workers often only make sense in the private conception of the job held by the worker, while supervisors and the public still expect an allegiance to a more complex set of goals. In some cases agencies impose a particular orientation on the work from above, and in others staff may develop a collective perspective on their work contrary to their supervisors. Recruitment to the service of like-minded people also contributes to the collective adaptation to bureaucratic stress, since it excludes staff members who may challenge the work-force goal consensus.

Withdrawal from work is one way of dealing with the tension between capabilities and objectives, either by leaving the service or by psychologically withdrawing and thereby rejecting personal responsibility for agency performance (Lipsky, 1980). Absenteeism, high turnovers of staff and general withdrawal from involvement with clients are, for Lipsky, all responses to the pressures of job stress. He argues that for some people the gap between the reality of providing public services and the desired way of providing public services is too wide, and that recently trained young people are particularly vulnerable to leaving services for this reason. Moreover, Lipsky contends that because of this tendency for more idealist individuals to opt out, public agencies are: 'left with a work force least bothered by the discrepancies between what they are supposed to do and what they actually do' (1980: 143). Although some people 'retire on the job', many continue to be reasonably dedicated to occupational objectives, as they define them.

Finally, Menzies' (1970) work on 'sick' organisations and defensive regimes, is also of central relevance to a discussion of institutionalised professional practices and cultures. The major themes of her work are briefly described next to highlight their importance for the analysis of the empirical data gathered in this study. Menzies studied the social organisation of nursing during the latter part of the 1960's and her best known work is *The Functioning of Social Systems as a Defence against Anxiety* (1970). In her analysis of nursing, Menzies draws on psychoanalytic theory stressing the importance of understanding unconscious anxiety and emotional defences as an intrinsic part of personality development. Menzies' key proposition was that the anxiety felt by nurses, primarily because of their relationships with patients, leads to the development of socially structured defence mechanisms which then appear as elements in the structure, culture and mode of functioning of an organisation. These defence mechanisms develop into aspects of external reality which members of the organisation must then abide by. She argues that the closer and more concentrated the relationship between nurses and patients, the more likely they are to experience the impact of anxiety. The nursing service attempts to deal with this and protect nurses by splitting contact with patients into a list of tasks. This task-based approach creates detachment, which in turn helps nurses to control their feelings, maintain professional independence and learn techniques to deal with emotional stress.

Menzies proposed that due to the inflexible and mechanistic nature of the social organisation of nursing, many anxieties present themselves that nurses have few resources to deal with. It was her belief that the threat of crisis and operational breakdown was one that generated considerable pressure:

> The nurses seem to have a constant sense of impending crisis. They are haunted by fear of failing to carry out their duties adequately as pressure of work increases. Conversely, they rarely experience the satisfaction and lessening of anxiety that come from knowing they have the ability to carry out their work realistically and efficiently (1970: 26).

According to Menzies, the use of social defences also inhibited the capacity for creative, abstract thought; thus preventing the full development of understanding, knowledge and skills that would enable reality to be handled effectively. The anxiety is, therefore, never addressed or managed successfully, and self-knowledge and emotional maturity are consequently denied. Social defences also work against individuals being able to realise their full capacity for concern, compassion and sympathy, and the ability to use these feelings to guide practice. Menzies concludes her work by stating the importance of understanding the functioning of an organisation in order to diagnose its problems and achieve social change. She argues that failure to address the common anxieties and social defences of organisations and their members will mean that change is unlikely to take hold and be accepted.

This section has outlined some of the main sources of literature on institutionalisation and professional practices. It has described some of the entrenched positions that exist in service contexts faced with the challenge of opening up processes and involving those whom they are meant to serve. There is a wide variety of literature that now evidences the disempowering cultures that exist within many institutional and community services for vulnerable people. This literature draws attention to the many ways that the powerlessness of individuals is maintained within and through these systems, and the resistance of these systems to change. One of the most important aspects of this literature for this study was the notion that staff can be simultaneously powerful and powerless in their role as providers. This creates, according to Wardhaugh and Wilding (1993), a 'dangerous ambivalence' which has implications for the findings and implications of my study.

Together with the work described earlier in Chapter one, on participation in the context of inequalities of power, this section has indicated the extent of the challenge that exists if changes are to be made to the bureaucratic and professionalised service cultures inherited from the days of the large institutions. The work of Wardhaugh and Wilding (1993), Lipsky (1980) and Menzies (1970) has been particularly useful in illuminating the ways in which professionals seek to manage their own anxieties through their dealings with patients/users. Their work has been central in framing my research questions in this study on the barriers to user participation and to organisational and professional resistance to change, and will therefore be used in the discussions of the findings of this research to illuminate these dynamics more fully.

Theories of Empowerment

To understand participation requires an appreciation of the concept of empowerment. The term empowerment holds a variety of meanings depending on the context and academic discipline. Most agree that empowerment is a 'contested concept' (Taylor, 1992) and most easily comprehended by its absence. Interestingly, although the concept of empowerment is frequently discussed in the social care literature, few writers actually deal with the relationship between empowerment and the notion of power itself. Similarly to the conceptualisation of power, because of the different uses of the word empowerment, there is no one single definition. As Skelton (1994) suggests, competing meanings and definitions of the term empowerment illustrate rival and sometimes ideologically opposed positions.

Servian (1996) describes empowerment as a process in which individuals are enabled to meet their own needs or as 'moves towards autonomy' (9). He also identifies nine different uses of the term empowerment however, including spiritual enlightenment, access to the democratic process, freedom from government and advocacy. One of the greatest influences on the conceptualisation of empowerment was Paulo Freire (1972) who wrote:

> In order for the oppressed to be able to wage the struggle for their liberation they must perceive the reality of oppression, not as a closed world from which there is no exit, but as a limited situation which they can transform (32).

Here, empowerment is clearly linked with social transformation in the interests of the oppressed.

Different definitions and understandings of empowerment address individual and/or collective levels of empowerment, empowerment as a process or product, internal and external dimensions and principals of self-determination, participation, choice and respect. For example, empowerment has been defined by Zimmerman and Rappaport (1988) as the following:

> Empowerment is a construct that links individual strengths and competencies, natural helping systems, and proactive behaviors to matters of social policy and social change. It is thought to be a process by which individuals gain mastery or

> control over their lives and democratic participation in the life of their community (1988: 726).

In this analysis democratic participation in the community is clearly given precedence. A politicised approach implies an attitude of anti-domination and a concern with methods of empowerment. Some view empowerment as a comprehensive personal as well as collective strengthening. McWhirter (1991) for example describes it as

> ...the process by which people, organisations, or groups who are powerless (a) become aware of the power dynamics at work in their life context, (b) develop the skills and capacity for gaining some reasonable control over their lives, (c) exercise this control without infringing upon the rights of others, and (d) support the empowerment of others in their community (224).

Zimmerman (1990) proposes a conceptual model of empowerment that incorporates intrapersonal, interactional and behavioural components. He describes the intrapersonal level as related to how people perceive their capacity to influence social and political systems using notions of self-efficacy and perceived control. The next level, interactional, includes knowledge about needed resources and problem solving skills. The behavioural component refers to actions taken to influence through participation in organisations and activities. There is some evidence that personal empowerment is necessary for broader, collective empowerment. Empowerment at the group and community level appears to involve a politicisation process that takes place within individuals as they move towards having a greater awareness of the wider social and political issues that influence their condition or status.

In terms of empowerment within health and social care services, Lupton, Peckham and Taylor (1998) propose that there are different philosophies of empowerment contained within the consumerist and democratic approaches to participation and involvement. While the consumerist approach to empowerment places the focus on individuals and their need for information, access, choice and redress, the democratic approach sees empowerment as occurring through wider socio-political processes such as the development of social rights and the redistribution of income. Barnes and Walker (1996) describe eight key principals that they believe should underpin attempts to empower service users:

1. Empowerment should enable personal development as well as increasing influence over services;
2. Empowerment should aim to increase people's abilities to take control of their lives as a whole, not just increase their influence over services;
3. Empowerment of one person should not result in the exploitation of others: either family members or paid carers;

4. Empowerment should not be viewed as a zero-sum: a partnership model should provide benefits to both parties;
5. Empowerment must be reinforced at all levels within service systems;
6. Empowerment of those who use services does not remove the responsibilities of those who produce them;
7. Empowerment is not an alternative to adequate resourcing of services;
8. Empowerment should be a collective as well as an individual process; without this people will become increasingly assertive in competition with each other (381-385).

They suggest that the personal and collective development that arises as a result of participation in decision-making, demonstrates the way in which power may develop in places it previously did not exist. They note that this empowerment is not achieved at the expense of anyone else and therefore does not fit with the zero-sum model of power. Some of these theories about the nature of empowerment will be applied to the findings of this research, in particular to the questions about user and user group empowerment and will be discussed again in later chapters.

The relevance of theories of New Social Movements (NSM's)

There is a separation in the literature on social movements between what are described as the 'old' and 'new' social movements. This is by virtue of the non-class, non-material considerations of the 'new' movements and the merging of their social and cultural aims (Fainstein and Hirst, 1995). Offe (1990) suggests that NSM's are based on personal integrity, recognition and respect. Jordan and Maloney (1997), however, cite arguments suggesting the exaggeration of the differences between new and old movements however, for example, the argument that NSM's are potential old social movements at a different stage in their development. Examples of new social movements (NSM's) include the Gay rights movement, the environmental or 'green' movement and the disability rights movement. These movements place an emphasis on asserting new collective identities and cultures; demanding that society include them, recognise their right to be 'different' and give them full civil rights. NSM's contribute to social change by politicising areas of experience previously excluded from the political agenda by extending politics into the cultural sphere. They are not concerned to overthrow the whole system, in the main, but are concerned with 'selectively radicalising' values achieved through collective action and a more democratic public life (Crowther and Shaw, 1997). Although there are major debates about the differences between NSM's, pressure groups and interest groups (see Jordan and Maloney, 1997), I shall deal with NSM's only in this brief discussion, despite the definitional problems inherent in lumping the range of diverse groups and movements together.

Social movements are often seen as dating back to the 1960's but they have a longer history in movements that have resisted colonialism and racial and economic exploitation. Some of the most powerful NSM's are ones which have used race, culture and nationalism as a basis for radical groupings (Sondhi, 1997). The social movement perspective emphasises a lack of hierarchy and formal organisation (Jordan and Maloney, 1997). Citizen participation in organised pressure groups can be seen, it is argued, as a healthy aspect of the political systems of democracies, although some dispute that protest group politics significantly extend participatory democracy (Jordan and Maloney, 1997), According to Everett (1994), members of NSM's recognise the importance of symbolic change as an important precursor to real change, and therefore seek to make power relations visible. NSM's are oppositional, and progressive ones reflect aspirations that are antithetical to the marketised culture of 'competitive individualism' in Western society. Not all NSM's are socially or politically progressive however. For example, some elements of the men's movement are aimed at reasserting male privilege and reversing the gains made by women. Some groups ignore the social consequences of campaigning on a single issue like the environment and some are purely concerned with individualised lifestyle politics with little interest in wider social change (Crowther and Shaw, 1997).

NSM's can be distinguished from other forms of collective behaviour because they generate, according to Eyerman and Jamieson (1991), a 'cognitive praxis'; a challenging of dominant understandings and the construction and legitimation of new knowledges. Contentious politics can be defined as 'collective activity on the part of claimants or those who claim to represent them relying at least in part on non-institutionalised forms of interaction withelites, opponents, or the state' (Tarrow, 1996: 874). The primary goal of new social or grassroots movements, according to Wittig (1996), is the desire to change power relationships through local organising. Through membership of social and grassroots movements the self-efficacy and self-esteem of individuals may improve, new identities may be formed, skills and resources may be acquired and attitudes towards the political system may be altered (Wittig, 1996). New social movements, Wittig (1996) argues, involve the 'transformation of norms and values and the social shaping of knowledge at the cultural level' (5).

How are these NSM's relevant to discussion about the mental health user movement? As discussed in the first chapter, the user movement has been described by some (Emerick, 1991) as a new social movement because of its radical agenda, social and cultural aims, and an emphasis on self-advocacy, direct action and non-hierarchical forms of organising. The similarity of the activities of user groups described in this chapter above, with other social movements for change, bears witness to a civil rights agenda, within mental health, that is becoming stronger and more demanding. Beresford (1997) states that members of the mental health service user movement and disability movement are conscious of their relation to other new movements. He also highlights the areas of overlap between the user movement and the disability rights movement using the social model of disability (Beresford and Wallcraft, 1997).

The main reason for using social movement theory as a tool to analyse the development of user groups is the focus on producing new identities and self-definition that NSM's often embody. Identity, in the politics of new social movements, is commonly associated with the experience of oppression (Beresford, 1997). According to Beresford (1997), movements of disabled people, older people and other service user groups, have transformed the administrative categories in which they have been placed by market-led consumerism, and created new political identities of their own. Reclaiming and renaming these identities is a process that other oppressed groups have undergone in, for example, the Black civil rights movement and Gay Pride movement. To help with this point Rucht (1990) identifies two ideal types of movement strategy, reproduced below in Table 2.3.

Table 2.3. Rucht's (1990) typology of social movement strategies

Logic of action	*General Strategy*	*Specific Strategy*
Instrumental	Power-oriented	Political participation bargaining; pressure; political confrontation
Expressive	Identity-orientated	Reformist divergence; Subcultural retreatment; Countercultural challenge

Source: Rucht (1990: 163).

The power-oriented strategy is concerned with the outcomes of political decision making and distribution of political power whereas the identity-oriented strategy is concerned with cultural codes, personal identity, authenticity and relies mostly on expressive behaviour and trying to change cultural codes by practising alternative lifestyles (Rucht, 1990). This is an interesting differentiation that can be drawn upon to analyse the mental health service user/survivor movement in the UK and shall be returned to in the later chapters of this thesis.

Summary

This section of the chapter on theoretical and conceptual frameworks has described some of the main literature on institutionalisation and professional practices, power and powerlessness, theories of change, of empowerment and of social movements. The aim has been to consider the terrain within which this research is situated and the way this work has shaped the issues and questions that my study addresses. I have indicated some of the most persuasive theories of power, institutionalisation and empowerment, and these will be used in the analysis and subsequent discussion of this thesis. The theories of Bachrach and Baratz (1962), Lukes (1974) and Foucault (1972, 1973, 1976) were seen to be most useful to inform my analysis of power in the research data. The work of Lipsky (1980) and Menzies (1970) was found to be most illuminating in terms of explaining the current dilemmas faced by front-line staff in institutional, statutory services; despite their work being over twenty and thirty years old. The definitions of empowerment by Zimmerman and Rappaport (1988) and McWhirter (1991) were considered to be most helpful for examining data on user empowerment. And theories of social movements, particularly those that discuss the role they have in constructing new identities, were also considered to be of use to this analysis.

Concluding Comments

This chapter has aimed to provide some of the theoretical reference points for this study in terms of participation in practice. As Milroy and Hennelly (1989) suggest, power and powerlessness are central features of mental health services. Three main points emerge from the literature summarised above on the theory and practice of collaboration in health and welfare services. Firstly, user participation is a complex and controversial subject that has been inadequately conceptualised and appraised by health and social care practitioners. Indeed, it appears that professionals are not comfortable talking about user involvement in terms of power, as Church and Reville (1988) have noted:

> In the mental health field, it creates discomfort to talk about power. People prefer to talk about 'care', 'services' and 'service delivery' (1988: 25).

Secondly, because of structural inequalities in society, it appears from the literature that legislation of the type that created the 'quasi-market' reforms can only go so far towards achieving change. It can not completely reform the way 'care' is thought about, nor the way that responsibility for defining 'need' is designated. Most fundamentally, it does not impact on structural inequalities. Finally, because participation is seen as 'A Good Thing' (Richardson, 1983), there is a danger that service organisations and professionals may change their language without changing their practice: with tokenism and incorporation the common consequences.

The contradictions and ambiguities that are inherent in the concept of participation can now be better understood in the light of the theoretical work presented on power, powerlessness and institutionalisation. This chapter has shown the necessity of more work being undertaken to describe the tensions of participation in practice, in the light of the work that has been presented here, because of the tendency for participation to be separated from understandings about power, empowerment, change and identity. The theory on power and participation and the empirical work on the problems of participation in practice played a central role in the framing of my research questions and the focus of the research as a whole. On the basis of this review of the background and theoretical literature, the central thesis of this research study is that participation will not succeed as a strategy to improve services, or change relationships between service users and service providers, if it is disengaged from an understanding of power and its effects. The goal of this research is therefore to contribute to the work described in the last two chapters by investigating the experience of a group of professionals and service users who are heavily involved in participatory contexts, to attempt to further illuminate some of these tensions and ambiguities. The ultimate goal is to provide recommendations for policy and practice based on the findings generated that can help move practice forward for all involved.

Chapter Three

Research Strategy, Questions, Design & Method

This chapter describes the research strategy for the study and draws upon relevant theory to explain the reasons for using a variety of somewhat divergent epistemological paradigms to inform the study's approach to inquiry and knowledge production. It includes a discussion of theoretical approaches to research methodology in respect to power relationships, the representation of researched groups, the nature and status of truth and knowledge, and of human agency and personhood and other such dilemmas; in order to explain and account for the theoretical assumptions underpinning my work. The necessity of interweaving different epistemological perspectives in order to answer my research questions is elaborated upon. Links are made between the research strategy and the development of my research questions; acknowledging the importance of an analysis of power and powerlessness for the study as a whole. The last section will describe the consequent research design and methods in detail; the research context, interviewing techniques, approach to sampling, problems of access, ethical considerations and my approach to the analysis of the data. I also describe some of the challenges I faced trying to address power inequalities in this study and one strategy adopted to try to build in additional reciprocity and participation to the study. Finally, comments on the generalizability of the research findings will be made. Before doing this let me first restate the aims and boundaries of this *research. The aims of this research were to:*

- Document the practices of user participation within the psychiatric/mental health system from a critical perspective;
- Identify and describe the barriers to user involvement;
- Provide an account of the 'unsettling relations' (Church, 1995) of participation; and to
- Develop understanding and build on theories about participation and changes in power relationships in the mental health field.

Part One: Research Strategy and Methodological Framework

> We cannot engage in research divested of ideology. We can come with an overt consciousness of ideology and an awareness that all ideology can obscure as well as enlighten (Opie, 1992: 66).

In this section of the chapter I set out my research strategy and explain the methodological choices made in the research process, detailing what I felt to be the necessity of interweaving different and somewhat contradictory epistemological perspectives, in order to answer my research questions. As Opie (1992) describes above, ideological beliefs underpin all research approaches, potentially obscuring as well as providing new insights and meanings. Because of this I chose to use a variety of different approaches to counter the danger of becoming overly dependent on one perspective. I also believed that adopting only one methodological approach could be limiting for a project which aimed to describe as well as explain and to deconstruct as well as construct, dimensions of participation in practice. I was impressed by a number of different epistemological traditions and wished to draw on their insights but not be constrained by their limitations.

Investigating a subject as complex and multi-dimensional as participation and power relationships required use of an eclectic approach to knowledge production because of the multifarious ways that these concepts can be understood and made sense of. Some propose that social phenomena like participation and power are not concepts that can be understood outside of their social and historical contexts: they are not fixed entities that mean the same thing to different people (Parker, 1998). Not only are there different theories of power and participation these different theories hold assumptions about broader phenomena such as truth, human agency, personhood, identity and subjectivity, which are often contradictory and constantly evolving. Burr (1998) calls these the 'knotty problems' that create dilemmas for researchers keen to investigate social phenomena of this type.

The ideas of postmodernism and poststructuralism have done most to unsettle previously straightforward research accounts of social phenomena that have sought to 'tell it like it is'. Telling a 'true' account of a social phenomenon is now a contested activity as the ideas of social constructionism have succeeded in undermining the idea that there can be a true and knowable reality 'out there' that can be researched. Indeed, some theorists believe that discourse is all there is, with no reality or truth independent of our own descriptions and interpretations of it (Burr, 1998). In this analysis the hopes, desires, intentions and actions of human beings become less the products of human agents themselves and more related to the cultural and discursive structures than underpin, shape and construct our social world.

Qualitative research contains a myriad of approaches with different assumptions about the nature of knowledge, truth, personhood and agency. Although many researchers continue to use methods that investigate the social world as 'knowable', many are now using multi-method approaches that acknowledge the ideas of social constructionism. How we understand social phenomena has huge implications for how we then intervene or change the social world with the aim of improving it. This thesis uses theories that contain different assumptions about the nature of social phenomena that are sometimes contradictory for this reason, both in the subject of user participation and in the methodologies used to investigate it as a phenomenon. This creates problems not only in making truth claims but also in making suggestions for action and change. This research has therefore involved learning how to navigate through these conceptual minefields. The issues raised by postmodernism have not been resolved in the literature on method and were not resolved in this research; this remains a disputed area and this research is merely one contribution to the experiment of mixing different methods. I will now elaborate on the reasons why I chose this eclectic journey and the main traditions drawn upon to inform the journey.

The methods chosen by researchers appear to be influenced by the personal preferences and values of the investigator and by their past experiences, as well as by the utility of the methods for the research in question. Methods need, therefore, to have a resonance with one's own value systems and world-view as well as having the ability to produce data able to answer the research questions. Most of the studies described in Chapter one on user participation in health services (Barnes *et al.,* 1999; Church, 1995; Lupton and Hall, 1993; Marsh and Fisher, 1992; Wadsworth and Epstein, 1998) addressed the subject from a qualitative perspective; giving precedence to the expressed views of professionals and service users. Qualitative research methodologies do appear to be best equipped to investigate this topic area because they have the capacity to acknowledge different subjective positions and vantage points held by respondents, allow for 'thick description' of the subject, and give due regard to the socially constructed nature of social phenomena. As well as quantitative research not being the most appropriate research approach to answer the research questions in this study; it was not commensurate with my personal preferences because of my desire to make the research a collaborative or shared venture.

The methodological choices I made in this study were based on a substantial review of the literature on qualitative research methods and their epistemological/ontological foundations. A research framework was required which was both able to adequately frame the research questions and their constructionist/relativist and realist/foundationalist underpinnings, as well as address the danger of the research further contributing to the marginalisation of the group under study. Importantly, the research framework also needed to be informed by an analysis of power as described in Chapter one, because of the centrality of the concept of power to the research questions. I therefore drew upon four main interpretative traditions, using aspects of each of them, to meet these methodological requirements. These four traditions were:

- Work on power and powerlessness in knowledge production and participatory research approaches;
- Standpoint theories as described in feminist methodologies;
- Constructionist and discourse approaches; and
- Analytic/critical realism.

I shall now describe these four traditions and the relevance of each to my overall research strategy. Figure 3.2 at the end of this section (page 91) provides a visual presentation of the way my research strategy is located within these four traditions.

Theories of power and powerlessness in knowledge production and Participatory Research approaches

Power, its uses and misuses in mental health services is located at the centre of this study. It is my belief that to engage critically with issues of power within mental health services requires one to also look critically at the uses and abuses of power within one's research activity. Since I have already summarised work on power and powerlessness in the previous chapters I shall discuss work *that attends to power and powerlessness in relation to research activity and* knowledge production.

Some authors have demonstrated the inadequacies of previous research paradigms to deal with questions of power (Church, 1995; Lather, 1991; Oliver, 1992; Zarb, 1992). However, research that does attend to relationships of power and attempt to make changes to the social relations of research has been criticised as unsound and unscientific, due to its explicit ideological basis and sometimes avant-garde methods (Cooper and Stevenson, 1998; Morgan, 1998). Even research that attempts to meet both of these aims; to equalise relationships and to be reliable scientifically, is criticised as 'appropriating' the groups or individuals it tries to represent (hooks, 1990). Research with oppressed, marginalised, excluded or over-researched groups is, therefore, not to be undertaken lightly.

To undertake research sensitive to power issues involves critically examining the socially ascribed characteristics of power i.e. the race, gender and class of the researcher and the researched, in order to challenge the transparency of traditional research relations. According to Lather (1991), all inquiry methods have a political bias that express a relationship between people. Indeed, Church (1995) comments that all knowledge serves certain purposes. The process of knowledge production is, therefore, embedded in wider social and political relations and has social and political effects on those other than merely the researcher and participants (Oliver, 1992). Discussions on the social relations of research often lead to a polarisation of views and it is an aspect of research that is consequently hotly debated and contested (Cooper and Stevenson, 1998; Morgan, 1998).

Since the early 1970's, criticisms of the disempowering nature of much social research have been made. There has been an acknowledgement that the social sciences have more frequently studied people who are mentally ill, disabled, poor, Black and old, than those from more powerful groups. Study of the 'Other' was indeed the very substance of traditional anthropological theory and practice which contributed to the construction of non-western peoples as strange and savage through 'ethnographic exotica' (Wilkinson and Kitzinger, 1996). The representation of Others through academic research and knowledge building is now seen as problematic; in part through the portrayal of oppressed groups or peoples in ways that reinforce the power and superiority of those with control over the processes of representation (Wilkinson and Kitzinger, 1996).

Since the early 1990's there have also been damning critiques of the use of traditional research in the field of disability: these critiques have accused the traditional research model as being alienating, having little positive effect on disabled people's lives (Barnes, 1992; Oliver, 1992; 1996; Zarb, 1992). Oliver (1992) has applied the 'rape model of research' (Reinharz, 1985 cited in Oliver, 1992) to disability research. He describes a process where researchers benefit by taking the experience of disability, rendering an account of it and then moving on, while the disabled research 'subjects' remain in exactly the same social situation they did before the research began. There has also been an accusation from disabled people that research has added to their marginalisation and misrepresentation, through voyeurism and appropriation. Some disabled researchers argue, in fact, that research has nothing at all to offer, exerting little influence on policy or disabled people's lives. Oliver (1987) has remarked that as disabled people have come to analyse their segregation, inequality and poverty in terms of discrimination and oppression, their view is that research functions, on the whole, as part of the problem rather than part of the solution. This response has been mirrored by the development of groups who deliberately distance themselves from professionals or from people or groups they consider to be a threat to their purpose of developing enlightened and politicised action for self-help and change. This separatism is common amongst oppressed groups who realise the need to cut their bonds to the dominant group in order to begin the process of radical conscientization (Chamberlin, 1988; Freire, 1972). Disabled people are now demanding the right to define their own lives and problems, and to identify and take action that they see as appropriate, rather than allowing others to assume that responsibility.

People who are members of oppressed groups often feel that they are not heard. People who have used mental health services can have even more difficulties being listened to (Rogers, Pilgrim and Lacey, 1993). Views of people who have been diagnosed as having a mental illness are often, by definition, invalidated; especially views that are critical of services (Rogers, Pilgrim and Lacey, 1993). Rogers, Pilgrim and Lacey (1993) propose that most evaluative research on psychiatric patients' views of services has reflected professional interests, with evidence of patient/service user dissatisfaction not taken seriously. They describe four ways that user views are invalidated in research:

- The disregarding of users' views which do not coincide with those of mental health professionals;
- The continued prevalence of the notion that psychiatric patients are continually irrational and so incapable of giving a valid view;
- Patients and relatives are assumed to share the same interests and, where they do not, the views of the former are disregarded; and
- Giving partial credence to the client's perspective provided that it fits in with the expert's view (Rogers, Pilgrim and Lacey, 1993, 6-11).

Although Rogers, Pilgrim and Lacey (1993) cite a few small-scale studies that have not treated user views in this way, they conclude that these are overwhelmed by the dominant majority that do. They advocate the need for research for and by users, as opposed to research on users, to be central to new research in the mental health field. For these authors, any researcher needs to take seriously the meaning that users themselves give to their experiences and the implications that follow.

Similarly, user and survivor experiences of government consultation, research and partnership exercises have been described as tokenistic where nothing changes, leading to disillusionment and scepticism (Department of Health, 1996). This has, unsurprisingly, resulted in groups and individuals being reluctant to waste their time taking part in these exercises and refusing to get involved, due to an understandable suspicion of government, professionals and researchers. The presence of people who have direct experience of psychiatric services within academic and policy-making environments has so far had little influence on mainstream policies and priorities. However, organisations and networks of people who are developing their own theories about policy and practice are producing accounts that are significantly different from those produced by mainstream academics (Beresford and Croft, 1993; Faulkner, 1997; Oliver, 1996; Rose, 2001). Although service user knowledges are still largely ignored and marginalised within the discourses of mainstream social science and psychiatry, there is now a growing body of literature, research and other products[3] that report the views/perspectives of people who commonly do not have a voice within the dominant 'culture-making' institutions.

One example of this type of development that has made an impact within academia is that of the social model of disability. This theory was developed by disabled activists/academics who eschewed the dominant model of disability as part of the structure that kept the world a hostile and oppressive place for disabled people (Oliver, 1996). The social model of disability has now achieved the status of legitimacy within mainstream academia as an important way of making sense of disabled people's experience. Another less influential but important example within the mental health field is the Hearing Voices movement, this movement seeks to challenge psychiatric understandings of voice hearing by privileging the experiential knowledge of people experiencing voices in order to develop alternative models of understanding and explaining these experiences (Romme and Escher, 1993). Similarly, the Mental Health Foundation's user-led research on alternative and complimentary therapies (Faulkner, 1997), and 'strategies for living' (Mental Health Foundation, 2000), explores the diverse ways in which people cope with living with mental health problems. These examples show that groups traditionally conceived of as 'outsiders' to the world of research are now making their own contributions.

One of the problems with doing research on behalf of the interests of a group to which one does not belong is that of representation or, more precisely, misrepresentation. Accusations from oppressed groups detail their feelings about appropriation and misrepresentation when researchers try to 'speak for' them. They describe even well intentioned research about the 'Other' as contributing to the annihilation of their own voices (hooks, 1990). Theories of 'Othering' and the connection with processes of colonisation, where people are represented as 'Others' in ways that reinforce the power and supposed superiority of those with control over the processes of representation, are beginning to emerge in social science debates. Kitzinger and Wilkinson (1996) have taken up the theme of representing the 'Other' in psychology from a feminist perspective. Much representation of 'Others' happens discursively, in and through language. By objectifying groups of people as 'Others', particularly through language practices, it is possible to construct their identity in ways that suit dominant interests and provide rationales for social practices and relationships.

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[3] For example videos, newsletters, pop concerts, web sites, email groups and art work.

Much of the criticism of the role of knowledge production or research can leave one wondering the point of 'speaking for' at all. Indeed, the user movement in Britain is divided on the role of professionals and non-user academics within it. Some groups see a role for professionals and non-user academics as 'allies' or radical workers, while others reject the notion of professionals and non-user academics being involved, arguing that the movement will get co-opted by professional interests and become ineffectual (Rogers and Pilgrim, 1991). The dilemma of the role of professionals is hotly debated and has become a critical one for the movement, particularly since there is evidence to suggest that successful social movements include a variety of different kinds of people, not just people from one marginalised group (Offe, 1987). There are also concerns, however, about the silencing that occurs if we, as non-user researchers, speak only for 'ourselves'; about what we directly experience and are part of. Unless there have already been substantial changes in power relations, getting people to listen and getting changes in policy and practice, can be a frustrating process. Using mainstream channels such as academic research can help to give credibility to a movement that otherwise may be easy to dismiss.

The literature outlined above had a fundamental impact on my research strategy. I was convinced that research that did not attend to power inequalities and to the danger of misrepresenting the group one researched was likely to be more part of the problem than part of the solution. I was also heavily influenced by the work of Church (1995) and Glenister (1994) who propose the importance of forging collaborative, honest and reciprocal relationships with users/survivors when undertaking research that concerns them. Also my work as a practitioner had been informed by similar ideas about reciprocity and equality and these ideas therefore had validity for me as a researcher too. So for these reasons, plus the original belief that a piece of research about participation and power should have a methodology that also addressed these issues, I decided that the research strategy adopted needed to incorporate these perspectives.

Despite the arguments set out above against research being used to 'speak for' or give a voice to oppressed groups, this post-graduate study therefore became premised on the view that the traditional silencing of mental health system survivors in mainstream research should be reversed. The research strategy was therefore based on a belief that productive alliances can and should be made between user and survivor groups and researchers concerned to work for social change. One way that productive alliances between researchers/academics and marginalised groups can be developed is through participatory research methods. A participatory research approach seemed relevant and necessary for this study because of my concern with power inequalities and making the research meaningful for those who took part. Despite an awareness that participatory research would be difficult to achieve within the limitations of a post-graduate study I nevertheless attempted to look for ways that I could use these ideas in my research strategy.

The development of participatory methods in research grew from a concern to do justice to the humanness of all those involved in the research process (Reason and Rowan, 1981), and in effect to begin a 'new paradigm' for anti-oppressive research. Participatory research (PR) is built on a belief that human inquiry should be based firmly in the experience of those it purports to understand. It suggests collaboration between 'researcher' and 'subjects' working together as co-researchers and co-participants. PR advocates that individuals and communities or groups who are involved in research should contribute to the analysis of their own reality and their own problems (Yeich and Levine, 1992).

The underlying motivation for PR is a commitment to social change and transformation. It commits to people whose lives are in struggle and to promoting the control people have over their lives, believing in the need to 'transform our idea of research from mere data gathering into a consciousness raising, transformative technique' (Friere, 1972: 135). It advocates getting away from individualist conceptions of social relations, where any problem is seen as personal, to be dealt with by the individual. Instead, participatory research is generally informed by theories that see human beings as part of larger systems and groupings, and constrained and bound by these systems. These ideas have their origin in the critical philosophy of Marxism which can be discerned clearly in the work of South American educationalist Friere (1972) who writes of 'emancipatory interest'. PR methods explicitly involve the researcher in the process of change requiring that the investigator be as open to change as the participants are encouraged to be. It is practised as an integrated activity combining social investigation, educational work and action, since the very act of obtaining knowledge creates the potential for change (Banister, *et al.,* 1994).

I used the ideas of participatory research, together with standpoint theories of knowledge described next, to build in opportunities for members of the researched group to influence the research agenda and process. However, trying to use participatory ideas became one of the most challenging aspects of this research and I detail some of the difficulties I faced later in this chapter.

Standpoint theories

Standpoint theories of knowledge (Harding, 1991), that originate from class and feminist analysis, emphasise the importance of the 'outsider within' and the struggle to articulate the forbidden or invisible experience that makes new politics and new theoretical insights possible. Although a number of people have written on standpoint theories (see Henwood, Griffin and Phoenix, 1998), I draw exclusively on Harding's seminal work: *Whose Science? Whose Knowledge? Thinking from Women's Lives.*

Standpoint theories can help to negotiate through the somewhat messy aspects of research that tries to work with marginalised people but is also in danger of misrepresenting them. Standpoint theories can help to move from the position of including other's lives and thoughts in research and scholarly projects, to starting from their lives to ask research questions, develop theoretical concepts, design research, collect data and interpret findings (Harding, 1991). Standpoint theories help to challenge the 'view from nowhere' stance common in science practised by dominant groups, by encouraging a relationship between experience and knowledge (Harding, 1991). Reclaiming identities that groups of people have previously been taught to despise is another theme of Harding's work. According to Harding (1991), feminist science has struggled to claim the 'perspectives that arise from our "despised" identities as women' (1991: 272). She elaborates:

> It has taken courage to claim these identities for such purposes when the gatekeepers of the intellectual traditions have insisted for centuries that we are exactly not the kind of persons whose beliefs can ever be expected to achieve the status of knowledge. They still assert that only the impersonal, disinterested, socially anonymous representatives of human reason... are capable of producing knowledge. Mere opinion is all that the rest of us can hope to produce (1991: 272-273).

Identity politics, or situated politics, emerges when a marginalised group develops 'political and knowledge seeking projects that originate explicitly from their own socially devalued lives instead of from "nowhere" or from somebody else's life' (Harding, 1991: 273). Standpoint theories illuminate the potential of contradictory identities and contradictory social locations. Here the notion of the 'outsider within', which is of relevance to this study, emerges. Harding (1991) proposes that speaking from a social identity, or from a social location that is perceived to be a contradiction, 'can be a serious disadvantage within political, economic and social structures, but such an identity can be turned into a scientific and epistemological advantage' (275). By being able to exploit the friction between being on the outside and on the inside, and between multiple identities, new opportunities for insight and understanding can emerge to enrich more traditional understandings. Bringing outsiders into the centre of analysis, for example, can reveal views of reality that have previously been obscured. According to Harding, 'outsiders within' do not just create new understandings for themselves and those of the group to which they belong, they can also illuminate the subject for those who do not have marginal identities who can also learn from and use the knowledge generated.

Harding's work was used in this study to draw attention to the socially situated nature of knowledge production, and the competing or contested knowledges that emerge when groups, traditionally considered to be outsiders to the creation of knowledge, challenge their role and force entry to this privileged world. Standpoint theories were used, alongside ideas from participatory research, as a rationale for including 'outsiders within' more deliberatively in the research process of this study. One aspect of standpoint knowledges that was particularly useful for this research was the way that they offered opportunities to blend constructionist and naturalistic approaches to theory building.

Standpoint theories situate the researcher, and those they are researching, in their social and historical context; thereby allowing accounts to be viewed both as constructed as well as being 'reality reports'. This is because of the theoretical assumption that one's knowledge is always going to be partial and dependent on the standpoint one is speaking from. Standpoint theories also provide a method of managing the relativism that dogs discussions about constructionist epistemologies; a subject described in more depth next. They can help to manage the relationship of the researcher to the research accounts in useful ways because of the standpoint that the researcher takes within the research, and the accounts given for this. This approach does not privilege either the voice of the researcher or the voice of the interviewees giving accounts, but instead attempts to recognise the partiality of all positions and the need to balance 'reality' with interpretation. Recognising that standpoints can and do shift over time, as mine did as a researcher, is also necessary to avoid seeing identities and views/knowledge as fixed and rigid. Understanding 'reality' as fluid and consisting of multiple realities is also pertinent to research of the kind carried out here.

There have been critiques of standpoint theories, predominantly on the basis of the desire of theorists to undermine or transform the binary thinking at the heart of the foundationalism/relativism debate (Scheurich, 1997). Identity politics, a development with conceptual roots in standpoint theories amongst others, has likewise been criticised, being accused of creating more division and inequality through the focus on difference and on separatist solutions. Nationalistic tensions have been identified within the ideas of identity politics, alongside the problem of sub-groups being subjected to normalising pressures to conform to identity group stereotypes (Sampson, 1993). Despite these criticisms, standpoint concepts had utility for this study in the way they were able to negotiate ideas of difference and position. Using these theories, and influenced by the work of Church (1995), I decided to build a role for a user/survivor co-supervisor, into the research using the 'outsider within' perspective, a strategy that is outlined in Part three of this chapter.

Constructionist/discourse approaches and analytic/critical realism

As stated above when describing standpoint theories, a methodological approach that blends naturalist/foundationalist/realist and constructionist/relativist approaches together, can leave itself open to the criticism of making contradictory truth claims as well as confusing the boundaries between traditionally distinct paradigms. Because this area is theoretically complex I shall briefly describe the main conceptual debates before elaborating upon the position I adopted in the research.

Using methods that understand reality and truth as fixed, at the same time as using methods which understand reality and truth as provisional and constructed, can be viewed as problematic. Some writers have advised against such methodological convergence because of the conflicting epistemological positions contained within these different paradigms (Scheurich, 1997). It is my view, however, that as long as one is aware of where the contradictions lie, where the pitfalls may be, and how these tensions may be resolved, then interweaving approaches can have creative and constructive consequences. I agree with Parker (1998), who states that 'realism' and 'relativism' are metaphorical constructions in themselves, and need not necessarily be considered as opposites or complete dichotomies. With the realism/relativism debate itself considered to be a social construction, it becomes possible to envisage a more critical appreciation of the different approaches and positions, rather than conceiving alternatives as 'either or'. Perhaps, as Burr (1995, 1998) describes, we can talk of things as being, at one and the same time, both 'real' and socially constructed. Also, some realist and relativist approaches share common ground, for example, both critical realists and social constructionists recognise the social and historical construction of knowledge.

Much of the current angst reflects the challenges posed by postmodernism that has questioned how we can know anything about the world. Fashions come and go in debates about appropriate methods. According to Denzin (1998), the age of a putative, value-free social science appears to be over; requiring any discussion of method to discuss political, personal and experiential implications. There are many ways to move from the field to the text, and many ways to inscribe and describe experience. Denzin (1998) suggests that there are four major paradigms; positivist, post-positivist, constructionist and critical, and three major perspectives; feminist, ethnic models, and cultural studies, that now structure qualitative writing. Adopting these paradigms, he suggests, gives the writer a public identity and directs him/her into specific theoretical and research traditions which each have their own 'taken-for-granted' rules about the nature of knowledge production. There are now substantial criticisms of all these different paradigms and perspectives along with their associated defendants.

Having agreed on the inadequacies of positivism as the over-riding contrasting model for knowledge production and research in the social sciences, there are now numerous views held by qualitative researchers: from that of viewing truth as fixed, to viewing it as completely dependant on the social and historical factors that produce it. In psychology, for example, the last twelve years have seen an increasing interest in constructionist approaches; in particular ones that view discourse as fundamental to conceptualising human psychology as an 'ensemble of social relations' (Parker, 1998). But, as Parker (1998) warns, the discursive turn in psychology and other human sciences carries conservative as well as progressive prescriptions for research and other academic activities:

> At the same time as deconstruction, discourse theory, pragmatism and postmodernism cut away the positivist ground from beneath traditional psychology and relativize their claims about the nature of human nature, these theoretical currents also relativize the truth claims of the critics and sabotage principled resistance to abuses of power in the discipline' (1).

Sustaining a critical perspective on abuses of power, as my research aimed to do, becomes problematic if the relativism present in social constructionism is taken to its full conclusion.

As Burr (1998) emphasises in her analysis of the realism and relativism debate, there are moral as well as methodological questions situated within these arguments. The debates involve complex discussions about the role of the social sciences in society as a change agent, as well as their role in constructing what is known about people and social life. One of the main differences between approaches is whether reality is viewed as existing as an entity, separate from our knowledge and descriptions of it, or not. This is linked to beliefs about whether social problems and social relations have their roots embedded in material social structures or whether they are rooted in discourse and language and its constructive effects (Burr, 1998). Taking a position on power inequalities in society, such as that informed by the feminist research perspective or the participatory research perspective, also has consequences in terms of the epistemological standpoint that one can then coherently adopt. The terrain becomes fraught if one assumes a position that attempts to reverse, or at least address, traditional unequal power relationships and powerlessness, as perspectives such as feminist and participatory research do.

Critical or analytic realism are approaches that some researchers have taken in order to address the fear that relativism may thwart the radical political awareness in psychology that writers such as Parker (1998) have argued needs to become stronger in diciplines such as psychology.

Indeed, some realist approaches can be loosely categorised as constructionist if they break away from a preoccupation with pure realism towards a more interpretative and creative approach to theory generation (Denzin, 1998). Altheide and Johnson (1998) describe the position of 'analytic realism' as an approach founded on the view that the social world is an interpreted world, interpreted both by the research subjects/informants as well as the researcher. Although this approach to knowledge production does perceive the value of trying to represent the social worlds being studied faithfully and accurately, it assumes at the same time that 'the meanings and definitions brought to actual situations are produced through a communication process' (Altheide and Johnson, 1998: 292). Analytic realism recognises that knowledge is based on purposes and assumptions and is, therefore, a human construction. However it rejects the complete abandonment of the idea of knowable phenomena. Some critics such as Scheurich (1997) argue that this realist approach is faulty, in that it posits the view that a body of knowledge about the 'real' world can be created. He states that there is no such thing as a value neutral approach to the world. While I agree with him on this point, I think that there is a need to collect bodies of knowledge about versions of the lived world that allow opportunities for people to speak about their lived experiences and have these accounts taken seriously.

The constructionist ideas also hold much promise for those who wish to analyse power and social relations, as this study intended to do. Not only because of a focus on the infinite numbers of alternative constructions of the events one is studying, and the meanings of these events, but also because of the potential these ideas have for individuals and groups who wish to re-construct the way identities and social categories are conceptualised and understood. Social constructionism draws attention to the diversity and difference in humanity, as well as the diversity of our interpretations of it. However, in the extreme, the relativistic approach can also lead to what Burr (1995, 1998) has described as a social and personal paralysis. This paralysis is in part due to the abandonment of any notion of a fixed, discernible reality, and the replacement of one reality with an array of alternatives; all of which make claims to being true. If all these alternative truth claims are mere constructions, and all worthy of a fair hearing, Burr (1998) asks how then we can claim that some groups or others should be given a social 'voice' and others not? She questions whether it is indeed possible for researchers working within the constructionist framework to arbitrate between constructions of reality; indeed, whether it is appropriate within this paradigm to give greater social space to marginal groups who are viewed in certain terms as less powerful than other social groups. Without some notion of truth or reality, she asks, 'how can we advocate one view of the world over another'?

Where researchers and other social scientists position themselves in relation to these questions, and to the wider issues of what reality and truth mean to them and their research, varies considerably. Burr (1998) considers that most academic researchers have accepted the existence of social constructionist ideas, but vary in the distance that they are prepared to travel along the relativism continuum:

> ...the decision about where to get off the constructionist wagon seems prompted by the fear of losing our critical edge on important social phenomena, such as inequality or oppression, which threaten to become casualties of relativism and turn into just another story, just another way of interpreting the social text (15).

Another difficulty with constructionist or relativist approaches to knowledge production, is the hesitancy that those who use these methods necessarily employ when it comes to making recommendations for social change on the basis of research findings. Because of the fear of reifying certain accounts over others, those who use constructionist methods often remain commentators, without following the process of knowledge production through into suggestions for social action. Burr (1998) expresses her dissatisfaction with this aspect of constructionism thus:

> Social constructionism provides us with little guidance for how we should chose a course of action, what 'discourses' we should support, which marginal voices we should allow to speak... (16).

She argues that while making space for marginal voices to be heard, we are in danger of losing a collective base, and of denying the chance to identify collective interests from which to proceed.

Denzin (1998) is one of the few commentators that has tried to bring some unity to these debates, rather than further contributing to this increased polarisation of methods. His 'interpretive interactionism', for example, seeks to include symbolic interactionism, participant observation and ethnography; semiotics and fieldwork; postmodern ethnographic research; naturalistic studies; creative interviewing; the case-study method; hermeneutic phenomenology; cultural studies and feminist critiques of positivism. Denzin's (1998) work indicates the possibility of creating new connections between methodological approaches. For him, many of the more simplistic classifications just do not work, since any qualitative researcher can be more than 'one thing' at the same time. It is in the spirit ofDenzin's interpretive interactionism that the multi-dimensional research strategy in this study was constructed.

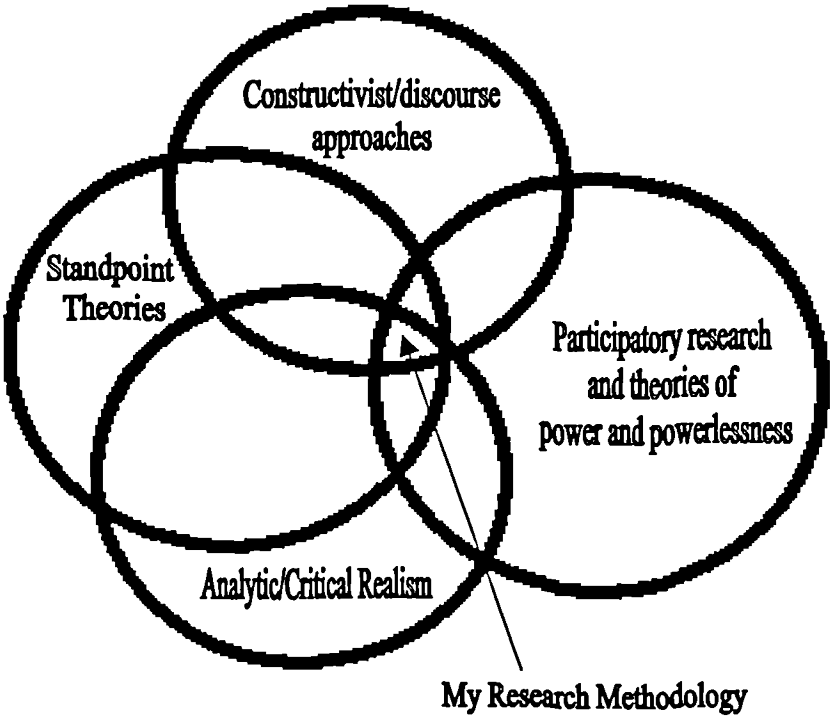
This summary of some of the methodological tensions within different approaches to knowledge production/construction, indicates the contested and value-laden nature of the decisions that need to be made when embarking on a piece of social research into subjects that concern, for example, power, powerlessness, social relations and social structures. I now turn to explicating how the decisions I made regarding these tensions and debates informed the research strategy and design.

A Multi-dimensional Research Strategy

My initial review of the methodological literature convinced me of the need to work across the realist/relativist chasm because of the value these different approaches had to offer the study. As stated above this was because my research questions aimed to describe as well as explain, and deconstruct as well as interpret, the social phenomena of participation in mental health services. Although the research methodology draws upon constructionist approaches (ones concerned with acknowledging the presence of multiple realities, the importance of the researcher's perspective and a belief that language has a role in producing realities), naturalistic or realist approaches to data analysis such as grounded theory (Glaser and Strauss, 1967; Strauss and Corbin, 1990), were also employed. This methodological plurality, while contentious, was necessary because I would be collecting accounts of the processes and social relations of participation from different groups of 'stakeholders' or interest groups: professionals, users/survivors and user workers.

I wished to view the respondent's answers in interviews as cultural stories (Silverman, 2000) about the subject of participation. Viewed in this way the rhetorical force of what interviewees say can be examined. However, the methodological approach adopted also had to somehow acknowledge the status of the 'reality reports' respondents gave; especially those of user/survivor respondents whose accounts are often not taken seriously (Rogers, Pilgrim and Lacey, 1993). With the acknowledgement and awareness of unequal power relationships between users of welfare and health services and professionals, described in detail in Chapter one, the approach also had to allow scope for a critique and deconstruction of professional and managerial accounts of participation. This was important in order to determine the social, discursive and material consequences of inequalities of power, in relation to the research questions. This is one example of the way in which an analysis of power intersected the methodological decision-making in this study. See Figure 3.1 overleaf for a visual presentation of the way in which the four interpretative paradigms described framed my research design.

Figure 3.1. Graphic Presentation of the Multi-dimensional Approach



As shown in the diagram above, the space in the middle of the four circles represents the interpretative space within which this study resides. It demonstrates the number of important methodological facets and tensions implicit within this study and its approach to knowledge production. Firstly, the necessity of working within an understanding of unequal power relationships and the need to open up research and knowledge production processes to those whom the research concerns (participatory research). Secondly, the importance of understanding knowledge production as a political activity, of challenging the 'view from nowhere' approach to knowledge production and validating previously excluded Others' versions of reality (standpoint theories). Thirdly, a concern with language as an analytic tool, and the need to view knowledge production critically, in order to be cautious about making truth statements that lie outside of historical and social experiences (constructionism/discourse analysis). And lastly, the importance of viewing individual accounts as meaningful in their own right, despite them being only partial, incomplete and co-constructed (analytic/critical realism).

The methodological aims of this study were therefore the following:

1. To be concerned with the social relations of my research; attending to issues of power and reciprocity by acknowledging the role of research in the marginalisation and misrepresentation of groups;

2. To attempt to straddle the divides between different methodologies, between theory and practice, between an individual project and a collaborative project and between academic work and social and political action;
3. To emphasise the contradictions and differences that are generated through the research accounts and interpretations, rather than seeking consensus;
4. To 'write in the challenges' and report the 'messy' elements of my research complete with the struggles and doubt of the process.

I shall now link the methodological and epistemological approaches chosen, to the development of my research questions.

Part Two: The Research Questions

The research questions of this study have been through a number of phases of development. The original research questions devised at the start of the research were adapted after the literature review described in the first two chapters. They were revised because of my growing awareness the relationship between participation and power and powerlessness gained through my analysis and the literature. Conceptual issues of power and participation, detailed in the literature review, together with the methodological decisions described in Part's one and two of this chapter, had a fundamental influence on the development of the research questions; not least because of the concern to address issues of power within the research design. Finally, the research questions were also revised again after the experiential phase of the research that I describe later in this chapter. The original questions and the associated participatory video project proposal have been reproduced in the Appendices (Appendix A) along with the project proposal (Appendix B) submitted in April 1996 for selection as a PhD candidate. These proposals have been included to indicate the changes made to the research questions over the life of this research project.

The questions I wanted the research to address aimed to describe and interpret a range of different aspects of participation in practice in mental health services. Some of the questions I wanted to answer were ones that required me to work with the narratives of the respondents using them as descriptive/inscriptive (Denzin, 1998) accounts, drawing upon realist methods such as the constant comparative approach of grounded theory (Strauss and Corbin, 1990). Other questions required a constructionist approach to the data; where the respondents' interviews were viewed more critically as cultural stories and texts where power and authority could be discerned and analysed using theories of power and participation. As stated in detail above, the difference between approaches was necessary, in my view, because I was interviewing both service users/survivors and professionals/managers. A sensitivity towards users' experiences of abusive, disempowering and undermining service contexts was an important aspect of the research approach. I took the view that to critically appraise these texts without this sensitivity would be abusive in itself, continuing the trend of not taking user views seriously, highlighted by Rogers, Pilgrim and Lacey (1993). Although professionals and managers were also often in very difficult circumstances, I took the analytic position that interrogating professionals' talk as text, using theories of power, participation and language, was an appropriate technique if one was to discern patterns of power and tensions within the participation process.

The research questions can be grouped into three main categories. The first category is a collection of questions that are concerned with: *describing the current policy and practice environment of user participation in the context studied.* These questions concerned the meanings, motives, conditions, incentives and obstacles, surrounding collaborative activities between users and professionals/managers. Significantly, this first category of questions aimed to document the *personal views and experiences of different players, at different levels of practice, in different organisations.* The sub-questions identified were:

- What is the nature and extent of user participation in the context studied?
- What meaning does user participation have for different actors/stakeholders and is there any consensus across different interest groups?
- What are the motives for involving service users individually in their treatment and collectively in the delivery of mental health services?
- What conditions support participative practices?
- What rewards, incentives and opportunities does user participation present to individuals involved?
- What are the barriers or obstacles to participative practice in mental health services?

The aim of this first group of questions was to document the current policy and practice environment and context, in order to use this as a baseline for further exploring some of the more complex relationships and tensions within participation. To analyse this category, a grounded theory approach was used to elicit the themes present in the accounts obtained. Constructionist methods, such as rhetorical analysis (Wetherall and Potter, 1992) were also used.

The second group of questions were concerned with mapping any tensions that existed in participatory contexts, particularly in relation to power. Theories of power were seen as central to the subject of this thesis and therefore played a significant role in the development of the research questions in this category. This category was most significantly informed by the literature described in previous chapters concerning problems with participation in practice. When analysing the data related to this category I used different theories and models of power and participation to illuminate tensions in the interview accounts. I was particularly interested in examples of professional and organisational resistance to the involvement of users, as can be seen from the main subset of questions below:

- What challenges does the sharing of power in mental health services pose to those professionals involved? For example, what examples of conflict can be seen?
- Can participation in mental health services be understood using the consensus model of involvement, or does the conflict model offer a more accurate tool for analysis?
- Is there evidence of professional resistance to user participation and power sharing?
- If so, how is this resistance manifested in structures and processes?

As described previously, interviews used to address these questions were viewed as cultural stories that could be analysed for evidence of power relations.

The third and final group of research questions was concerned with documenting user group empowerment. I wished to explore whether signs of resistance to professional or organisationally led user involvement could be detected. I wanted to use theories of power, empowerment and resistance, to assess whether user groups or individual service users were more empowered after a decade of being 'involved' in their mental health services:

- What has been gained by groups and individuals in the process of user involvement?
- What strategies and tactics are used by user groups to demand power and create their own agendas for change?
- Is there evidence of capacity building within user groups?
- What factors impact on the ability of user groups to create change?

In this group a mixture of analytic tools were used including grounded theory and models of power, consumerism and participation. As with the first category of questions, a grounded theory perspective was utilised, because I would dealing in the main with user/survivor accounts.

To summarise, my research questions were developed after a thorough analysis of theories of power, powerlessness and participation and their utility for the study; and were therefore informed by, and framed within, this theoretical analysis. They were also based on my own personal experience of working as a psychiatric nurse in different institutional contexts and a support worker and team leader in community mental health settings; in other words, they were questions based on my experience of professional practice. The questions were also developed further in conversations with service users and critical professionals that took place throughout my initial fieldwork in the first and second year of the study (see figure 3.2 on page 91). Although the study set about asking a number of different questions they can be situated within three main questions that were concerned with:

1. Describing the current policy and practice environment/context of user participation;
2. Mapping the power dynamics of user participation; and
3. Documenting user group empowerment; in the context studied.

The next section will address the way in which the study was designed in order to answer these three sets of questions.

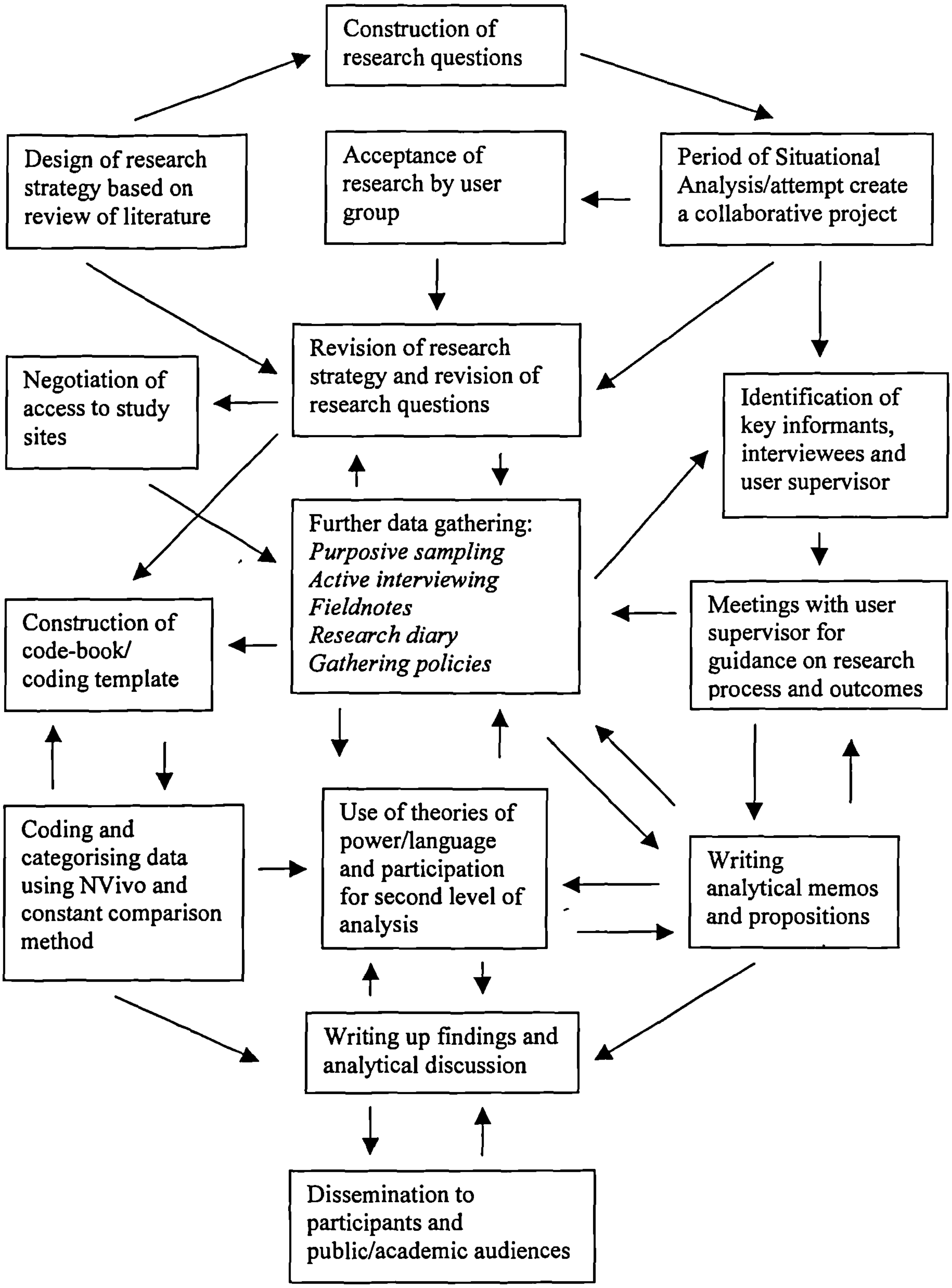
Part Three: Research Design, Methods and Context

This section explains the detail of my research design providing an overview of the methods used in the study. I describe the research context, interviewing techniques, approach to sampling, problems of access, ethical considerations and my approach to the analysis of the data. I describe some of the challenges faced trying to address power inequalities in this study. The use of a co-supervision model, in which supervision is extended beyond the academic model to one in which a member of the group 'being studied' is involved in the process of direction and supervision, is described. This was one tool used to attend to the power inequalities common in most social research, identified earlier in the chapter.

Research Design

Because of the different epistemological positions I adopted in order to answer the research questions, the research design became relatively complex for a post-graduate study undertaken by one researcher. The research process was organic, growing with new insights, new discoveries and with the inevitable setbacks that occurred; and the research design had to be organic and flexible to accommodate these changes and learning curves. A multi-method approach was devised that was consistent with the multi-dimensional research strategy adopted and consisted of a two phases: a period of situational analysis (Robson, 1993) followed by a period of in-depth active interviews (Holstein and Gubrium, 1997). Figure 3.2 overleaf is a visual presentation of the research design from start to finish.

Figure 3.2 Flow-chart of Research Design



Reason and Rowan's (1981) methodological framework involving the systematic use of multiple cycles and feedback loops, where issues emerge through the movement from field to theory building and back again, can be discerned from the arrows in this flowchart. In order for sufficient background to be given to the research interviews, Trust policies on user involvement (Appendices A and B) were also collected and analysed, from the two main Trusts in the study. The first phase also attempted to make the research a collaborative activity and I briefly describe some of the problems I had in this phase and how they were resolved next.

Phase one: 'situational analysis' and an attempt to create a collaborate project

Life and method are inextricably intertwined (Denzin, 1998: 315).

Situational analysis, an approach described by Robson (1993), was used in the first phase of the study to establish rapport with potential participants and build trust through reciprocity. This technique has some similarities with participant observation methods. The aim of this phase was to get to know the local context of the area under study, to identify key people, and to generate themes that could be explored in more depth in the later stages of the research. It was also an attempt to create a shared agenda with service users and a shared set of research questions and aimed to identify people who would be interested in taking an active part in the research as co-researchers.

However, when I first approached the Trust A user group, at the invitation of a member I had met at a conference, some people were suspicious that I would appropriate their cause as others had done before. Earning the respect of the people with power and commitment in the user group involved building trust with user group members over time. This process involved 'getting clear where I stand', as Heron (1996) has described, particularly becoming clear about my own power, powerlessness, values and motivations. There was a need for me to be as clear as possible about my motivations, hopes, limitations, fears and uncertainties. Questions of loyalty, allegiance and legitimacy become important 'tests' requiring honest feedback and clarity. I had to work hard to gain the trust of the users with whom I wanted to work in order to succeed with this research.

This preliminary period in 'the field' made me realise that most user group members were not interested in being centrally involved with a piece of research in, and of itself. As Armstead (1995) illustrates, academic work is often viewed as irrelevant to those outside of academia:

> In my struggle to carefully describe and analyse working-class women's lives so as not to distort or create an alienating picture, as well as in my attempt to reduce a power differential, I overlooked an important aspect of academic life: it is irrelevant to those outside of the university. It may in fact be arrogant to assume that the power to write is the power to define reality. It may be overstating the case to argue that the power to do research is the power to impact on the world (Armstead, 1995: 632).

Although I believed that academic research had the capacity to contribute towards social change, this was not a belief necessarily shared by others. I decided that true reciprocity would only be possible if a joint project was initiated; one that met the goals of the research *and the* goals of the user group. I decided that undertaking a participatory video project was a tool that had this potential: through the process of making a video, user group members would get the opportunity to get their views into a format they could then use themselves and I would use the video material for the research. I put funding bids together to try to raise money to make this idea a possibility, without success. At the same time a key person, someone with filmmaking skills who had supported the idea, went back into hospital and I had to rethink my whole approach to the study.

Reflecting on the first six months of fieldwork, I realised that I had immersedmyself in the real life dynamics of power, and that this groundwork had given me insights that would inform the research in valuable ways. During this phase many issues were raised that made me think differently about research roles, power, alliances, reciprocity and trust. I kept a journal in which I wrote about the sense of powerlessness I felt at this time. Facing my own power as a researcher and powerlessness as an 'outsider' was not easy and this was an anxiety-provoking and insecure time. Writing about the emotional aspects of the research helped me to realise that what I was experiencing were the 'unsettling relations' (Church 1995) that I was hoping to study. I also began to understand that the issues I was facing were part of the process of doing research of this kind and decided to go back to the literature I had initially read to try to make sense of what was happening. There I found descriptions of many of the difficulties that I was encountering (see Acker, Barry and Esseveld, 1983; Armstead, 1995; Greenwood, *et al.*, 1993).

Armstead's (1995) work, for example, helps draw out some of the more complex issues in trying to do research with an emancipatory aim. One of her discoveries was that collaborative research, while democratic in its ideals, may in fact pose an additional burden for participants, who are already juggling multiple roles or feeling overworked and. Her findings mirrored my recognition that it was not realistic, with the time and resources available, to expect others to engage with my project sufficiently enough to feel able to meaningfully contribute to the agenda setting. A wide variety of people did shape the project, however, by offering comments, opinions and experiences. I was able, therefore, to partially ground the research in their concerns and at the very least make the final information gathered relevant to them. This period of returning to the literature helped me to move out of this early paralysis and move on, clearer about where I had been, and with my priorities for the next research phase in place.

To summarise, this first phase grounded and informed my research questions, and enabled me to go forward with further data collection in the form of interviews. It allowed the opportunity to try out different ideas regarding the participation of user group members and to ensure that the research questions would be relevant and useful to the service users concerned. The understanding that full participation is never completely realised but that a project will be situated along a continuum of participation, because of the amount of positive features needed for it to work fully (Greenwood *et al.*, 1993), was an enormous breakthrough for me in this research. It enabled me to reframe participatory research, for this piece of research at least, as ethical reciprocity. Reciprocity, based on an awareness of the limits of what I was able to give and receive, became the way I managed the complexity of power and partnership in this research. The main way I attempted to create reciprocity and dialogue in the second phase of the study was through the use of standpoint theories and a user/survivor co-supervisor.

Phase two: active interviewing and continued participant observation

Phase two moved into exploring the detail of the themes raised by the initial work in Phase one. I decided that interviewing a range of different stakeholders involved in user participation, in different institutional contexts, would be the most suitable method to answer the research questions that had evolved from Phase one. It was also important to continue to be involved in the environments I had been involved with in Phase one, as participant observer. As well as spending time with people in the user group of one hospital Trust, I continued to be involved in informal participant observation through my role as activist in an organisation called Psychology, Politics and Resistance (PPR). As part of PPR I was involved in campaigning activities and initiating discussion forums, where mental health issues could be debated between professionals and users/survivors. This gave me access to wider networks of people who were attempting to create change within the mental health system and became a source of some of my interviewees.

Because of my desire to use both realist and relativist paradigms I needed an approach to interviewing that would allow me to analyse interview accounts using both these perspectives. I therefore chose to base my interviewing method on the active interviewing approach described by Holstein and Gubrium (1997). This is a method of interviewing where talk is treated as social action in which both interviewer and interviewee co-construct the social world that is being described. This method of interviewing attempts to move away from the more conventional 'vessel of answers' approach, viewing interviewing instead as a site for the production and co-creation of meanings. According to Holstein and Gubrium, the rigour of the research is maintained through a preoccupation with both the 'hows' and the 'whats' of interviewing, and by making explicit the connection between the knowledge produced and the actions taken to obtain it. In their view, the role of the interviewer is to 'incite responses', by activating respondents' knowledge and bringing it to bear on the discussion at hand in ways that are most appropriate to the research agenda (Holstein and Gubrium, 1997). Here the interview process becomes a crucial site for the production and co-creation of meanings and particular truths. Consequently, interviewers themselves are thoroughly involved in the production of the knowledge they purport to be gathering through the interview encounter. From this perspective the interviewee and interviewer partake actively and collaboratively in the production of knowledge through 'meaning-making work' (Holstein and Gubrium, 1997).

If one is to take this approach to interviewing, the interview process becomes transformed from a situation where involvement is seen as creating distortion, to one where involvement is seen as completely natural and necessary. The rigour here lies instead in being sensitive to the 'creation' of the process and product; in other words, to the *assembly of knowledge*. Interviewee responses are therefore considered for the ways they *construct* the reality that is being investigated, rather than as true reality reports as such. However, this method of interviewing also allowed me to use the data to elicit themes and categories through a grounded theory approach, and thereby build a picture of participation in context.

Addition to Phase two - Building in a User/survivor Co-supervisor Role

Qualitative research in the social sciences can involve the practice of using key informants (Gilchrist, 1992), where people who are close to the research topic or field, so-called 'insiders' (called 'outsiders within' by Harding, 1991), are used to illuminate the subject of inquiry. This is usually done at the start of a project, and can be particularly useful as an aid to the sampling process (Gilchrist, 1992). Having insiders and non-academics involved in research is one way of acknowledging the specialised, expert knowledge that insiders (and ideally the group they belong to) have in relation to the research topic. In this study the key informants were people who enabled me to access other participants and those who provided the most detailed 'insider' accounts of the subject under investigation. This was an informal role that these individuals took on because they were interested in the research and wanted to help. The key informants were identified in the first phase of the research.

In this research I developed the idea of key informants further in order to give a more direct, formal acknowledgement to the special knowledge gained through active collaboration. I built in a role for a 'second supervisor' or 'co-supervisor' who was a mental health service user/survivor, something that Church (1995) describes in her account of doing post-graduate research with users/survivors in Canada. The use of non-academics or activists as supervisors of research projects, I believe, takes the concept of key informants considerably further (Parkes, 2000). The 'insider' co-supervisor or user/survivor co-supervisor not only offers a different perspective, by virtue of being close to the subject matter being investigated, but also has additional authority and involvement in helping to guide and shape the project through all its stages. Having this relationship with a user/survivor of services helped to build in accountability to the participants individually and to the user movement as a whole; a process that I originally attempted to realise through the group video project.

Another important aspect of the use of a user/survivor co-supervisor is that it offers the opportunity for the student and the user/survivor co-supervisor to 'work together across difference' (Church, 1995). This enables one to explore 'insider-outsider' relations and reciprocity in depth. This is particularly pertinent in fields such as mental health, where there are tightly drawn boundaries between groups. Reflexivity, as stated earlier, is one way for the researcher to examine his or her motives, weaknesses and biases, and can be an excellent way of honestly engaging with power issues through the examination of one's research practice. Opening the research process up to scrutiny from a member of the researched group; a non-academic or an activist, takes this process of reflexivity further by forcing many aspects of the research to become even more transparent. It also requires the researcher to describe, explain, justify and account for, what he or she is doing, in practical and political terms as well as academic terms. It forces the researcher to examine the research from a user/survivor perspective.

The person that undertook this role had extensive experience of services and of the user movement. The part played by this role in my research included advice on sampling decisions, help accessing organisations and users, identifying key people to speak to and identifying new themes for investigation. He also provided a commentary on most of the transcripts. For the process to work well the practicalities of the student-user-supervisor relationship had to be thought through and discussed in detail. Because having a user/survivor as research supervisor was an unusual addition to the research process, there were no guidelines to follow. My academic supervisor, the co-supervisor and myself therefore drew up guidance covering the aims of the supervision sessions, where and how often to meet, the keeping of records, remuneration and the details of and limits to confidentiality. Having a user/survivor involved in this way made me clarify the boundaries of confidentiality in detail, in order to ensure the protection of respondents. The aims and guidelines drawn up for the co-supervision process are listed in Appendix C.

The user co-supervisor read about three-quarters of the anonymised interview transcripts and gave me detailed commentary on his interpretations of the main themes, the most significant aspects of the interviews and why these were significant, and any contradictions and inconsistencies between the interviews. I have included a list of some of the key themes that were identified as most important by the co-supervisor in Appendix D. Although these comments were originally commentaries on the interviews, I have decontextualised them for simplicity and brevity.

One of the most interesting aspects of this exercise was how similar our analysis, as 'insider' and 'outsider', were. The same quotes were picked out, by and large, with similar comments and analysis made on the interviews. There were some differences, but these were not substantial and usually provided a difference in emphasis. Three different examples of aspects of the data that I had interpreted differently, or not given precedence to, need to be noted to illustrate these points. The first was a comment which indicated that the co-supervisor had a strong view that the psychiatrists who initiated joint meetings with the user group (Chapter four; page 141-142) were motivated purely by the credibility that this gave them to impress government and senior management. The psychiatrists saw this very differently and saw their involvement with users as potentially harming their careers. I had interpreted the psychiatrist as genuine in his comments and my co-supervisor viewed the comments much more critically. This may have been an instance where my professional 'outsider' position led me to give the professional the benefit of the doubt. On the other hand my co-supervisor may also have been too harsh on professionals he perceived as largely uncommitted to the principle of empowerment. Having both views helped me to give this issue more thought rather than taking my interpretation, or his for that matter, for granted. Another instance was a quote in an interview, which led the co-supervisor to emphasise the point that users were being used as a 'battering ram' against the staff, for management purposes. This was a very interesting point and one that although my analysis did note, had not explored thoroughly enough. Lastly, the co-supervisor made the comment that many users came across in the data as quite naïve about their involvement, something that would have been politically difficult for me as an 'outsider' to say.

This 'extra set of eyes' on most of the research data was also a key benefit given that there were no other research team members to provide this function. It provided an excellent reason to go back to my data again and see whether another person's interpretation echoed mine. It was also useful to have so much of my analysis substantiated and validated, making me more confident of my conclusions. A further commentary on my final analysis of the data by my co-supervisor was unfortunately not possible.

The Research Context or 'Case'

It is important at this stage to say more about the research context within which this study became based. The research began in a hospital Trust where I had made connections with the user group. This Trust was chosen as a result of an invitation I had received in the early summer of 1997, from one of the members of the user group. The first phase of the research was therefore based within this Trust (Trust A) and was contextualised by my wider activist activities. Later on, in 1998, I approached another Trust (Trust B) to prevent the research being too narrow in its focus. I also included people from other areas of the city to give a broader context to the material I was collecting from Trusts A and B.

Trust characteristics

Both of the Trusts in the study had similar features. Both of them had begun user involvement initiatives around 1994, had a similar geographical catchment area in terms of deprivation indices and percentages of people from minority ethic groups, and both Trusts had policies and terms of reference for user involvement (Appendices E and F). However there were also considerable differences. Trust A was a hospital Trust with a strong reputation for research and for influencing government policy. The opinion of those in other Trusts was that it had powerful medical interests that tended to dominate in terms of leadership and direction of policy and practice. Trust B, in comparison, was described by one if its senior managers as being led by managers who had been more successful in 'managing' the medical professionals to prevent them dominating Trust decision-making.

In terms of the catalysts for user involvement within the two Trusts: Trust A initiated user involvement activities and appointed a user development worker following a development consultant's recommendations for specific actions to address user issues within a broader remit of equal opportunities. Trust B had undertaken a survey of staff and users on user involvement, which had uncovered much confusion as well as variation in practice, and this had become the prompt to develop a user involvement code of practice. Although Trust A's development worker post commanded some authority within the Trust, it was not a Directorate level post and hence was limited in terms of influence and power. Trust B, alternatively, had a Directorate level post that had corporate responsibility for leading and co-ordinating user involvement within the Trust. The person in this post had been largely responsible, with allied colleagues, for initiating user involvement within Trust B and had a personal interest in having users more centrally involved in the running of the Trust. Alternatively, in Trust A each of the directorates had to nominate a staff member to 'lead' on issues of user involvement and draw on the user development worker to support this.

Trust A's approach to user involvement was to invite service user representatives from the two user groups within the Trust to sit on planning and decision-making committees at 'strategic and day to day' levels in the Trust, along with other stakeholders. This Trust funded two user groups/forums to provide input:

> It is recognised that users' groups also provide a forum for mutual support for users and this is a feature that the Trust acknowledges and wishes to encourage. The Trust does not see its role as organising users' groups but is keen to facilitate their development by the provision of suitable meeting places, transport or transport costs, and the provision of tea and coffee etc. it will also supply back-up administrative facilities where necessary, and a personal resource in the form of a user development worker and a half-time administrator. A budget will be available to provide training for users in skills in committee work, skills in training and interviewing skills. A budget will also be available to pay users for time spent in consultation about Trust issues (Trust A policy, Appendix E)

The importance of involving users in staff training, staff recruitment and quality assurance and evaluation activities is also highlighted in the policy of Trust A. Trust B also had a policy of paying people to attend Trust meetings and involved users in training and staff recruitment. Support was provided to a range of user groups to enable them to participate in Trust business. Trust B policy/terms of reference state that it provides a:

> ...regular forum where user representatives and key Trust staff may discuss important service delivery issues with a view to identifying development and improvement areas (Trust B policy, Appendix F)

So, in comparison to Trust A where users were involved alongside other stakeholders in a range of committee structures, Trust B had a designated forum that discussed and debated issues raised by the representatives of six different user groups, with senior managers responsible for policy and practice within the Trust. This forum met quarterly to help oversee the different strands of the involvement/empowerment policy. As can be seen from the membership of this forum (Appendix E), the Chief Executive, Trust Chair and all the Trust directors and senior managers were members.

One further difference between the two Trusts was the different language chosen to describe user participation. Trust A used the term user involvement, whereas Trust B used the term user empowerment. Trust A policy states support of:

> ...the principal of involving service users in a meaningful way in the planning and delivery of services. The philosophy behind this approach is that in order to provide a high quality service that meets individual needs, it is vital that the views and

> perceptions of people on the receiving end of services are taken account of, valued and acted upon' (Trust A policy; Appendix E)

The Trust A policy describes the empowerment of users though their involvement in the operation of the Trust but this is viewed as a secondary outcome of involvement:

> This policy sets out ways in which users are invited to become involved in the operation of the Trust in a way that empowers them and leads to an organisational culture in which users have a central place (Appendix E)

Trust B's aims could be said to be broader:

> We aim to enable and support individual service settings to involve service users in the planning and day to day management of existing services. We also aim to support the development of a range of generic and specialist services which enable service users to make real choices in line with their own priorities (Appendix F)

Trust B's policy aim seems broader than Trust A's policy because it states that users should be enabled to make choices in line with their own priorities. In Trust B's policy the involvement and participation of users was just one element of a number of 'empowering' aims that the Trust expressed including; dignity and respect, information and choice, safety, advocacy, activities, independence and access to records. Here involvement could be viewed as being part of a wider commitment to good practice.

The user groups

In terms of the user groups involved in the study it is harder to give concrete information to differentiate them since I was unable to gather detailed comparative information, due to time and resource limitations. The information given here is therefore based on my observations of some of their activities and interviews with their members.

Trust A had two user groups: one hospital based and the other developed through a local voluntary organisation in a different geographical area. The hospital based user group was the one that I had become involved with first, and was therefore the group I got to know best. I interviewed the user development worker in the other user group to find out about some of the similarities and differences of approach between the two groups. While it is difficult to generalise when most user groups contain such a diversity of people with different aims and approaches to change, the two groups could be said to be different in the way they approached the task of involvement with the Trust. The hospital-based user group, partly due to some strong, political leadership within the group and a politically minded worker, was more willing to take a conflict approach when involved with the Trust. This conflict was often apparent in their dealings with the Trust, both in forums such as committee meetings, and in external, public campaigns used to draw attention to the conditions within the hospital. The other user group tended to use a consensus model of change, (the differences between the consensus and conflict models of change were described in Chapter two) and, in the main, kept good relations with senior Trust managers. They did get involved in legal and media campaigns but mostly these did not involve direct confrontations with Trust A's management.

I was not able to interview or observe all of the user groups that had input into Trust B's forum since there were about six different groups represented. Given the time taken to develop trust and rapport with the first user group contacted in Trust A, I was not able to replicate this level of work with any other user group. I was also aware that one of the main groups that contributed to Trust B's forum had been contacted by a post-graduate colleague in my department, and had consequently become involved in her research on mental health self help groups. Because of an awareness of the danger of over-burdening and over-researching small groups, I decided against contacting that group for these reasons, even though it would have been of benefit to my research. I therefore limited the interviews to a key member of the forum from one of the user groups represented in Trust B's strategic forum, and two interviews with users who were members of a user group that was completely independent of the Trust and uninvolved in their forum. Both of these groups considered themselves to be independent of the Trust and therefore able to provide a critical input. These groups also prioritised the self-help/mutual aid/social support aspect of the group as much as, if not more so, than being involved in mainstream service provision. Some of the members of the independent/separate group were also members of Trust A's hospital-based user group because the geographical boundaries of the two Trusts were very close together. It was, therefore, impossible to use the data to compare the Trusts in any way.

Although there was an initial idea to have an element of comparison between different organisations and their approaches to user participation this was dropped due to time and resource constraints. The potential of the research to make direct comparisons was therefore very limited due to the small sample of data collected, but some brief comments will be made throughout the findings and analysis chapters that draw attention to possible implications of the different organisational styles adopted in the two Trusts. To aid the reader in making links between the quotes from interviewees and their location in these different environments Appendix G provides information on the settings each interviewee came from: Trust A, Trust B or Other (the general category used for interviewees outside of the main two Trusts). This is included with other background information such as gender, 'race', age, and identify/occupation/profession of the interviewee.

Research sample: Selecting participants

The qualitative sampling strategy used in the study was that of 'maximum variation' (Kuzel, 1992). Sampling in most qualitative research is explicitly driven by theoretical concerns rather than the attempt to get a random or wholly representative sample. For Banister *et al.* (1994), sampling of informants should be led by the question: who will best exemplify the perspectives or range of perspectives relevant to my research question? Kuzel's (1992) view is that qualitative sampling should be driven by a desire to illuminate the questions under study, to uncover multiple realities and to increase the range of data exposed. The literature on sampling in qualitative research, points to the need to be concerned with data sources that are information-rich and people who will be a source of this rich data (see Kuzel, 1992). It recommends that as the research develops it is also pertinent to keep asking additional questions such as: which data sources confirm or challenge my emerging understandings? According to Henwood and Pidgeon (1994), contacts should then be made with informants who will provide further challenges to the emerging analyses.

The maximum variation sampling method prioritises accessing the views of the disenfranchised as well as the powerful, and seeks to document diverse variations and to identify common patterns (Crabtree and Miller, 1992). It is through this that the 'emergent nature of the within-group and between-group comparisons eventually lead to the discovery of the categories that develop grounded theory' (Crabtree and Miller, 1992). 'Maximum variation' sampling occurs in conjunction with the emerging data collection, where the emphasis is on the 'information-rich' data described above. Here the search for negative cases continues to the point of saturation. Although this description might suggest large numbers of informants, the number advocated by proponents of this design is around twenty. I also used the technique of snowballing where people interviewed were asked to recommend another person with different beliefs or positions than themselves: another mechanism that helps in the search for negative cases.

Within the sample I also wanted to ensure that people from ethnic minority groups, equal numbers of men and women, people of different ages, class and educational backgrounds were included. This was partially successful as can be seen from the tables in Appendices G and H. I collated background information from the respondents to provide a participant profile that ensured a range of views and experiences were gathered and presented in the research. This information was gathered immediately after the interviews using a self-report questionnaire (Appendix I). The interviewee's demographic details are presented in Appendix H. This demographic information was not used for analytic or comparative purposes, but purely to record the extent to which I accessed a range of respondents.

Although I deliberately tried to include some user group members who were not activists (see advert placed in user group newsletter in Appendix J), most of my interviewees agreed to be interviewed because I had met them in person and asked them if they would like to be involved. Personal connections through my co-supervisor, key informants and contacts with senior managers in the two Trusts, elicited most of the interviewees. The data, therefore, reflects the experiences of users and professionals who held relatively strong views about user involvement. Because of the exploratory nature of the research, and a concern to build conceptual links between theory and practice, this was not deemed to be problematic (Kuzel, 1992). About a third of those I interviewed I knew fairly well because of my participant observation work, another third were people I had met once or twice, and the rest were people I had never met. Because I made no attempt to conceal my involvement with the user group, some professional interviewees may have been more guarded in their interviews, however I do not think that this distorted the interviews significantly however. Indeed, all interviews will have some element of distortion due to the phenomenon of 'interviewer effects' (Breakwell, Hammond and Fife-Schaw, 1995).

In the professional sample I also attempted to gain a variety of different voices in terms of professional role, status in the organisation, level of training and awareness of user involvement issues. This was not successful, however, predominantly because of the Trust mergers and the consequent stress and anxiety felt by many staff in these organisations. In Trust B only one nurse working at ward level agreed to be interviewed. Professional's views are, therefore, biased towards those of managers rather than front-line workers. Although I deliberately tried to seek out conflicting as well as complementary accounts from professionals, I was completely dependent on those who agreed to be interviewed. The challenges of identifying professionals willing to be interviewed meant that it was not possible, unfortunately, to include staff from equivalent jobs in each Trust in any systematic way.

As shown in Table 3.1 overleaf, I interviewed nine people from Trust A; six user group members, five from one user group and the user development worker from the other user group, two professionals/managers and the hospital user groups user development worker. Of the eight people I interviewed from Trust B there were three users; one from a hospital user group (DB) and two who attended a user group outside of the hospital, four professionals/managers and one user-worker. I also interviewed seven people; user group members, user-workers and professionals, who worked or were connected to groups in other areas of the city. These interviews attempted to draw out more general insights on the processes of user participation. In total I interviewed twenty-four people between April 1998 and May 1999.

Table 3.1. Sample of participants

	PROFESSIONALS	PEOPLE IDENTIFIED AS USER/SURVIVOR WORKERS	SERVICE USERS/ SURVIVORS
TRUST A	EN SW	MG BM	MB LG PF HK RW
TRUST B	NP TB CD YT	BA	DB GC PH
OTHER	WA AC	KM JR RM SH	FN

Negotiating access and other ethical considerations

Traditionally, access to research in organisations has focused on the need to get formal permission from 'gatekeepers' such as managers or ethics committees. Many institutions or organisations are naturally wary and suspicious of outside researchers and can demonstrate resistance to researchers to varying degrees (Bryman, 1988; Punch, 1986). Although 'top-down' access is important, so too is informal access. Informal access is the acceptance of the researcher and research goals by the individuals who are to take part (Horn, 1996). After having my research accepted 'informally' by the user group in Trust A; a process that took about a year (See letter in Appendix K), I spent over six months attempting to gain 'top-down' access to Trust A in order to interview key staff members. The research did not involve in-patients of the hospital but I was informed that any research taking place within the hospital had to go through the Trust's ethics committee. However, because of the requirement that only professionals and researchers that worked in the Trust could apply to the research ethics committee to do research within that Trust, I was unable to submit my research proposal to the ethics committee for consideration. This brought the study to a stand still. Key correspondence shown in Appendix K illustrates the major problem that access became in this study. The situation was eventually resolved by advice from the Chair of the Ethics Committee to bypass the committee and go directly to the Trust Chief Executive to ask permission to interview staff. This proved to be successful and permission was granted (see letter in Appendix K) I was given permission to access staff in Trust B by a Trust director who was interested in the research.

Because my sample of respondents was reached through the ethnographic approach of 'time in the field', and through my role as activist in this area, I was able to interview the service users without going through formal gate-keepers by contacting them in their roles as activists or citizens (accessing people through community health councils and local user groups for example). Specific ethical issues concerned the information that interviewees received about the research, consent to taking part and payment. Information sheets were produced for respondents to introduce the study. Confidentiality, anonymity, payment, right to reply and dissemination were explained. The information sheet for user group members has been reproduced in Appendix L. A consent form (Appendix M) was also drafted and signed by each interviewee after the interview, once we had discussed how the data would be used, and interviewees had understood what their involvement in the research would entail. As part of the interview process, £10 was paid to thank people for their time. All these issues were raised in an application to the ethics committee in my department and advice taken on ways of ensuring the ethical nature of the research.

The preservation of anonymity has been considered carefully throughout this research. Due to the sensitive nature of the research data, the names of the respondents, Trusts and the user co-supervisor have been removed. Throughout the findings and analysis chapters I make reference to Trust A and Trust B, however, in an attempt to prevent these Trust's being identified, I do not always make it clear which Trust I am referring to. All interview quotes are given initials so that each interviewee's background characteristics can be viewed using the demographic charts in Appendix H. These initials are not the initials of the people interviewed but have been randomly assigned.

Approach to Analysis and Theory Construction

The interview guide was based on the themes generated from the agenda-setting work done in Phase one and can be seen in Appendix N. The interviews took between one and two hours and were recorded and transcribed in full to guard against the danger of prematurely discarding material of potential relevance. Two copies of the transcripts were sent back to interviewees, one for them to keep and the other for them to check, amend any misunderstandings and send back to me. Field notes were written up after interviews that summarised the information gathered, in order to glean surprises, negative cases, new information, new ways of approaching the issues, relationship dynamics and the relevance of the interview to key themes. These notes were structured using the following three criteria adapted from Bogdewic (1992):

- a subjective description of the events of the interview, of the setting, mood, degree of rapport established etc;
- list of keywords that emerge in the interview; and
- appropriateness of the questions asked and revisions if necessary.

In terms of the relationship between concept development and data collection, I required a method that allowed for constant discovery and ensured a recursive and reflexive movement between concept development and data sampling, collection, coding, analysis and interpretation. I therefore used Reason and Rowan's (1981) methodological framework consisting of the systematic use of multiple cycles and feedback loops, where issues emerge through the movement from field to theory building and back again. This iterative process ensures a constant recursive movement between concept development and data collection, coding, analysis and interpretation. In this model, analysis runs alongside interviews to allow the emerging data to inform the data gathering by constantly refining the questions; something many researchers recommend (Crabtree and Miller, 1992).

According to Melia (1997), analysing interviews presents a critical methodological challenge: are the data to be regarded as straight accounts of interviewee experiences or are they to be considered stories about those experiences told as a self-presentation exercise by the interviewee? Again the status of the data is called into question. Can the interviews be used, as in grounded theory, as a way of communicating the view of the informant and then placing this within a more general second-order framework? As stated earlier in the chapter, the interviewee responses and documents were examined, in the main, for the way they constructed the reality being investigated, rather than as 'true reality' reports. However, I needed to balance this with my concern to take much of what user participants said as 'real', because of the tradition of not taking their accounts seriously. I therefore approached the data set with two main goals:

1. Firstly, to identify emergent themes and issues using a template analytic technique.This approach views the interview data as 'straight' accounts and is well suited to the use of computer support to facilitate data management and coding. The software programme Nudist Vivo (NVivo) 1.2 was used for this purpose.

2. Secondly, to use relevant theory to further illuminate the dynamics of user participation in mental health services. This stage aimed to explain the complexity of user participation using existing models and theories of power and participation, and viewed interview accounts as constructing rather than reflecting reality.

These two goals/approaches are now discussed in detail.

1. A Grounded Theory Approach – Coding, template analysis, memoing and propositions

The first aim of data analysis using a grounded theory approach was to interrogate the data in a rigorous and systematic way, testing for negative cases and unverifiable conclusions in order to produce findings and conclusions that were accessible and transparent to the reader and that 'fitted' well with the data. Qualitative analysis can be described as involving 'ladders of abstraction', where data moves through a series of analytic episodes that condenses it into a more and more coherent understanding of what, how and why (Miles and Huberman, 1994). The data is transformed as it is worked and reworked over time using methods such as coding, identifying themes and trends, testing 'hunches' and ideas in order to build theory or 'explanatory frameworks'. Throughout the active interviewing attention was paid to 'meaning construction' through a focus on how the research data was constructed throughout the interview process (Holstein and Gubrium, 1997). Reflexive work on my role as interviewer, through an analysis of the fieldnotes for example, became vitally important.

A grounded theory approach was used on all the three main research question groups listed in Part two of this chapter. I used coding as a way of segmenting the data to see what emerged as significant. Coding has three primary purposes according to Crabtree and Millar (1992). First, to identify 'chunks' of text to facilitate future data retrieval and analysis. Second, to identify key data areas. And third, to generate initial hypotheses. Analysis using a template orcode-book has been described as a template analytic approach (Crabtree and Miller, 1992). Like coding itself, it is a means of organising text for subsequent interpretation. In these approaches the template is open-ended and undergoes revision after encountering the text, where the generation of themes, patterns and interrelationships is an interpretative process. The template can either be developed prior to data collection (a priori, based on the research question or theoretical considerations from a literature review) or created after collection of data has begun though detailed readings of the texts. Although I developed my code-book using themes that emerged during the first phase of the project I continued to amend it throughout the data collection phase. The coding framework/template I used was also informed by Lofland (1971, cited in Miles and Huberman, 1994), who proposed dividing codes into the following categories:

- Acts
- Activities
- Meanings
- Participation
- Relationships
- Settings

The template I devised at the start of detailed coding is set out below:

- Setting/Context/Background information
- Practices, Acts and Activities
- Definitions of user involvement
- Ways of talking about involvement and power
- Motives for involvement
- Methods of involvement
- Conditions for involvement
- Meanings of involvement
- Strategies and tactics used
- Relationships/interactions between key players
- Personal responses to power changes
- Conflict
- Different agendas
- Representation
- Training/academic/professional issues
- Barriers/limits to involvement
- Consequences of involvement and power sharing
- Social inequalities: gender, race and class issues.

These categories contained descriptive, interpretative and pattern codes. Once the template had been devised it was applied to the interviews with the aim of identifying meaningful units. The template was modified in relation to the challenges it received from the texts. Once the template had been modified and revised in relation to the data and no new revisions were required, the analysis proceeded to the interpretative phase where the units were connected into an explanatory framework consistent with the texts (Crabtree and Miller, 1992).

When I was coding I also used the convention of member identified categories (Riley, 1990). This is the practice of finding a phrase that categorises the people/group/situation being studied. Searching for language that is evocative of the subject is a useful way to build themes. Some of the codes that were named in this way were:

"the emperor's new clothes"
"scratching each other's backs"
"jumping before you're pushed"
"icing on the cake"
"too much like hard work"
"it's about ticking the box"
"the same old faces"
"feathers and thorns"

The use of member identified categories can powerfully illuminate the subject area on their own, with the need for minimal researcher commentary.

Once the data were coded using the template, they were summarised in order to determine which themes were recurrent. Pattern codes pull together large amounts of material into more meaningful units of analysis or 'meta-codes'. Pattern coding is a way of building on the first level coding described above, by grouping the coded segments into more cohesive, integrated and coherent sets for understanding the data. Pattern codes usually consist of four main summarisers, according to Miles and Huberman (1994); themes, causes/explanations, relationships between people, and more theoretical constructs. I constructed pattern codes after coding about a quarter of the interviews. Because pattern codes often begin with 'hunches', I then sought to substantiate these by comparing them with coding from subsequent interview data. Most of my pattern codes fitted with the emerging data and some were qualified and further substantiated.

I used the practice of memoing to aid the development of ideas and hunches about the data as it was worked with; through coding, patterning and clustering. Glaser (1978) describes a memo as:

> ...the theorising write-up of ideas about codes and their relationships as they strike the analyst while coding.... It can be a sentence, a paragraph or a few pages... it exhausts the analyst's momentary ideation based on data with perhaps a little conceptual elaboration (cited in Miles and Huberman, 1994: 83-84).

Memoing has also been described as annotating the record (Riley, 1990). The writing of memos can generate mini-theories that pose explanations and aim to reflect on the data using related theories that may illuminate the findings. They report the analyst's growing conceptual links between data and theory. I used memos to note reflections on interviews from field notes that I felt were particularly relevant, surprises in the data, theoretical links and to remind myself to follow up what initially may just have been a flicker of an idea. I found that writing memos was one of the most creative and enjoyable aspects of the research process.

In the latter stages of analysis I used the technique of developing propositions (Miles and Huberman, 1994). This takes the emerging thoughts and ideas on the data, that memos describe, into a more formalised phase where what were unrelated notes become synthesised into statements about the data. I used propositions to systematise my thinking into a more coherent and integrated set of explanations for what I believed to be going on in the data.

2. Theory building using existing models and theories of power and participation

It is my belief that although qualitative research should be largely concerned with data-driven methods in an explorative study such as this, it is insufficient for most studies to stop once this stage has been completed. Within a template analytic approach, the analysis is complete once the interpretative phase, in which the meaningful units from the coding are connected into an explanatory framework, is completed. It is these final connections that form the reported outcomes (Crabtree and Miller, 1992). In my study I wished to take these connections further, while still in the analysis phase, and, as is common in qualitative research, I looked to broader theoretical frameworks to make sense of the emerging interpretation. It is my view that for new understandings to be generated, research findings need to be situated within their broader empirical and theoretical context in order to estimate their relationship with work done previously and therefore, ultimately, to assess the contribution to new knowledge.

After using a grounded theory approach to analyse the whole data set and locate the main themes and sub-themes that respondents addressed in the interviews, I then used analytic tools such as theories of power (Bachrach and Baratz, 1960; Lukes 1974), and models of participation (Arnstein, 1969; Cornwall, 2000; White, 1996), to further interrogate the data. The rationale for this was to see whether the social relations of participation in mental health services, in the settings researched, could be explained more fully by drawing on insights from wider social theory. As stated earlier when describing the research paradigm and the construction of the research questions, both grounded theory and constructionist approaches were utilised throughout the research. Constructionist methods, using theories of power and discourse were used particularly in the second set of questions on mapping the dynamics of power in participation. This stage of the analysis occurred after the first stage was fully completed and the data had been coded and categorised using the grounded theory approach described above. It involved returning to the literature and relating the themes that emerged in the first data-driven phase, to both the theoretical literature on power and participation, and the empirical literature on participation in practice. It was at this stage that different models and theories of power and participation were drawn upon for the purpose of making sense of the findings in terms of broader frameworks of social theory. After working to find links and broader relevance between my research findings and wider theory I then wrote up the findings and analysis, continuing to make further links between theory and data. The writing itself was viewed as an analytic process (Richardson, 1998).

Comments on Generalizability and Validity

Silverman (2000) proposes four different answers to the question of obtaining generalizability within qualitative research studies:

- Combining qualitative research with quantitative measures of populations;
- Purposive sampling guided by time and resources;
- Theoretical sampling; and
- Using an analytical model which assumes that generalizability is present in the existence of any case (234).

I used purposive and theoretical sampling methods. I also used the constant comparison method which assumes that generalizability is present in any case, provided the data analysis has been thorough and complete. I shall, therefore, be claiming that my findings are generalizable to similar settings to the ones this study was concerned with; user participation within statutory mental health services in the NHS. I shall not be proposing that the findings reported here will necessarily be able to be generalized outside of the types of settings I studied because my sample was not large or varied enough to make such claims of the data.

Finally, I wish to say something very briefly about the way validity was managed in the study. Despite different interpretations of validity, depending on the methodological approach taken, I interpreted validity as meaning the attempt to ensure accurate stories, rather than 'true' accounts and to try to use a variety of conceptual frameworks in the analysis to avoid conceptual closure. Throughout the research I searched for negative cases in the data that could have contradicted my emerging findings using the research diary and field notes for this purpose. Triangulation of different data gathering methods, such as situational analysis in Phase one and active interviewing in Phase two, and the practice of interviewing a wide range of informants, was also useful for confirming the validity of the findings. Returning the transcripts to the respondents for checking was another strategy used to ensure validity of the stories produced.

Reflexivity is one of the most well known ways of subjecting qualitative inquiry to validity checking. It involves making explicit the process by which the research knowledge is produced and the understandings that are formed, and involves acknowledging and incorporating the influences that impact on our research (King, 1996). Reflexivity was used throughout the study, through the use of a research diary, through 'memoing' on the research process, and through the use of my supervisor and user co-supervisor to check out the emerging ideas and concepts from the data.

Concluding Comments

> The link between what a researcher does and the philosophical position set out to justify the method is often problematic (Melia, 1997: 29).

This chapter has described some of the thorny issues that dog many qualitative research projects. It has sought to make the process of this research transparent: a process necessary for any piece of research. I have placed the study within wider epistemological and philosophical debates and illustrated my rationale for drawing on a number of different research paradigms and frameworks, in order to illuminate my research questions. From my review of the methodological literature there seems to be a tendency to treat methods as belief systems and to attempt to find one that has all the answers and then adopt it uncritically. In some respects the subject of method has become so conceptually complex and laborious that novice researchers like myself can become completely paralysed by the range of options available. So although there are many interesting facets to the epistemological debates, I agree withMelia (1997) when she suggests that as the debates on methods have become more philosophical, they have become less useful for the doing of research. She recommends that a pragmatic approach can be most helpful when negotiating a way through the methodological quagmire. Although the philosophical traditions are important to consider, when choosing which methods to adopt for a study, Melia warns against becoming so preoccupied with them that any form of research can be vetoed on some ground or other:

> Whatever high-flown rhetoric is adopted about uncovered meanings and understandings of discourse and narratives, what is required for a discussion of empirical work is some means of translating data from the field – interviews, observations, documents – into an explanation of the topic in hand which can be conveyed to others and understood by others ... If we can collect data with which to tell a plausible story, perhaps we should settle for that (Melia, 1997: 35).

The multi-dimensional approach, that became the research strategy used in this study, attempted to do just this: to collect data to tell a plausible story, while displaying an awareness of countering theories and arguments that draw attention to the limits of telling such a story. Although this approach proved complex, particularly during the analysis phase of the research, I believe it was immensely valuable in comparison to more conceptually straightforward approaches. I shall leave more detailed comments about the strengths and weaknesses of the research design to the discussion chapter at the end of the thesis.

Chapter Four

The Current Policy and Practice Environment of User Participation

This chapter is the first of three chapters that present the findings of this study. Involving mental health service users in all aspects of service delivery, planning, commissioning and evaluating, has been proposed as a solution to the problems in mental health services, described in Chapters one and two. Within the consumer model, user participation is a strategy to effect change. These findings chapters explore whether user participation can indeed be a strategy for effectively addressing the power inequalities that exist in mental health services, and the impact it has had on user experience to date. In particular, these chapters interrogate the research data in relation to my central thesis; that participation will not succeed as a strategy to improve services, or change relationships between service users and service providers, if it is disengaged from an understanding of power and its effects. This particular chapter is concerned with the first of the three groups of research questions: *to describe the current policy and practice environment of user participation in the contexts studied.* The sub-questions in this section are focused around describing the meanings, motives, conditions, incentives and obstacles that surround collaborative activities occurring between users and professionals/managers in the context studied:

- What is the nature and extent of user involvement in mental health services in the context studied? (Addressed in Part one of the chapter)
- What meaning does user involvement have for different actors/stakeholders? How is it defined by professionals and service users? To what extent can the meanings of involvement for professionals, managers and service users be considered shared? (Part two)
- What are the motives for involving service users as individuals in their treatment and collectively in the delivery of mental health services? (Part three)
- What conditions support user involvement practices? (Part four)
- What rewards, incentives and opportunities does user involvement present to the individuals involved? (Part five)
- What are the barriers or obstacles to changing power relations between users and professionals in mental health services? (Part six)

Part One: The Nature and Extent of User Participation

I have chosen to introduce the findings in this chapter with the words of the respondents because I believe their views best represent why change is necessary in UK mental health services. The first three quotes are from service users and describe their experiences of disempowerment, lack of rights, abuse and inequality in statutory mental health services. They illustrate the vulnerability and distress that users have to endure when they are most in need of help and support. The final quote is from a senior psychiatrist, who acknowledges the extent of the problems faced if mental health services are to change, and become more than simply a mechanism for containment and surveillance.

> *The hospital has always said they don't know what's wrong with me so I say "well leave me alone and let me do my own thing" and they let me do that to an extent. But in 1995 I was assaulted. I woke up because at night I don't sleep when I'm in hospital so I lay there for a while and then I thought this is hopeless, I'll just get up and watch a bit of telly. So I got up and someone shouted at me "What are you doing out of bed?" And I said "I can't sleep" and they said "well go back to bed, I'll give you some medication" and I said "no, it's hopeless I won't get to sleep, I've been lying there for hours not being able to sleep". Well they all dropped down on me and had me on the floor and the pain was going down my arms and up my back and everywhere. I don't know what they were doing with me the pain was excruciating. Then they marched me back to the bedroom and threw me on the bed and left me alone and I said "why do you do these things. I'm not violent, I'm not going to do anything out of order so why do you need to hold me down?" They just wanted a bit of power. It was crazy I just can't understand things like that. I reported it and the first time I reported it I thought that something would be done but to this day nothing has been done and I've had excruciating pain in my back... utter agony for months and months... I couldn't even get out of bed some mornings. I saw a solicitor and he was going through with it and then I saw this other woman who was in charge of the nurses and she took complaints about nurses and I was asked by her to take it away from the solicitor and they would deal with it and I didn't know if that was a good thing or not. They said they would deal with it but nothing gets done and they know it. They say there's something wrong with me and I must admit I do get high from time to time but it's nothing out of the ordinary, I've always been that way and it doesn't cause me no problems. It's natural for me but they don't like it.* MB

> *The fact that you have to talk about empowerment is the worrying thing, because the only reason people need to be empowered is because something has been done*

> *to them by services to dis-empower them in the first place... So yes I think a lot of it is just repairing the damage that has been done.* DB

> *There is a great deal of inequality in the psychiatric system. I had a baby in the general hospital in my Borough and then 16 months later I entered the psychiatric system and it was like stepping into a different universe. In terms of the power relationships I think that you have no rights really especially when you're on section and as a woman you are extremely vulnerable whatever your diagnosis is whether you are high or whether you are low, I think that the system will inevitably abuse you... the reality of being on a ward is really not understood by the public as a whole. I couldn't believe there were men on that ward when I got there. I could not believe it.* PF

> *My dilemma is that you don't feel that it's fair or safe to leave people in the community because they are exposed to a lot of distress and they are having great difficulty holding their lives together and yet when you admit them to hospital for something that ought to be therapeutic asylum in the best sense, problems ought to be resolved, finances ought to be sorted out, suitable accommodation ought to be found, people ought to talk to them and hear their distress, medication should be reviewed and more helpful medication given... All those things that one would hope for from an admission sadly in this busy, chaotic, under-resourced in-patient environment where people come in and out too rapidly, just don't happen.* EN

These comments are not unexpected, in view of the literature outlined in Chapters one and two on user experiences and professional critiques (Campbell, 1990; Copperman and McNamara, 1999; Rogers, Pilgrim and Lacey, 1993; Williams *et al.*, 1993). Profoundly negative experiences especially of Black service users and women, remain a feature of conversations about using the mental health system in the UK.

Respondents' views on user participation in practice were exposed in one of the first questions I asked service users: 'Were you involved in your treatment?' Few felt they had been involved, even people who were happy with the way they had been treated:

> *No, no. Not when I was in the psychiatric hospital, definitely not.* PF

A user-worker whose role was visiting wards and giving people information and support said:

> *When I talk to people on the wards, I'm for ever saying to them, "you are entitled to information about your care, about your treatment, about your medication" and yet so many people still have the same old complaints, "oh well I don't even know what my medication's called", or "I wasn't told about the side effects", or "I wasn't given any choice".* KM

On the issue of knowing your rights in hospital this service user commented:

> *They don't tell you your rights you know. They don't like give you anything that would empower you in any way, not usually.* LG

And a user-worker commented similarly:

> *Whether people are happy or not seems to depend on how well they feel they get on with their key worker but in terms of actually being informed about CPA and their rights to be involved, that hasn't really changed or for some people it has but its very, very patchy.* KM

The last two comments draw attention to the fact that practice varies. In some places users are told their rights, are involved and given information; in other places they are not. In terms of staff, the majority insisted that user involvement, at least in hospital services, was more rhetoric than reality, as remarked by this ward nurse:

> *It's definitely not going on in the wards no. We were trained to put patients first and help them to help themselves but it doesn't really happen like that. You sort of do everything for them and they don't really have much say in anything.* CD

And a senior manager responded similarly:

> *There's inevitably quite a gulf between the experience of being on the wards or in the services and the public face of an organisation. There's an aspiration that users will be involved in things like service planning but as far as I'm aware that doesn't really happen.* TB

The responsiveness of Trusts to complaints from their users, was a subject of consternation in one Trust:

> *Another complaint we had... this is a classic. The night-dresses that are supplied by the hospital are split up the back like operation gowns because they're in the NHS pool so they're just NHS night dresses. A user took it on and there was a big campaign to try to get it altered and we tried all sorts of things and didn't get anywhere, tried for about a year, and then went through formal complaints process. We waited three, four weeks and got a letter back from the hospital administrator saying she would look for a new supplier and in the meantime get all the current night dresses sewn up the back. This was a few months ago, we've got the letter on file. Now this particular user has just been admitted again and she said the night-dresses are just the same. There's absolutely no difference. So although she had a resolution letter promising change nothing has happened. There's a resolution on paper, no resolution in practice. So she's taken her night-dress back to wash and she's going to parcel it up and send it to the hospital administrator!* MG

One senior nurse gave her opinion as to why user participation was not happening in the wards of her Trust:

> *The problem for direct care staff is that there is a lot of things going on in the background you know stuff like user empowerment policies that they don't know about. All they know is "I'm at the coal face", "I'm under pressure all the time" and they don't feel heard or listened to. So if you've never been heard or listened to, are you going to really hear or listen to other people? There's a lot of talk about the nurses being in the office all the time but it's not surprising when you see the situation that they're under... its just grind, grind, grind every day. And the organisation is saying we want this and we want that.* YT

The quote below is taken from an interview with a ward nurse in the same Trust. It epitomises the stressful circumstances created by the gap between the practice that is expected by managers and policy makers, and the practice delivered in reality. She was asked; "Have you been influenced by the Trusts' policies on user involvement from management?" and replied:

> *What have they said? I'm not sure that I've definitely seen it. No... no way. I don't know about other wards but it doesn't happen here. We write care plans and we don't even tell patients what's in them. Sometimes we do... sometimes they have contracts and we are supposed to plan a contract with the patient but most times you don't. It's like a pro-forma contract "you will not barge in the office, you will knock and wait, you will not keep asking several nurses to meet your needs", "work with your key worker". It's all quite regimental. The care plans are quite basic they just talk about risk assessment and safe environment, assessing the patient and stuff like that but they are not involved, they've got no say really. I can't see how they are an integral part of the care team. ... They would really have to come from whatever desk they're sitting behind and show us how we are supposed to implement that because it doesn't work. Most patients, you might write a contract for them and they'll just rip it up and just throw it at you. So how are you supposed to write a care plan with them? Most patients just don't care 'cause they know the system, they'd write such ridiculous stuff that it would be totally unfeasible. What we are trying to do here is standard care so no one gets special treatment or anything.* CD

This nurse is clear that in her working environment, involving patients or users in their treatment is not everyday practice. Practice on this ward was described as "*regimental*", preoccupied with risk assessment and providing only "*standard*" levels of care. The ward described was an intensive care/secure unit within an acute service, so these features may have been exaggerated compared to a less secure environment. However service users in this research described similar experiences in wards not categorised as secure, so the level of user involvement described previously may not be unique to secure environments. This nurse (CD) attributes the push for user involvement to managers disinterested in making it happen in practice:

> *Of course with the political agenda... they've got to say that they've got user involvement because they're supposed to aren't they. They can say, "well we've written a policy and it's up to you nurses if you don't implement it, that's your own lookout". It's about what the management needs but it's no good if the nurses don't use it. I think the people who write the policies should be aware this is what happens. Why don't they try and write something that we can work with? We do what we've got to do and if they're not making sure their policies are implemented or making sure they are even feasible why should we?* CD

Summary

These commentaries begin to paint a picture of services in statutory, institutional mental health settings, as not having progressed recognisably in terms of service user consultation or involvement. Although practice obviously varies, respondents expressed the view that user participation was more rhetoric than reality. The interviews did not reveal any views that disagreed with these findings: even people who felt they had received good treatment within services still reported that they had not been involved in their care or treatment. What I shall be describing throughout the findings chapters as the 'top-down' approach to involvement; where managers issued codes of conduct or involvement policies, was not viewed favourably by ward staff, who felt incredibly burdened and pressured by demands made on them. Political expediency was blamed for this lack of connection between policy and practice. A number of staff identified that the managerial preoccupation with issuing policies, with little attention paid to how staff were going to operationalise these polices in under-resourced, poorly-staffed wards, was not helpful to them in improving standards of practice. Standardised, regimented practice was noted to be particularly resistant to top-down policies if managers were seen to be out of touch with the day to day reality on the wards.

Part Two: Meanings of User Participation

This next section presents respondents' experiences of the meaning and significance of user participation; setting the scene for later sections concerned with a critique of practice, of meaning and of intention. The data has been ordered into a display (Table 4.1 Pages 120-123), describing responses from the three main sets of respondents: service users/survivors, user-workers and professionals. Although there are limitations and potential problems with these groupings, there are also benefits in terms of identifying separate interests or associations. This thesis is concerned with power and power inequalities, so for this analysis it was important to see speakers as members of particular groups. The use of data displays, as mechanisms to aid the process of contrasting, comparing and summarising a large amount of information, is a qualitative analytic technique advocated by Miles and Huberman (1994). The displays include all the responses elicited from the interviews, unless there were two or more similar points then only one is included. No negative cases have been omitted.

Table 4.1. Meanings of User Involvement

GROUP	MEANINGS OF USER INVOLVEMENT	COMMENTARY ON USER INVOLVEMENT AS A VEHICLE FOR CHANGE
USERS	‘PEOPLE WHO HAVE HAD MENTAL PROBLEMS RUNNING THEIR OWN AFFAIRS OR HAVING A SAY IN RUNNING THEIR OWN AFFAIRS’ ‘A TRENDY WORD’ ‘APPEASEMENT’ ‘GETTING A SAY IN POLICY DECISIONS’ ‘BEING TALKED TO’ ‘LIKE A SUPPORT SYSTEM, SUPPORTS PEOPLE ON A PERSONAL BASIS’ ‘SHARED EXPERIENCES’ ‘USER PARTICIPATION, USER INVOLVEMENT, CALL IT WHAT YOU LIKE, AS LONG AS PEOPLE WHO ARE USING THE SERVICES ARE ACTUALLY THERE TO SAY HOW THEY’RE WORKING’ ‘BEING DUPED’ ‘EVEN THE TERM USER INVOLVEMENT, IT’S LIKE WE’LL GET USERS INVOLVED IN WHAT’S ALREADY GOING ON’ ‘BEING NAIVE’ ‘SUCKED INTO MEETINGS’ ‘OUR USER GROUP RESPONDS TO TWO DIFFERENT THINGS, THE NEED OF THE USERS TO HAVE REPRESENTATION, ACTIVITY AND INPUT IN THE RUNNING OF THE HOSPITAL AND THE NEED OF THE TRUST TO HAVE THE USERS INVOLVED’ ‘THE SAME OLD FACES’ ‘RHETORIC’ ‘WHERE PROFESSIONALS DON'T JUST HAVE A HEAVY HANDED APPROACH WITH THEIR TREATMENT THINKING THAT THEY KNOW BEST BUT THEY TRY AND WORK HAND IN HAND WITH THE PATIENT AND TRY AND EMPOWER THEM, INSTEAD OF JUST GIVING THEM WHAT THEY THINK THEY SHOULD NEED, LIKE TRYING TO WORK OUT WHERE THAT PERSON'S COMING FROM, WHAT'S MORE SUITABLE AND TRY TO HELP EMPOWER THEM SO THAT THEY KNOW HOW TO DO THINGS FOR THEMSELVES’ ‘FEATHER IN THEIR CAP - THORN IN THEIR SIDE’ ‘JUST TALKING, TALKING, TALKING’ ‘...WE DO GET THE IMPRESSION THAT WE’RE LISTENED TO QUITE CLOSELY’ ‘TO MAKE THE HOSPITAL LOOK GOOD’	‘THEY WOULD BE HARD PRESSED TO DO SOMETHING WITHOUT HAVING ANY USERS INVOLVED AND THERE WOULD BE A FUSS AND MOST PEOPLE WOULD TAKE NOTICE OF THAT FUSS’ ‘THERE IS A CERTAIN NUMBER OF PEOPLE I WOULD TRUST BECAUSE OF OUR SHARED EXERIENCES’ ‘THE WARD MANAGER IS MOST EAGER TO ANYTHING I SUGGEST TO HIM... HE'LL SAY OK, IT'S NEVER TOO MUCH TROUBLE AND HE'LL GET ON WITH IT SO IT'S VERY, VERY GOOD AND I FEEL LIKE THERE IS INPUT AS I CAN SEE LOTS OF DIFFERENT CHANGES ON THE WARD. I FEEL USED APPROPRIATELY AND CONSULTED’ ‘USER INVOLVEMENT IS NOT WORKING SATISFACTORILY AT ANY LEVEL’ ‘I THINK IT'S BEST TO BE CAUTIOUS’ ‘USER INVOLVEMENT IS GOOD BUT IT’S NOT SOMETHING THAT CAN HAPPEN OVERNIGHT. A LOT OF PLACES HAVE TRIED TO DO IT LIKE THAT, DRAWN UP POLICIES SAYING SOME USERS HERE, SOME USERS THERE AND GETTING US COMPLETELY INVOLVED BUT TO WHAT ENDS? TO WHAT PURPOSE? WE’RE NOT BEING LISTENED TO! WE SIT ON INTERVIEW PANELS WHEN IT’S ALL SET UP WHO GETS THE JOB. IT’S A RIDICULOUS WASTE OF OUR TIME, THEY’RE NOT INTERESTED IN WHAT WE’VE GOT TO SAY’ ‘THEY HAVEN’T CHANGED THEIR COMMITTEES ONE BIT. YOU’LL BE LUCKY TO GET A SEAT SOMETIMES. THINGS ARE AS THEY WERE. IT’S JUST TO APPEASE THE USERS THAT’S ALL, THEY ARE NOT GOING TO DISCUSS ANY NEW PROTOCOL OR ANYTHING THAT CHANGES THE WAY THEY TALK OR THE WAY THEY BEHAVE. WE’RE JUST A COUPLE OF EXTRA BODIES YOU KNOW, WHO COME FROM A VERY DIFFERENT PLACE TO THEM’ ‘IT CAN BE A MANIPULATION OF THE USERS FOR THE PURPOSES OF APPEARANCE. A FAÇADE THING, PUBLICITY FOR THEM. SO THE MANIPULATION AT THE MOMENT IS MORE IMPORTANT FOR THE HOSPITAL THAN THE USERS. I THINK THE WEIGHT AT THE MOMENT IS... THE MANIPULATION BY THE TRUST... OF THE USERS’ ‘WE SHOULD BE CONCENTRATING ON CAMPAIGNS AND FIGHTING FOR CHANGES IN MEDICATION AND THE RUNNING OF THE WARDS. I MEAN ARE WE JUST HERE TO BE MANIPULATED BY THE SYSTEM? BECAUSE THAT IS THE DANGER’ ‘THERE’S GOT TO BE A MEETING OF MINDS FOR INVOLVEMENT TO WORK AND I CAN’T SEE A MEETING OF MINDS HAPPENING FROM THE AGENCY/AUTHORITY END OF THINGS’

GROUP	MEANINGS OF USER INVOLVEMENT	COMMENTARY ON USER INVOLVEMENT AS A VEHICLE FOR CHANGE
USER-WORKERS	'WHETHER OR NOT IT'S A MEANINGFUL TERM...IT'S A VERY HARD TERM TO DEFINE AND PIN DOWN' 'THEY ARE ALL BUZZ WORDS, THEY ARE A BIT OF A CHIMERA, I WANT TO BE AWKWARD ABOUT IT' 'EQUALITY OF THE PARTNERSHIP OF THE INDIVIDUAL AT THE LEVEL OF THEIR OWN TREATMENT, ABOUT HOW MUCH THAT PERSON CAN INFLUENCE' 'IT'S SOMETHING ABOUT SITTING IN A ROUND WITH PEOPLE AS FELLOW HUMAN BEINGS LOOKING AT PROBLEMS AND SOLUTIONS TOGETHER' 'GIVING PEOPLE REAL CHOICES ABOUT MEANINGFUL THINGS IN THEIR LIVES' 'PARTICIPATING IN THE WHOLE PROCESS OF OFFERING CARE IN ALL IT'S FORMS, INDIVIDUALS ABLE TO SAY WHAT THEIR NEEDS ARE AND WHAT THE MOST APPROPRIATE SUPPORT AND CARE IS' 'PARTICIPATION IN DECISION-MAKING PROCESSES SO THAT THE KIND OF SERVICES AVAILABLE REALLY DO REFLECT WHAT LOCAL USERS WANT TO MEET THEIR NEEDS' 'IT'S CHANGED IT'S MEANING FOR ME OVER THE YEARS... IN THE EARLY PHASES THERE WAS GREAT HOPES AND EXCITEMENT ABOUT WHAT IT COULD MEAN, COULD USERS HAVE A REAL INPUT, MAKE A DIFFERENCE, BE TAKEN SERIOUSLY? BUT IT WASN'T GIVEN THE CHANCE TO MEAN MUCH IN PRACTICE' 'EMPOWERING PEOPLE TO BE ACTIVE PARTNERS' 'TAKING PART IN TRUST DECISION-MAKING,THOUGH I THINK THE TRUST WOULD SEE IT AS USERS BEING CONSULTED ABOUT VARIOUS ISSUES AND THEN THE TRUST EITHER TAKING IT INTO ACCOUNT OR NOT' 'A CERTAIN AMOUNT OF LIP-SERVICE' 'IT DEPENDS ON HOW PROFESSIONALS DEFINE USER INVOLVEMENT. I DON'T THINK IT'S THE PROFESSIONAL'S ROLE TO DEFINE IT, THAT CONTRADICTS WHAT USER INVOLVEMENT IS. USER INVOLVEMENT IS WHAT USERS WANT TO DO AND WHAT USER'S GOALS, AIMS, COMMITMENT AND ENERGY ARE' 'THE LOGICAL CONCLUSION OF INVOLVEMENT IS USER AND SURVIVOR LED SERVICES'	'IT'S THE EXTENT OF IT THAT CONCERNS ME REALLY' 'WE'VE GOT AN EXCELLENT RELATIONSHIP WITH SOCIAL SERVICES. BUT THE HEALTH AUTHORITY WERE SLIGHTLY MORE RETICENT' 'I DON'T THINK IT'S VERY MEANINGFUL WHEN IT COMES OUT OF PROFESSIONAL'S MOUTHS AS IT TENDS TO BE USED TO MANIPULATE THE AGENDA IN THE DIRECTION THEY WANT IT TO GO IN' 'THERE IS A LOT OF WINDOW DRESSING AND TOKENISM, IT'S VERY, VERY FRUSTRATING' 'YES IT'S MEANINGFUL BUT WITH RESERVATIONS' 'IT'S AMAZING HOW QUICKLY IT'S EMBEDDED INTO MANAGEMENT SPEAK AND JARGON' 'IT BECAME VERY CLEAR THAT FOR SERVICE PROVIDERS, PEOPLE WITH POWER WHO MAKE DECISIONS AND HAVE CONTROL OF BUDGETS, USER INVOLVEMENT IS FINE AS FAR AS IT GOES, AS LONG AS IT DOESN'T CHANGE THINGS. ONCE IT STARTS TO CHANGE THINGS WE DON'T WANT TO KNOW. WE DON'T WANT THE STATUS QUO TO CHANGE WE JUST WANT TO SAY "WE'RE DOING USER INVOLVEMENT"' 'THERE ARE USERS ON HIGH POWERED COMMITTEES BUT WHETHER THEY FEEL EMPOWERED THAT THEY CAN MAKE A DIFFERENCE AND DON'T FEEL TOO INTIMIDATED IS HARD TO SAY' 'AT LEAST PEOPLE ARE TALKING ABOUT USERS AND USER-LED SERVICES AND MEANING IT NOW... IT'S SEEN AS A POSSIBLE GOAL' 'THERE'S A GROWING EMPHASIS ON IT NOT BY VIRTUE OF IT BEING THE RIGHT OR ETHICAL THING TO DO BUT BECAUSE IT'S NOT PRACTICAL TO AVOID IT ANYMORE' 'A HUGE AMOUNT OF INVOLVEMENT IS VERY MUCH THE AGENDA OF THE PEOPLE WHO ARE PLANNING SERVICES, ASSERTIVE OUTREACH, OPERATIONAL POLICIES ON LOCKED WARDS. YOU CAN GET INUNDATED WITH THIS STUFF AND WHETHER ONE EFFECTS IT RADICALLY IS VERY DOUBTFUL' 'IT SEEMS TO BE VERY EASY TO MARGINALISE A USER AT A PROFESSIONAL MEETING & PEOPLE ARE LEFT WONDERING WHY THEY ARE THERE' 'USER INVOLVEMENT IN PRACTICE IS JUST WHAT PROFESSIONALS WANT IT TO MEAN. PARTICULARLY IN PATIENT'S COUNCILS. THEY JUMP UP AND DOWN TILL THEY'RE BLUE IN THE FACE BUT IF THE SERVICE MANAGERS DON'T WANT TO CHANGE, IT WON'T CHANGE' 'A LOT ON PAPER... I OFTEN FEEL LIKE THE LITTLE BOY IN THE EMPEROR'S NEW CLOTHES STORY... WELL WHERE IS IT?'

GROUP	MEANINGS OF USER INVOLVEMENT	COMMENTARY ON USER INVOLVEMENT AS A VEHICLE FOR CHANGE
PROFESSIONALS	'IT'S ABOUT PEOPLE WHO USE SERVICES RUNNING SERVICES OR HAVING A PROPER SAY IN THE RUNNING OF THOSE SERVICES IF THAT'S WHAT THEY WANT... MANY USERS JUST WANT US TO GET ON AND DO IT' (VOL.SECTOR[4]) 'USERS OF THAT PARTICULAR SERVICE AT THAT MOMENT INVOLVED IN MAKING DECISIONS LIKE SETTING QUALITY STANDARDS OR DECIDING WHAT KIND OF PEOPLE TO EMPLOY, OR MORE MINOR DECISIONS LIKE THE COLOUR OF THE WALLS AND WHAT FOOD TO HAVE. BUT THEY MAY MISS OUT ON KNOWING WHO THE CHIEF EXECUTIVE IS OR WHAT THE BUSINESS PLAN IS FOR THE NEXT FIVE YEARS' 'HOW A SERVICE USER FEELS ABOUT THE CARE THEY'RE HAVING DELIVERED, HOW THEY'RE INVOLVED IN DETERMINING WHAT CARE IT IS, THEIR RELATIONSHIP WITH THE MENTAL HEALTH WORKERS DIRECTLY WORKING WITH THEM' 'INVOLVED , IN DEVELOPING NEW SERVICES, CONTRIBUTING TO ONGOING MANAGEMENT, SPECIFIC INITIATIVES TO DEVELOP THE SERVICE, SATISFACTION SURVEYS AND EVALUATION' 'INVOLVING SERVICE USERS IN OUR OVERALL STRATEGIC DEVELOPMENT, THE REALLY BIG DECISIONS ABOUT WHERE WE ARE GOING, WHAT'S IMPORTANT TO US, OUR PRIORITIES' THREE LEVELS - INDIVIDUAL, SERVICE DELIVERY AND ORGANISATIONAL	'I'VE WORKED ON TEAMS WHERE USER INVOLVEMENT HAS OPERATED AND IT'S BEEN A SOURCE OF TENSION, YOU KNOW THE NURSES ARE FEELING OVERBURDENED AND UNDER-RESOURCED AND THEY ARE STRUGGLING TO HOLD THE WARD TOGETHER. IT DOESN'T NECESSARILY FEEL CONSTRUCTIVE TO HAVE A GROUP OF USERS COME ALONG AND SAY "YES THE WARD IS DIRTY, UNDERSTAFFED AND UNPLEASANT"' Q: ARE YOU AWARE OF THE USER INVOLVEMENT OR USER EMPOWERMENT POLICY THE TRUST HAS? 'VAGUELY... BUT I WOULDN'T BE ABLE TO TELL YOU MUCH ABOUT IT. ALL I KNOW IS THAT IT EXISTS' 'IT CAN BE VERY GOOD TO HAVE A CHALLENGING, INSIGHTFUL AND THOUGHTFUL CONVERSATION WITH SOMEONE WHO HAS DECIDED TO GET ACTIVELY INVOLVED. SOME OF THE PEOPLE WHO GET INVOLVED IN THE USER GROUP ARE THE MOST INTELLIGENT, THOUGHTFUL AND CONSTRUCTIVE... THEIR EXPERIENCES ARE MORE INTERESTING THAN THE MAJORITY OF PATIENTS WHO SAY "OH *WELL THANKS FOR THE TABLETS I'M* A BIT BETTER NOW"' 'I'M NOT SURE THAT WE ARE BEING REAL ABOUT IT, IT NEEDS TO BE ACROSS THE BOARD' 'I DON'T THINK TOO MANY PEOPLE COULD ARGUE WITH IT. I SUPPOSE THE THING ABOUT IT IS, IS IT RHETORIC OR IS IT WHAT'S ACTUALLY GOING ON? WHETHER OR NOT IT'S AN 'ACROSS THE BOARD THING' FOR THE WHOLE OF THE TRUST... I WOULD SAY SOME OF IT IS ASPIRATIONAL RATHER THAN WHAT IS ACTUALLY GOING ON. BUT HAVING A CODE THERE YES I THINK IT IS IMPORTANT BECAUSE IT SAYS THAT THE ORGANISATION RECOGNISES AND SUPPORTS THE FACT THAT USERS MUST BE INVOLVED IN EVERY LEVEL OF THE ORGANISATION TO MAKE IT WORK. NOT BEING 'DONE TO' BUT SORT OF... IN PARTNERSHIP WITH'

Shared meanings: user views

The definitions of service users demonstrate a striking range of meanings about user participation. I have developed a continuum of meanings (Figure 4.1) shown on the following page, in order to demonstrate the extent of differences of opinion and degrees of scepticism held by service users, using their own words:

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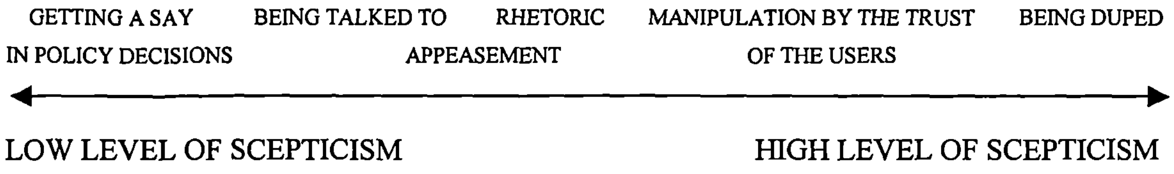
[4] This is the only comment from a professional who works in the voluntary rather than statutory sector.

Figure 4.1. Meaning of user involvement for service users

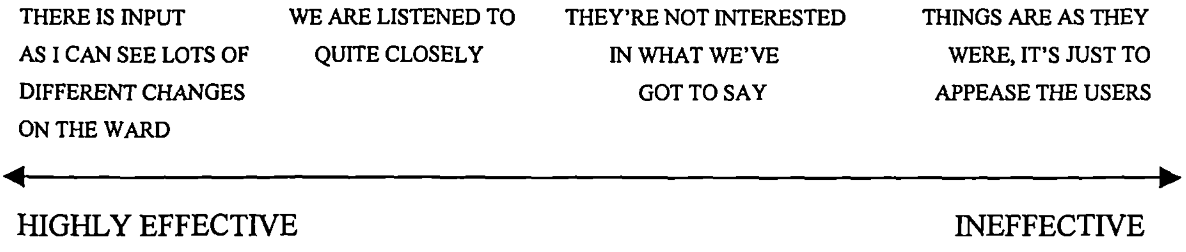


There was no consensus amongst service users/survivors on the meaning of user participation; nor on whether it was an effective vehicle for change. Part of this difference can be explained by whether the respondent viewed the question asked: "*How would you define user involvement?*" as meaning 'what *should* user involvement be about', as opposed to 'what user involvement was about *in practice*'. The question deliberately left the issue of emphasis to the respondent. Those who answered the question less sceptically; saying things like 'having a say' and 'being talked to', tended to be those who believed that user involvement in practice, represented a genuine effort on the part of the organisation, and was, on the whole, a positive thing. Those who were more critical of user involvement tended to answer the question as they saw it happening in practice.

Another theme that emerged from users' views on meanings of user participation, is one of shared experiences and support. This illustrates one of the key benefits to users and can perhaps be viewed as an unintended consequence of user involvement/participation. This theme will be explored in more depth in Chapter six on user capacity and empowerment, but it seems clear from the data that some users are connecting user involvement with opportunities to get together on their own terms. This, in itself, might be viewed as offering a basis for empowerment.

A key phrase that stood out of this section was: "*even the term user involvement, it's like. we'll get users involved in what's already going on*". This epitomises the frustration that some users experienced and connects well with the next focus of the analysis: whether user respondents believed that user involvement could be an effective vehicle for change. Figure 4.2 below, displays the range of responses I received on this question, in another continuum.

Figure 4.2. User involvement as a vehicle for change



Some respondents felt there were noticeable changes, leading them to believe their input was valued and worthwhile. Others felt very differently, believing that professionals and managers were not listening or responding to their views and that consequently no changes were discernible.

Shared meanings: User-worker views

Comments by user-workers appeared to be more consistent than those of service users. Most stated, in some way or another, that user involvement was about participation in decision-making processes so that the services available reflected what local users wanted. The words/phrases that stood out when considering different definitions were: *"influence", "input", "participation", "equality", "choices", "together", "empowering", "making a difference", "being consulted", "taken seriously"* and *"active partners"*: though most user-workers commented that this was rarely how user participation worked in practice. Many pointed to problems in the way user participation is conceived by professionals, and questioned whether it was meaningful at all. Some of the words indicating scepticism were: *"buzz words", "chimera", "wasn't given the chance to mean much in practice", "the Trust either taking it into account or not", "lip-service"* and *"the emperor's new clothes"*.

In considering the question of whether user involvement is meaningful, and whether it can be an effective vehicle for change, there was general agreement. Most respondents were willing to admit that there had been some changes as a result of user involvement policies, though they were also quick to add their reservations. These reservations included concerns that user participation was largely window dressing and tokenistic, used to manipulate agendas, and that without a will for change among staff it would not happen. Overall, there was a belief that user involvement had not affected the status quo in a way that allowed users to feel sufficiently empowered, and feel that they could make a real difference. This quote from a user-worker captures these concerns:

> *User involvement is fine as far as it goes, as long as it doesn't change things and once it starts to change things "we don't want to know".* SH

Shared meanings: Professional views

The professionals interviewed were, on the whole, less clear about the meaning of user participation, and most were hesitant in committing themselves to the meanings that this term had in their work. However, a clear position was offered by one senior manager who stated that user participation was about:

> *Involving service users in our overall strategic development, the really big decisions about where we are going, what's important to us, our priorities.* NP

This position was unequivocal, while other responses contained inherent contradictions making it more difficult to define positions. A discernible set of conflicts or tensions is contained within the following statement, for example: "*it's about people who use services running services or having a proper say in the running of those services if that's what they want... many users just want us to get on and do it*" (AC). This betrays a strong sense of ambivalence. First it contains a statement on what is, or should be, happening; people having a say in running services, but this is followed by an adjunct that throws this first definition into question: *"if that's what they want... many users just want us to get on and do it"*. This can be taken at face value; many users of psychiatric and mental health services do not want to stay involved with the system but rather just wish to leave and get on with their lives. Moreover, professionals are being paid to do a job and should be expected to do it well: service users who are 'involved' are only very rarely paid or salaried.

Having said this, another reading of this comment could be that the concept of service user choice, denoted by the phrase *"if that's what they want"*, is being used to undermine the first part of the sentence *"it's about people having a say in the running of those services"*. Rhetorical theory is useful in analysing such responses, giving a central place to conflicts and tensions within text and talk. If a speaker feels caught in a dilemma of 'stake or interest', a considerable amount of work will go into constructing evaluations that are 'facts simply described', rather than being a personal expression of a point of view (Wetherell and Potter, 1992). Rhetorical analysis looks closely at the mobilisation of meaning and the development of argumentative practice. Wetherell and Potter's (1992) suggestion that liberal and egalitarian principals (equality, choice, rights, freedom) can be put to work within different argumentative contexts, and mobilised for or against many types of outcomes, is particularly relevant for this analysis, as they argue below:

> Conflict, ambivalence, inconsistency and contradiction seem to be endemic. They do not, that is, seem to be associated with just one group of individuals or one type of person. Everyone is a dilemmatician – anti-racists to the same extent as racists. The appeal to conflicting principals and practical considerations is a useful rhetorical ploy, which can be used by anyone; it is not a state of mind which uniquely distinguishes one group of white Americans (1992: 198).

The use of disclaimers is a strategy to avoid being seen as either prejudiced or as going against a social norm. All interviewees in this study were aware of user participation being viewed by most users and many professionals as a commonly accepted goal. As one respondent put it: "*I don't think too many people could argue with it*", and some respondents were aware of my own position as a supporter of the principle of partnership working. Using this device of developed disclaimers it could be said that the professional quoted previously was positioning himself as a proponent of service users either being involved in, or running their own services. But in concluding that in some situations, professionals maybe should just 'get on and do it', this position becomes less assured.

A further tension apparent in the data display (Table 4.1) of professional's views can be described as: is user involvement rhetoric or reality? There was an acknowledgement that having a code of conduct or a charter on user involvement or user rights is part of the road to change, but also an awareness that most of this could be aspirational in practice rather than reflecting reality. Like the service user respondents, some professionals believed that policy statements on user involvement were a reflection of a changing reality, while others viewed them as wishful thinking. A related point, made by a few respondents, concerned the extent of involvement. Some workers believed that service user influence only extended to areas that directly concerned them; the ward environment, the food, or the staff that were going to work with them. Other professionals expressed strong views that the involvement of users could be seen right at the top of the organisation; affecting strategic development and Trust priorities. Some differences of opinion were likely to be due to the fact that the professionals interviewed came from different mental health Trusts, all at different stages in adopting a user collaboration approach to their work and taking differing approaches to change. Nonetheless, it seemed that professionals whose responsibility it was to make user participation happen, tended to speak more positively of what had been achieved.

Another tension lies between the desire of professionals to have service users more actively involved and engaged, but a reluctance to open up their practice to criticism. These two quotes by the same professional demonstrate this:

> *It can be very good to have a challenging, insightful and thoughtful conversation with someone who has decided to get actively involved. Some of the people who get involved in the user group are the most intelligent, thoughtful and constructive ... Their experiences are more interesting than the majority of patients who say "thanks for the tablets I'm a bit better now".* EN
>
> *I've worked on teams where user involvement has operated and it's been a source of tension, you know the nurses are feeling overburdened and under-resourced and they are struggling to hold the ward together. It doesn't necessarily feel constructive to have a group of users come along and say "yes the ward is dirty, understaffed and unpleasant".* EN

The inherent tension that user involvement brings gains and losses for professionals, as well as for service users, is evident in much of the data gathered in this study and these gains and losses will be explored in more detail in Chapter five.

Differences in terminology

An interesting finding among responses to questions on definitions and meaning, was the differences of opinion regarding the words used to describe the participatory process. Words such as participation, involvement and empowerment were used interchangeably. Some of the interview questions tried to probe the use of language and terminology and ask specifically about views on what these different words meant to the respondents. The responses below are good examples of the interchangeable nature of the vocabulary used to describe 'involvement', by indicating disagreement over which words denote less tokenistic involvement or participation by users. The following two quotes are from respondents with roles promoting user interests through advocacy and development work:

> *...participation for me means less. With involvement it implies more of a partnership though I'm not sure. I think the most important thing with user involvement is... empowering people to be active partners or at least partners in what they need.* BA
>
> *I'm always pushing for user participation really, not involvement, so users are actually taking part in the actual decision-making. That's not always easy. I think the Trust would see user involvement as the users being consulted about various issues and then the Trust either taking it into account or not... I always push for participation.* MG

The response below from a statutory manager came after I probed her use of the word empowerment, rather than involvement or participation. I wanted to know whether empowerment was being used purposefully or simply interchangeably, by professionals:

> *Empowerment does suggest something very different than involvement. I do some training that I call service user involvement which is about working with staff on the ground looking at really practical ways that they can involve people in a range of initiatives. And it may well be that the end result is empowerment but it's not about being grandiose it's just that it is about different means and mechanisms. I think what the Trust is about at that level is empowerment and it is substantially different from involvement and of course they are part of the same thing but it is about recognising that we need to create an environment where people can empower themselves and can say what they want to say to us, can help to have a joint responsibility for improving things even within the constraints we've got. So it isn't just semantics or words, it substantially does mean something different than a whole range of other things which you might describe as valid activities but they are a sub group of that overall goal which, which is empowering our service users to be full partners in determining what happens for our services and for them as individuals. I know it all sounds a bit grand but I do think words are important.* NP

Here the participatory processes of involvement are being linked more specifically to the broader aim of affecting service users' power position in services and, perhaps, more widely in their lives. This manager also linked the end process with 'different means and mechanisms' and in this case the words 'involvement' and 'empowerment' were used purposefully to mean different outcomes, processes, means and mechanisms.

Summary

This section has analysed the meanings of user involvement across the three different sets of respondents in this study; service users, user-workers and professionals/managers. One of the aims of this analysis was to consider the extent to which these meanings were shared. Across the three groups there was no consensus on what user involvement meant, nor on whether people viewed increased involvement as an effective vehicle for change. The most commonly shared view of user involvement was one of overall scepticism. The level of scepticism amongst senior professionals was particularly surprising and I sensed during the interviews that some respondents were saying things to me that they would not have been comfortable saying publicly. Talking about the practice of user involvement was a particularly sensitive matter for some senior professionals and one on which there was an obvious 'party line'. In both Trusts there was clearly a perceived pressure to be 'on message' on the topic of user participation and empowerment. User and user-worker respondents articulated a greater sense of frustration with the process of user participation in their commentaries. Professionals, in contrast, tended to describe user involvement in 'matter-of-fact' or 'common sense' terms. There were sceptics and proponents across the three groups in relation to viewing greater involvement of users as a mechanism for achieving change. Most respondents believed that there had been some changes as a result of user involvement policies, but also expressed many reservations. For others, the meaning of user involvement was quite straightforward and changes were happening, albeit slowly.

Part Three: The Motives for User Participation: Opportunities for Change or Jumping Before you are Pushed?

This section of the chapter is concerned with the motivations for user involvement and participation in mental health services. The analysis was based on comments that emerged strongly as part of respondents' 'narratives' of involvement. I have used these narratives to address the question of whether user involvement was viewed positively, as an opportunity for change, or a case of 'jumping before you are pushed'.

The ideology of consumerism

These quotes, both by user-workers, describe the Conservative government's policy of consumerism that prevailed within the health service during the 1980's and 1990's, as providing the main impetus for change in the way services were run:

> *It was part of a larger ideology that just said let's just get the NHS on the consumer market-driven model, we have consumers as a kind of drive or focus to make the NHS more efficient, to get people to think like consumers.* RM
>
> *I think it was a good beginning and it was a good place to start and I don't think as much as we have achieved now could have been achieved without that, even if it was the Tories and it was consumerism and all that happened with the split into Trusts. We had to start somewhere and it was an OK place to start.* SH

One respondent saw the mobilisation of users into groups, in order to create an impact on policy development and service delivery, as manipulative. This user-worker had been actively involved in starting user groups in the 1980's, and believed that these early user groups were used to add weight to the re-provision agenda that followed plans for the closure of the large institutions and the move towards community care:

> *The involvement of users always served different agendas. You could say that there was a genuine issue back in the 60's and 70's where involvement of users was seen as a professional development issue, it was seen as part of critical awareness. You had a number of different services coming together which was actually a very exciting time, you know person-centred ways of working, user involvement was a natural progression. What we saw in the late 70's and 80's was a breed of management which was serving the re-provision agenda. Now what user groups and the user movement said after that experience is we've been conned left right and centre on this one. What we wanted was the services to become compassionate, we wanted to have more community services so that those of us that didn't need to go into the bins didn't have to, but we wanted the bins to be there, we just wanted them to be better. There's stuff in the bins that's good, there's space, there are grounds. We've been duped. User groups were formed but what they were used to do was to bash those in the nursing professions and others who were saying well we need to think very carefully about the whole process of closing down the hospitals.* BA

For this respondent, one of the key reasons for the interest in user involvement was the desire to use the user voice to support whatever changes were being advocated by senior managers and policy makers. 'Consumer choice', according to BA, was a ploy to promote decisions made in the interest of a political pressure group that had something to gain from the achieved outcome.

'Being seen to be doing'

Another theme, that of being 'seen' to do user involvement, was a significant finding to emerge from the data:

> *There's a lot of 'being seen to be doing it' going on because you have to fill in the bits of paper to send up to government to tell them what you're doing about it. I tend to take a cynical view that it's... largely about expediency and largely about... not feeling that there's been much choice as far as the management establishment goes. You know they've got to demonstrate some quite substantive moves in that direction to... a different culture. It's been interpreted in various ways and I mean it hasn't surprised me that some of the initiatives have been around documents because that's the culture here. It's about going for quite tangible things, going for things you can actually hold up at a Board meeting and say "we have produced this" you know "here is the Charter, the information leaflet about the Charter". It enables you to do some quite nice presentational stuff you know, put the Trust logo on it, put the words 'Users Charter' and that kind of stuff. That is a very cynical view but I think that has been a lot of what's there. It's about being seen to be... in there, in with the current thinking, in a sort of jump in before you're pushed way I suppose.* SW

This respondent continued by identifying other factors that he believed placed pressure on Trusts to force them down the route towards greater user involvement:

> *There has been a realisation that the thing isn't going to go away. It's come through various channels, not least through the Care Programme Approach and the whole emphasis within that. And I think for a while again that was defended against and the Care Programme Approach was all set up and talked about in terms of the forms and how you fill the forms in and what should be on the forms and what isn't on the forms. I think the Care Programme Approach is quite clever because it does embody the concept of the key worker and that role embodies a collaborative... dimension so the involvement thing has been pushed into the Trust through various layers. Through the contracting processes, through the pressure on the Trust to be involving users in policy making, through the kind of human resource issues around users being involved in interviews and recruitment and those kind of things. So I think the jumping before you're pushed kind of thing sort of sums it up for me really.* SW

These comments bring a contextual understanding to the issue of motivation by describing a historical process that created the opportunity for a different 'climate' or 'culture' to emerge in mental health services. This respondent linked the consumerist drive with wider developments in service provision and delivery like the Care Programme Approach (CPA).

'Lip service' and 'ticking the box' were two other phrases used by respondents to describe the motives behind user involvement. The following quote, from a voluntary organisation manager, illustrates the view that change has been mostly impressionistic:

> *It's very easy to give the impression that things are changing when in fact they're not. There are all these things that purport to be user involvement but actually aren't. There's a lot of that going on you know saying "oh yes we're involving our service users because we have written a questionnaire and given it to them and they all say that they think that we're quite all right". Then they tick the box - we've done user involvement. The view you get sometimes from some of our statutory colleagues is that user involvement is something you have to do, so it's the bit that's tagged on as an adjunct rather than an integral part of your underlying philosophy and I think they probably see it as another bit of bureaucracy where they have to be able to tick the box.* AC

A user-worker expressed a similar view:

> *In some areas lip service is paid to user involvement, it's just well we've got to have a user on the panel so that you can tick off the user involvement box.* BM

The important question to ask here, therefore, is whether power relations can be changed if most professionals and managers view user involvement as no more than a paper exercise. One comment, from a user who chaired Trust A's hospital user group, is especially revealing on this point:

> *It's come from the Department of Health, they don't have much of a choice and if they didn't start doing it they would have had to have done it anyway. So I don't think its good will on their part. I think they are a long way off realising that people who have breakdowns or whatever, people like us, actually do know what is good and what is crap, what works and what doesn't work.* HK

From this person's perspective it seems clear that the paper exercise had not been translated into a fundamental change in professional practice or attitude.

An observation of SW, a respondent quoted above, was the tendency of Trusts to produce documentation as evidence of their new 'consumer responsive' culture. This view was confirmed by the literature gathered from the Trusts for this study. In the mid to late 1990's there was considerable competition between Trusts for status and glossy annual reports and charters were displayed as evidence of good practice. Producing charters, leaflets and policies could be viewed as organisational responses to change. In the next chapter, I argue that this type of organisational response to demands for change can, in fact, serve to delay real, substantive change: time, energy and money is diverted to produce documents and superficial 'window dressing' activities, rather than developing new structures for power sharing.

Image making: talking the talk

What emerged from many of the respondents' commentaries was the view that the demand for users to be more involved, both in their own treatment and in the running of Trusts, was initially met with some trepidation and uncertainty. This uncertainty led mental health Trusts, and some voluntary organisations, to fall back on what they knew how to do, namely; the production of glossy documents, filling out questionnaires and ticking boxes. User participation did not mean working to service users' agendas and, given the changing political situation at that time, this would indeed have been an ambitious aim. One user-worker offered this critical perspective:

> *There is a very, very strong strain that runs through user involvement in lots of places, even in places that are known for being good at it... it's working to agendas and there's that "well who's agenda are we really working to?" and that has been identified many times but I think that there's an even more alarming development which is that there is now... for those that are astute, there is almost like a product, a set package of initiatives that can be undertaken to be seen to be empowering and involving users. And those that are astute will actually know that there are only a few key things that if you put them in place will deflect all criticism and win yourself a lot of praise for the organisation without actually addressing any of the... And I think that that has certainly been an issue in this Trust. That key individuals, senior people have got themselves the adoration of user groups because they have been politically astute enough to say the right things, in the right way, at the right time, to the right people and they've followed almost what you could describe as a formula... And it's not impacted on the wards... in fact what it's led to is a disempowerment because what you may find when you speak to some of the front-line staff is that users are getting everything... which they're not... but you're getting the worst of both worlds. You're getting the right things being said in the right places and the right venues, in the right circumstances and situations, but it's not translating necessarily into a... change of attitudes on the wards. That's a much more tortuous process, it's much more hard work than a few workshops, a few away-days, a few rather nice publications and articles. You're talking about the aspirations of ordinary nurses on the wards, you're talking about the management of those teams, there's a whole range of issues that... well in fact you don't have to get involved in all that if you have this rather glib little process and I think there is a risk for all Trusts and all services if they follow that line where they can do the easy stuff... when what's really hard is to really change it. And part of the glib stuff is to acknowledge it. Part of it is to say "well we know how hard it is... to translate". Well the reason it's hard is that, in fact, it demands a root and branch*

> *look at what you're doing. Like how you support staff, how you ensure that staff feel valued.* BA

This respondent describes how apparently easy it is to be convincing about the *desire* to create change in services through user involvement, while achieving very little change where it matters. Significantly, this comment conveys the political value placed on 'being seen to be doing' user involvement. The question this poses is whether the focus on image predominates because people who manage and work in mental health services do not *want* to change, or whether it is because it is too difficult or too anxiety provoking to try. The formulaic approach, described by BA above, may explain the disparity between what is talked about at conferences and in professional journals and annual reports, and the reality on acute psychiatric wards; where people often remain confused about what is 'wrong' with them, uninformed about their treatment, unsupported and disempowered. Transferring good intentions into a reality that re-humanises this experience for all involved, is an obvious challenge. But, if all Trusts have done is 'talk the talk', then much remains to be done if changes intended by the introduction of user participation are to have any effect.

A number of service users spoke of the importance of image to mental health Trusts:

> *It's in the interest of the hospital to appear to be a certain kind of organisation. I was often told that I was in the best possible place, and it's very hard when people say "this is a centre of excellence" and you think "is this a centre of excellence?!". But it is very categorical and there's no getting around it and I think that the hospital want to promote this image and one of the things that they've sought to do is to promote users because they see us as a way of retaining this image. However, they have very much underestimated the power of the users and it just so happens that there are currently a lot of very angry but very powerful, very articulate people who are not very sympathetic to the idea that this is a centre of excellence and therefore there is a great deal of conflict and although I don't think they will ever stop the user group they may wish to address how it runs because it may be too free or it may be coming too political. The disadvantages from their point of view is that it highlights the unsatisfactory nature of the service they provide.* PF

This respondent makes a connection between the concept of an organisation 'being a centre of excellence' and 'involving their users'. Another user from the same Trust agreed there was a need to prevent the group *"being used as fodder for the hospital to show the world how fantastic they are, that they have users doing this or that"*(HK). Competitive and self-conscious institutions, with very few other selling points, now attempt to claim the moral high ground above their competitors.

Genuine desire from professionals to involve users

Despite the largely negative interpretations of the motivations behind the push for user involvement, the data revealed a number of responses that identified a genuine desire to involve users. Two of these responses are included below, the first by a psychiatrist, the second by a user-worker:

> *Some medics are interested in how you get individual patient's views and use them constructively in the doctor-patient relationship so I would imagine that those people wouldn't need a health authority to send them a piece of paper telling them to get users involved.* EN

> *We are very fortunate in that there are some very good teams and individuals within good teams that are taking this forward but that's due just as much to their professionalism and their desire to do a good job and not to be seen to be prison officers rather than nurses, or to be tyrannical oppressors rather than doctors.* BA

In Trust A, the push for user involvement came from service users brought together to discuss spiritual issues by a chaplain, who then went on to set up a Patient's Council. An enlightened service manager who came from a business background, a consumerist position, was also involved in this process and started running public meetings to establish a dialogue with users. This provides an example of key personnel opening up opportunities and spaces that can then be exploited by service users.

User pressure

A small number of respondents suggested that pressure from groups of service users had had an impact on professional and management commitment to user involvement. The following quote emphasises this process and highlights the importance of having allies:

> *There was a small campaigning group in the area of active service users who were very informed and saw getting this paid worker post as a way to really achieve progress for the user group that was in existence and they had an ally in the management of mental health services, two or three allies actually that were ready and open to that idea.* SH

Other respondents referred to changes in society leading the public to be increasingly reluctant to hand over power to the medical profession when in need of health care or treatment. The nurse manager, quoted below, also made reference to the increasing demand for information and choice, noticeable throughout the 1990's and set to continue into the next century:

> *People are not as 'hands off' and 'oh my god' about professionals anymore, people will have a go at their GP nowadays when they wouldn't have before. Society is*

> *making more demands for information and choice so it's obvious that that would happen within the mental health service as well.* YT

As with the previous quote, although user pressure was mentioned as a driver for change, it was not seen as carrying the same weight as the drive 'to be seen to be doing' user involvement.

Summary

The data suggests a variety of motives for trying to involve service users in their care and treatment and in the running of services. Most respondents attributed the emergence of this demand to government pressure on Trusts to become players in the new 'market-place' of care. Although there was a simultaneous increase in demands from health consumers and mental health service users at this time, the newly created Trusts' preoccupation with image and 'being seen to be doing' user involvement, was viewed as the main motivating factor. This was a consistent view across service user, user-worker and professional commentaries. One of the most telling comments in this section was the view that some Trusts and individual senior professionals and managers had followed what was described as a 'winning formula'; by saying the right things at the right time to the right people. Involving users as a political strategy to gain further power, either as an organisation or as an individual, in order to increase one's marketable qualities, emerged as a key theme of this research and is referred to in Chapters five and six.

Part Four: Conditions for User Participation

One of the aims of this study was to see whether it was possible to identify organisational conditions that supported partnership working between service users and professionals. A related aim was to identify whether professionals had created any opportunities to practice in ways that increased user power over their care or services. In examining the question: 'What conditions support and encourage genuine user involvement and participation?' a number of factors emerged from the interviews and these are described in turn below.

Organisational climate and management approach

> *I think the culture's there and the culture is definitely about it's not OK **not** to work in partnership, but it's hard to know how that might be really working in every single contact between service users and individual mental health workers.* NP

This quote, by a senior manager in one of the Trusts studied, identifies the relevance of a supportive organisational culture for partnership working. It also highlights the difficulty of being able to ascertain whether the professed culture of an organisation, as identified and promoted by senior managers, impacts directly on everyday interactions between front-line workers and users. It was clear from the wider data set that there are staff working in all sectors of mental health and psychiatric services that *are* exceptional, caring, helpful, concerned and professional people. But the data also demonstrated that there are people working in services who do *not* have the qualities or aptitude to work alongside users. The presence of inappropriate people working as mental health professionals is one of the central concerns to emerge from some of the interviews. The quote below, from a user-worker, eloquently describes this concern and the role of institutional constraints in supporting bad practice, as well as ward level leadership in facilitating change:

> *It's something that happens in all service industries, everybody enters it with good intentions but they are exposed to such distress and such hard issues that it is inevitable. It's just part of how we cope, we start to become immune to the feelings and distress of people. It's something about the structure of the old institutional ward teams which in a sense allowed bad practice, that developed as a way of coping with the stress, to become the norm. That is the biggest task that we face, that we have inherited this way of working. So the emphasis has got to be on supporting the ward managers to really bring these issues live within the teams. It may be that there's institutional barriers for example, it's very good that there are good conditions of employment within the service, it's good that there is a strong contract, that there is a lot of protection. But against that there needs to be more flexibility built in so, for example, if you've got somebody that is clearly a bit of a thug, and I would say that we have several thugs working within our teams...They are experts. I have witnessed it myself where I will go into a ward and somebody will give me the smiling face where I've seen the face change as they've turned away from a patient, from a scowl... a sort of sneering scowl to a "Oh hello" (mimics friendly voice). It's something they've developed to survive.... I'm not sure that exercises like Customer Care training packages put together by management helps. They'll just say "well we're nurses we know all about care thank you very much, we don't need to be told by you".* BA

Finding ways of moving unsuitable staff members around, or getting rid of them altogether, was mentioned by a number of respondents as crucial if improvements to services were to happen. The respondent BA draws attention to the mechanisms in place that protect employees from unfair employers and practices, which he suggests makes it difficult to sack incompetent staff or those serially abusive to users, especially if they had been in the service for a number of years:

> *You need some way where long standing service thugs can be... moved around and exposed because often what holds bad practice in place is the fact that you have a set team, that the dynamic is the same and it's all kind of finely balanced. You've*

> *got to have some way of moving that around and breaking that up, it might mean that you say that nobody should work on a given ward for more than two years without a break of doing something else, I don't know. Users at the end of the day say they want to feel nurtured, they want to feel that people actually care for them and don't hate them... what they are sometimes feeling is that the teams hate them, detest them sometimes.* BA

Some managers were very clear, however, that the previous organisational attitude of 'turning a blind eye' to such individuals and their practice was no longer an option, and made assurances that they were being gradually forced out of their positions. A strong commitment by senior managers with clear leadership skills did seem to help to create a climate for partnership working. However, as will be shown in part six of this chapter on barriers to user involvement, a top-down approach can be severely limited in its ability to impact on 'front-line' ward cultures and may lead to front-line staff feeling even more pressurised and devalued.

Relevance of policies and procedures

The existence of organisational policies and procedures that contain a commitment to user involvement in running elements of the service, or statements about what users can expect from services, were identified as crucial by a number of respondents. More specifically, equal opportunity statements and policies were identified as having an impact on the organisational culture in a way that supported user involvement. Although these statements were not seen as necessarily preventing bad practice; they were seen as a tool that could be used to call the institution to account when indifference or hostility to user participation was displayed. In Trust A, a consultant was brought in by the equal opportunities committee which led to the formulation of an equal opportunities strategy for users, a mission statement, an equal opportunities statement and a user charter. The user development worker in this Trust commented:

> *User charters can be very helpful even though things don't necessarily happen because it can help to challenge things by saying "this has got to happen because it's hospital policy".* MG

Equal opportunities policies *can* be a way of forcing organisations to address user equality and inequality issues, although this can, in turn, lead to resistance by the holders of power. The same respondent illustrates this:

> *My worst interpretation is that getting the user-worker post in place was a slop to the equal opp's committee where they hoped there would be some tokenistic stuff that they could then parade. It didn't work out like that... but they leave the position pretty beleaguered in terms of resources and... the worker is not exactly aided by and large. They are allowed to get on with it without being interfered with which is*

> *good. But that has disadvantages in getting enough help really or being allowed to develop things.* MG

This view of tokenism coincides with the motives for user involvement discussed above. As demonstrated here, equal opportunities policies can be a motivating factor for developing user involvement, but being *"beleaguered in terms of resources"* was a danger inherent in user-worker posts put in place to address these inequalities. Such comments demonstrate the danger that equal opportunities policies, as well as user involvement polices, can be rhetorical, 'tick-box' exercises, rather than practices indicative of organisational change.

Staff skills and attitudes

Views on staff attitudes and skills were most frequently expressed when respondents were asked to consider the ways in which conditions facilitating user power could be extended to users' own treatment or to wider decisions about the delivery of services. Central importance was placed on the ability of staff to listen to people, as described by this senior manager:

> *The thing that's had the most impact on me is actually spending lots of time over the last five or six years with service users listening to what they say and my views have been significantly shaped by this.* NP

Similarly, views about the interpersonal skills and attitudes of staff shared a commonality:

> *It's about humanity and about how far you meet someone as an equal human being in this world. I think a job and professionalism is often set up against that somehow.* JR
>
> *You need to sit down with people and talk to them.* PF
>
> *Dealing with each other as fellow human beings.* PH
>
> *I got to know them as a person and I talked about me as a person.* NP
>
> *Being able to see the person and the healthy parts of the person.* WA
>
> *Being sound and genuine.* KM

The ability of professionals to be genuine, interested and to see themselves as equals, best sum up the comments above; equality being a recurring theme throughout this analysis. The openness of staff to considering different approaches to mental health interventions, was also noted as important to extending user power; as was having an interest in critical perspectives such as feminism and Marxism and having an awareness of ethics, advocacy and power relations.

"B*eing able to deal openly with conflict"* was another skill mentioned. The ability to create relationships over time, or *"longevity of relationships"* as expressed by one respondent, was another factor seen as heightening the opportunity for user-professional collaboration. One professional felt that having family and friends with mental health problems helped them to see their relationship with service users differently:

> *My mum took an overdose which got me more interested in that side of things so there's quite a big personal thing for me about knowing people on a personal level which makes me think about things quite differently.* WA

Being in a position to work with service users when they were well, not just unwell or distressed, seemed to have a considerable impact on the way workers viewed service users:

> *Some professionals don't see people when they're well... and that's been the difference for me because it just turns it on the head because I then just naturally assume that that's who people are and they have times when things aren't so good rather than the other way round. People have good times, bad times, some people get over things completely. It's this whole notion of recovery I guess. The reality of it for me is some of the people I work with are some of the most skilled and intelligent people I could ever meet. They are wonderful company, they are brilliant to have a really challenging discussion about the whys and wherefores and I think if you have those experiences you don't lose that ever.* NP

The notion of madness or mental illness as being just one state of being for that individual, and a belief in recovery, seemed to give this professional a different perspective on the users she was helping, compared to colleagues who came from a more traditional, medical approach. She was able to see users as people first, and to value their skills, strengths and individuality.

The level of staff self-awareness was mentioned by one user-worker, who believed the ability to be comfortable with oneself was crucial to being comfortable with those in mental distress:

> *It doesn't mean exploring our own navels, it doesn't mean being in counselling or being self-indulgent, it just means asking people who provide services to feel sufficiently comfortable with themselves to be able to feel at ease with the people who come for help. You have to get into the bath-water with them but in order to get into the bath-water, that requires taking approaches to ourselves.* BA

'Getting into the bath-water' is a useful metaphor to describe the act of 'being with' people in distress who come for help. One service user took this idea further, describing certain workers he knew as having *gone native*: by closely identifying with user experiences these staff members had become more helpful in his recovery.

Relevance of training and education on staff attitudes

One of the questions I asked specifically related to the perceived impact of training and education on professional's attitudes towards user participation. A wide variety of views were expressed, among them the perception that *"training trains the good stuff out of professionals so they can't see people as people anymore"*, illustrated by this voluntary sector manager:

> *Things are changing but that's not generated by people reading learned journals that's by people using common sense and common decency. It's just about not seeing people as 'other' and I think you either do or you don't. So the notion of training or teaching people how to do it is... I'm not saying it's pointless but all the people I've met who are really effective at doing it just do it naturally.* AC

A senior manager from Trust B offered a different perspective; citing her postgraduate academic studies as being directly related to her efforts to involve users within the Trust:

> *What helped me get it* (user involvement policy) *off the ground was actually doing a piece of work as part of my MA, because it was the way in. It was just that bit of extra support of having access to lots of materials that would impress the doctors and academics and such like. In terms of the organisation it was quite helpful to say "hey look everyone else thinks that too and I think what we ought to do is...". That was an important catalyst in the first instance to help me get a bit of momentum behind it.* NP

A third perspective came from a senior nurse manager who related a learning experience that was formative in changing her attitudes toward service users:

> *About two years ago I went to a conference which was almost entirely run by service users on self-harm. I would say I had always had negative attitudes towards people who self harm and in just one day it turned my thinking around totally. With people talking from their own perspectives of why they did it, what they got out of it, how they were treated by people in mental health services and I thought God yeah I can now see it in the context that it should be seen in rather than from the irritation, anger and helpless state that I was in before. So to me that was much more powerful... I wouldn't say it was academic writings at all.* YT

These comments offer a sense of the range of views on the relevance of training and education for staff attitudes towards user participation and the development of more equal relationships. Some believed that staff either had a positive approach or they did not, despite levels of training. Others felt that, certainly in their own situation, having access to wider views and being able to underpin the desire for change with academic evidence of the need for change, gave added validity to their quest for change. And the third perspective, as articulated by YT above, demonstrated the effectiveness of hearing directly from people previously viewed by her as

'Other'. Certainly for this senior nurse manager, the personal challenge she experienced was remembered as one of the primary influences on her practice.

Summary

One of the most frequently mentioned conditions of user participation was staff attitude and the qualities of staff, in terms of their ability to positively respond to users with high self-awareness and reciprocity. Exposure to a broad range of perspectives on mental health, including exposure to service users and survivors outside the mental health services was identified as another influential factor. One condition that seemed to promote user involvement was clear leadership from senior management that attempted to create a culture of partnership working as the norm, although questions have been raised concerning the ability of this cultural change to percolate down to ward level. Having equal opportunities statements and user involvement/empowerment policies also seemed to have a positive impact according to respondents.

Part Five: Rewards and Incentives

One of the areas neglected in the literature on user participation concerns the reasons why professionals might change their practice and work in partnership with service users. This section examines the rewards and incentives of user participation for both professionals and service users.

Rewards for professionals

The following comment from a psychiatrist emerged when asking respondents about the rewards of having closer relationships with service users:

> *Working closer with users through joint meetings has been a very powerful learning experience. Individual practice is enormously malleable and that's why meeting with users, if it's been useful for nothing else, has been useful for helping me and a few other psychiatrists to hear very different views and to try and have the gut reaction about being criticised, to get over that and try and learn to genuinely alter the way we interact with people on the basis of what we've heard. So our practice has changed and we hope that other individuals' practice can be changed and that individual members of the user movement feel better about their treatment because they know that some psychiatrists are not quite as simplistic as they might otherwise have appeared.* EN

This type of comment highlights the learning potential that comes from professionals attending joint meetings with users. It expresses an optimism that professional practice *is* amenable to change, and that changes in practice can be facilitated through exposure to critical views on one's own practice or on professional practice generally. EN talks of changes in practice already having occurred for some practitioners exposed in this way, and expresses his hope that this experience might happen to others. The psychiatrists who met with service users were themselves interested in changing practice within their institution, and the meetings were established to seek common ground between the aims of psychiatrists and the service user group. This was, therefore, not a 'mainstream' group of psychiatrists, nor a 'mainstream' group of users. Taking the initiative to meet with the service user group required a willingness to be exposed to critical views on professional practice; a willingness that could be described as unusual for doctors and psychiatrists. The respondent comments that this group of psychiatrists risked making themselves personally vulnerable, by meeting a large and vocal group of service users on a fairly regular basis over a period of months. The outcome had nonetheless been very positive: firstly in terms of extending his knowledge about what service users liked and did not like about their professional practice; and secondly, in providing a space to react to criticism and move on, towards better informed and more sensitive practice.

A further interesting point in this psychiatrist's comment, concerns his hopes for changes in service user attitudes towards psychiatry. It seemed that an additional aim of the psychiatrists, for these joint meetings with the hospital user group, was for service users to have an improved view of their profession. The rationale being the belief that user group exposure to psychiatrists who had an openness to hearing service user views and a wider view of mental distress than just a medical model perspective, would demonstrate that they were not all bad. One of the rewards for professionals who took the risk of closer involvement with critical service users, was therefore, the opportunity for them to be heard, to explain their perspective and to break down some of the barriers between 'them' and 'us'. Joint meetings and meaningful joint working may give professionals the opportunity to say *"we're not that bad really, some of us are really trying"*. Bearing in mind the work of Menzies (1970), described in Chapter one on the perceived importance of maintaining professional distance between patients/clients and the professional ego, expressing the *desire* to break down the barrier between 'them' and 'us', could be perceived as a significant achievement in itself.

Another professional, a clinical psychologist, spoke of the way she saw involvement impacting positively on both services and individuals, as a reward:

> *Seeing results, seeing that feeling spread, seeing people happy, knowing what's going on, people really having a say not getting stuck and disempowered.* WA

This respondent was working with people who had spent long periods of time in hospital and were, on the whole, very dependent on services. She had started a Hearing Voices group[5] with some of the service users and supported it with the hope that the group would eventually be able to run independently. For her, this group was about the involvement of people in their own care and support needs, and was part of an attempt to address what she believed to be the disempowering nature of most rehabilitation services. Self-help and mutual aid are not normally described as user participation, since they are about people doing things for themselves, but in this situation the professional saw herself as a facilitator starting a process that would lead to self-help and mutual aid. Helping service users who are dependent on services to see themselves as key players and to view fellow users as key supports, could be said to be enabling practice.

If service users and professionals work together over a long period of time, possibilities of new, enhanced relationships arise. Professional respondents acknowledged these as very rewarding. This comment from a senior manager, although not necessarily typical, is significant in articulating these rewards:

> *I think people see me as their ally. Some people see me as their friend. I have developed genuine friendships with some of the people I started working with as colleagues. I have really good relationships with people that I've developed over years now. I've got the benefit, just like any other relationships, where they are trusted relationships because they actually go back a long time. I think people feel comfortable to say what they really think... that they can give me a bit of a hard time sometimes, that I'll take that and do something useful with it rather than cry in a corner. I can get angry in front of them and I lose my temper sometimes and show my frustrations. They look after me, (laughing) I mean it's a very reciprocal sort of thing really. I'm not one of those people that believes that there's all these interesting boundaries between the work person and the home person. My work is my life. The people I work with are my best friends. I'm the absolute opposite of all that goes with professional boundaries and that crap and I know it's controversial but I think it's complete bollocks. People are people. Some people I like and some people I'm not so keen on but actually it just feels very real. They are very, very comfortable relationships. I'm extraordinarily fond of a wide range of people I work with. I am very grateful that people have trusted me, they've given me so much in terms of their time, their dedication, their commitment. It's the loyalty... I feel really honoured that people are so loyal to me and to the cause if you know what I mean.* NP

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[5] These are self-help/activist groups that aim to help people to understand and manage their voices; see Romme and Escher (1993) for an analysis of hearing voices outside the illness model.

This statement challenges conventional professional wisdom about boundaries and professionalism. It denotes an emerging discourse where professionals are contesting the traditional ways of thinking about the boundaries between themselves and service users. But another reading of this statement is required. The professional concern with boundaries also acts to protect service users from abuse that might result from the unequal distribution of power between users and professionals. NP is a woman but had these same words come from a man, alarm might have been raised in response to the idea that boundaries were seen here as *"complete bollocks"*. While there are cases of female professionals abusing service users and misusing their power, the majority of reported cases of physical, sexual and emotional abuse involve male staff members (Williams and Keating, 1999). Boundaries between staff and service users exist to ensure staff awareness of the vulnerability of service users. NP's statement describes a much more fluid relationship between home and work that is indicative of the more equal relationships with service users that partnership practice encourages. Given that mental health service settings are environments where service users report sexual, physical and emotional abuse (Copperman and McNamara, 1999; Williams and Keating, 1999), it is important to highlight the potential for abuse if professionals no longer see boundaries as important where power inequalities are left unchanged.

Alliances are also created between professionals and service users when there is a common threat or 'enemy', such as government ministers. This psychiatrist welcomed opportunities presented outside of the clinical setting, to relate to service users differently:

> *From the broader picture on the national stage, the conferences I've been to are enhanced by active, informed users in substantial numbers and that is a context where one really gets out of the power relationship thing. Conferences where users are on the platform speaking and some of them are being very critical and strange kinds of alliances form when we have a situation where the minister comes along and speaks to the whole conference and you get users asking critical questions and the professionals in the audience are sitting there thinking "yeah that's a good question, let's see her get out of that one".* EN

This indicates a shift in relationships, and one that is takingplace outside of the clinical context and service context. This is an encouraging development, but one that could mask the lack of substantive change in relationships *within* the service/clinical context; an argument that will be made later in the thesis.

High profile, visible expressions of power through direct action; verbally harassing a government minister speaking at a national Mind conference, for example, are indications of the confidence many people in the user/survivor movement now have about themselves and their cause. These activities could be seen as an indicator of empowerment and as an observer at the conference being referred to, I believe that these confrontational activities do have some impact. The government has not overtly changed their policies in response to challenges by groups of noisy, angry service users/survivors, and the impact on ministers and policy is impossible to gauge from a distance. But the impact is discernible on the professionals that attend the type of event described by EN, and also on the users themselves, who successfully disrupt the respectful silence ministers would expect during such speeches. Visible anger and disrespect for the power holders impacts on those that witness it; on the protagonists, on professionals and on the media that reported such events.

Rewards for service users

The main reward identified by service users was that of having a positive impact on what it was they were trying to change. Some service users also expressed the view that a desire for partnership is increasing, which is seen as a reward in itself. For some respondents, the fact that they now have access to the services they want and need, acts as a huge incentive, as this comment from a user-worker demonstrates:

> *I was in on the start of the crisis line so I saw how that started and I've seen it develop. I was involved in the campaign for the women's safe house and the odds are that I will end up using that at some point or another so you are getting very concrete rewards.* BM

The same respondent stated other benefits:

> *Plus there's the reward of knowing that you're making a difference to people's opinions because it's opinions that matter. If you can educate somebody and change their opinion of how they should treat somebody with mental health problems then the battle's almost won.* BM

The experience of being involved was described by a number of service users as leading to new opportunities. The learning that occurred for individuals and groups, through the process of trying to create changes in services, was seen as very valuable. One active service user described the experience as a stepping stone:

> *...it's definitely been a stepping stone for me and I know other people have learnt a lot from doing it, so it's good that it's there.* HK

Other associated benefits of going to meetings included getting access to information, feeling that what you are doing is worthwhile and, additionally, sometimes being paid:

> *It's a creative use of our time. We get lots of information. We can see we're having an impact. The payment is secondary because I'm not too badly off and lately we have been paid... but we don't do it for the money... the money is a bonus. I*

> *wouldn't have a hard and fast rule that you've got to be paid because I think it can be just as useful when it's voluntary...* FN

Service users differed on the issue of payment. Some saw being paid as a sizeable incentive for going to endless Trust meetings when they saw no other benefit:

> *You sort of think "fuck it I'll just go at least I'll have £25 quid", which I have done... a few times...I made a lot of money, well I earned a lot of money going to meetings and at the time I was on really low benefits and it propped up my fucking income, it was great! And I have to admit that was largely why I did a lot of stuff. I would do anything I was asked because I knew I would be paid for it. Now... I'm not in that situation anymore so I'm glad that I don't have to do that because it was a bit... I was doing quite a lot.* HK

Another service user agreed:

> *It's important that you get paid, and that it doesn't affect your benefits, they were trying to bring in like national insurance numbers and stuff but I don't think they did. There are perks, I think that's what attracts people as well.* DB

Money is certainly not the reason why people get involved in the first place, not least because the amounts are minimal; between £5 and £20 a meeting is usual. However, staying involved and attending meetings that one would not attend unpaid, did emerge as a definite incentive for some people. This was a subject that raised very mixed feelings among some of the service users, who felt strongly that payment to attend Trust meetings was a form of manipulation:

> *You talk about the perks... the money to go to meetings, but it's not just a perk, the perk is corruption because you create a need. The Trust know perfectly well that most people only get £70 a week but if they offer them £15-£20 now and then to go to meetings then OK... it is corruption in the system. So the users have been used but some don't see the relationship between the £15 and the Trust agenda and this is a difficult problem because they will say "no I go to the meeting and I say whatever I like". But just your presence in the meeting will justify and give points for them which they can use to look good.* RW

Some people may attend meetings for the money, as opposed to a greater benefit to themselves or to the group, but users are not always paid and being paid can depend on the status of the meeting, and whether it is official Trust business, or not:

> *It tends to depend on who's funding the meeting, what the meeting's about, whether there's any money in the pot really.* HK

Some hospital Trusts only pay service users to attend Trust meetings and not meetings the users themselves initiate. At first glance this seems reasonable; presumably Trusts wish to avoid user groups setting up meetings purely for financial benefits, but a more detailed reading suggests a question over whose agenda user participation is supposed to be addressing? One of the respondents felt strongly that this practice needed to change, since it failed to recognise the importance of the user group agenda within the Trust. Financial control of service user groups was seen on a number of levels and this theme will be returned to when the issue of 'whose agenda' is considered in more depth in Chapters five and six.

Summary

In terms of the question of why professionals might want to change their practice, the rewards and principle motivating factors were: learning about their practice and how it affected service users, the belief that their practice/service was more responsive to service user needs because of it, that they saw users as less disempowered, and the opportunities presented to create rewarding relationships and alliances. The breaking down of boundaries between 'them and us' was also identified as rewarding. Championing user participation had benefited some particular professionals, particularly as the climate towards it had become less hostile. As the respondent BA stated these individuals were noted to have built careers on saying the 'right things at the right time'. One reward for professionals has, therefore, been professional gain through their association with 'progressive' user participation policies.

For service users the main reward by far was seeing an impact on the services they used as a result of their actions. The knowledge that staff attitudes had been changed also inspired people to continue working for change, as did having access to new opportunities for personal learning and development. The activism of some groups presented opportunities for group and individual learning about the organisations they were struggling with and the power relationships they were part of; a subject that will be returned to in more detail in Chapter six. One respondent described these activities as intrinsically political, and argued that user group activities provided a political education to those who became involved. Material gain, while mostly small and piecemeal, was also identified as a motivating factor for user participation in activities such as meetings: for some service users it made a considerable difference to their quality of life because their normal income was so restricted. The last findings chapter, Chapter six on user group capacity, will return to the issues raised here with an additional emphasis on the power and empowerment of groups and individuals.

Part Six: Barriers to User Participation

As described in Chapters one and two, creating positive partnerships in mental health services is a difficult process, fraught with tensions and conflict (Church, 1995; Wadsworth and Epstein, 1998; Williams and Lindley, 1996). Responses to questions regarding the barriers preventing user participation demonstrate just how complex and challenging this can be. The barriers identified fell into two main categories: structural and attitudinal. The term structural is used here to mean barriers that have their origins in organisational cultures, institutional practices, bureaucratic systems and their associated power relations. However, categorising barriers as either structural or attitudinal is a simplistic interpretation and this distinction will be considered as relatively fluid. The work of Menzies (1970) and Lipsky (1980) will be drawn upon to examine some of the constraints attributed to working at the 'sharp end' of mental health services.

Structural barriers

A major barrier identified by respondents was institutionalisation. The institutionalisation of mental health services that persists into the present day was deemed largely responsible for preventing changes in user-staff power relations, according to some respondents:

> *There's the whole thing about how institutions function and the institutionalisation of mental health services which even community care was never able to shake off. So you've got the institutionalisation of staff where everything is run in the interests of staff and the institution. The patients are a sideline... it would be fine if it wasn't for the patients sort of thing.* AC

If patients are a "*sideline*", what chance do they have of being listened and responded to? Evidence of institutionalisation is not difficult to find in modern day mental health services and sentiments similar to the quote by AC were repeated by a range of respondents. Structural '*blockages*' that maintain the status quo were identified by a number of respondents, such as this voluntary organisation manager:

> *There are structural things built into statutory services that make it more difficult and that is about maintaining the status quo. So even if you've got loads of people in an NHS Trust really trying to do something there are still these blockages that occur.* AC

A senior manager from a statutory service offered a similar analysis:

> *There are lots of people who are just horrible anyway but there are a lot of people that are well meaning, but they have to work within structures that make it very difficult for them to develop their practice and their relationships in the way they'd like to. I'm more and more, as time goes on, feeling very uncomfortable about our*

> *continuing emphasis on professionals. Particularly the fact that there are all these different professions that are all meant to have their slice of the cake.* NP

Structural barriers are therefore evident from respondent interviews, but discerning exactly what these structures and blockages *are* is more difficult: could different professionals be laying claim to new territory as this interpretation above suggests? If professionals are clambering for more of their share of power and authority, based on claims of specialised identities and interventions, how does this effect user demands for power? The same respondent continues:

> *We've spent years and years and years developing a culture in mental health services where it is the professionals, the paid members of staff, who have the edge on knowing exactly how it is and what should happen to people.* NP

This quote links to another relevant theme that arose throughout the research; that of a concern with the increasing emphasis on professionals and on professional specialisation. With the arena of mental health services being a terrain that many professionals believe they have the necessary skills and competencies for, more and more professional specialities are appearing and offering their services in an increasingly crowded and competitive marketplace.

A number of experienced professionals also raised the issue of increased professional insecurity, especially in relation to the professions of nursing and psychiatry. One ex-nurse said he felt that nursing was at a crossroads and was insecure both about its role and its function. In many ways this is understandable; as psychiatry becomes more and more focused on bio-chemical causes and solutions and other professionals like therapists, advice workers and lawyers are expanding their services into the gap.

Policy changes: the public safety agenda

Part of the remit of mental health services has always been to try to eliminate or reduce the risk of people in acute distress, or suffering from mental illness, harming themselves or others. Because of a number of high profile cases of homicides in the community, by people who had had contact with psychiatric services, new national policies (DoH, 2000) are being drawn up to address concern that incidents such as these are on the increase. Both of the Trusts involved in this study had experienced a high profile homicide by one of their patients and a resultant high profile inquiry. During the period of data gathering, the White Paper (DoH, 2000) was a cause of great debate and uncertainty for both service users and staff. A double message was given to mental health professionals from the public, according to one senior nurse manager:

> *...they are demanding that not only do we care for people compassionately and therapeutically but we also stop them from doing this and stop them from doing that as well.* YT

One user-worker felt very strongly that these developments were working against user involvement:

> *The related legislation by the Labour Party seems to be more and more about control and manipulating freedoms... The dangerousness issue and the press portrayal of it is very big indeed and it's really putting the breaks on genuine user involvement.* RM

A statutory manager was less pessimistic, however, believing that good practice could and would continue, despite government policy. She believed that professionals would not reverse the progress they had made thus far:

> *You get on despite government policy rather than with the support of it most of the time. There is no way that the government can actually persuade the bulk of mental health practitioners to behave in a way they do not want to behave. There's no way we are going to turn round and suddenly start locking people up again and wrestling them to the ground in their own homes. We are just not going to do it. They can tell us to do it but we won't do it.* NP

Though these policies have yet to be implemented, the perceived association between dangerousness and those with mental health problems (see Dallaire *et al.*, 2000) was viewed by these respondents as detrimental to the development of increased participation of users in decisions about services.

Policy changes: health and social service restructuring

Health service restructuring was another structural impediment to user involvement evident during the time of this study. The plan to restructure health Trusts had been known for at least a year and a half before it happened; a period coinciding with my data gathering. Restructuring was taking place throughout the country and involved, amongst other things, the amalgamation of local Trusts into larger 'super Trusts' with expanded geographical areas. What this meant in practice was management structures being merged and post-holders having to apply for new jobs as their old ones disappeared. Fears about losing one's job, losing supportive relationships with colleagues, losing one's organisational identity, and a fear of change and the unknown, were all raised by senior manager respondents. These changes created considerable anxiety for professionals throughout both organisations, and seemed to slow many progressive developments, including user participation. Some users expressed complete frustration with the merger process believing that all their hard work and all their achievements were 'put on hold' for over a year while professionals worried about their jobs and prospective work domains. One active user in Trust A said of this time:

> *The last six months, because of this Trust merger, it's just like well forget it, we're doing nothing, so it was a waste of time even going to the meetings, so that's why I stopped really and said I'm not going anymore.* HK

Another service user active in this group was more concerned about the implications of the restructuring:

> *... the issue is going to be how you ensure that the voice gets to the top if they are that much more removed.* RW

The impact of this restructuring on the user groups in this study were severe, with professionals even taking steps to court favour with them in order to try to protect their own job prospects. The period before and after the restructuring of two Trusts appeared to have a massive destabilising effect on the user groups within them. Members of Trust A user group, after the formal data-gathering period for this study was over, described the process as devastating; with most of the key people in the group becoming unwell and being re-admitted into hospital. It is impossible, unfortunately, to make more direct associations between the user group disempowerment and this restructuring process. This is because most of these changes took place after the interviews had been conducted so I was unable to evidence any direct links between the admissions of user group members back into hospital and the Trust mergers. However informal conversations did suggest these links had substance and that user groups suffered huge set backs as a result.

Being at the 'sharp end' of services

Money and resources were mentioned by most of the respondents at some point when talking about constraints on user involvement. Staff shortages were evident in both Trusts at the time of the study, with shortages of experienced, non-agency staff in the acute wards most critical. Working at the 'sharp end' of modern mental health services in a large city, on the basis of evidence presented here, offers huge challenges to those looking to change power relationships. A number of quotes follow to illustrate these multiple demands and challenges:

> *There is the incredible pressure and workload. People may have good intentions but you have to cut corners to be able to complete the work that's required of you. So empowerment takes time. I heard the other day that one ward, for example, has an average length of stay of ten days so I mean how empowered can you be in that amount of time? User involvement feels like the icing on the cake. I guess that's what it is really.* YT

> *The work which has been most difficult is challenging the absolute basics of how we work with individuals in our basic practice. And that's so difficult within our Trust because so much of what we do is at the sharp end. Half our folk are*

> *sectioned on acute wards that are pressurised and they don't want to be there and we would rather they weren't there and they're horrible. And there is an awful lot of issues around the people that come via the justice system, the police and the whole issue of medication, They are familiar, any inner city anywhere probably have those issues. So with all that being the reality, what does user empowerment mean day to day at the sharp end of our services? As an organisation how will we know how individual workers are working with individual service users and how that's experienced? Huge numbers of our staff, by definition, only ever see people when they are really unwell, not just on acute wards where everyone knows that that's the case. It's almost by definition that we as staff are always engaging with people when they are probably the most unlike who they are.* NP

> *These days you don't get into hospital until you're killing the cat. You don't get in here until you're so mad that you're out of it and as soon as you can change the channel on the telly without falling over you're out! We're only able to work with people in the most acute distress, during the most acute phase, thereafter they're out. And that serves perfectly to protect you from too much criticism because what you lose is what you had in the old institution which was a chance to have people in before they went into the most acute florid psychosis or the most acute depression or whatever. You then supported them through a period where they were getting better. Interestingly, one of the biggest casualties of re-provision that users said they had lost, and this was something that nurses lost as well, was OK... you saw us when we were mad but there was an experience, a shared experience in common. As you were getting closer to discharge you had the chance to experience a peer relationship with the nurses. This was something that was quite wonderful where the nurses were able to relax more with you and your doctor was as well. There was this chance to emerge quite gently and naturally into a person-to-person relationship with the people who had been caring for you and this was tremendously therapeutic and that has been lost; that's out of the window. And it's lost to the nurses now as well because they never get the chance to be with somebody in the acute stage of their illness and into the next phase where they then forgive them for the fact that they poured their drink up the wall or whatever they did. You know they've missed out on that.* BA

This last observation is particularly interesting, because of the way it disrupts the traditional modernist narrative on mental health services that associates bad practice with the old-fashioned asylums. Describing the relationships between staff and users in this way challenges the idea of steady progressive change from bad practice to good, over time.

The other two quotes above from YT and NP also contain interesting expressions that merit further analysis. "*Good intentions*", "*empowerment takes time*" and "*icing on the cake*" were key phrases in YT's account, while in NP's narrative: "*they don't want to be there and we would rather they weren't there,*" and "*people when they are really unwell*" and "*come via the justice system*" stand out. These expressions all suggest that being at the 'sharp end' of mental health services, whether as a patient/user or as a staff member, is an unenviable place to be. A front-line nurse aptly described the tensions faced on a daily basis:

> *...it's almost impossible to empower clients to do anything for themselves apart from stay out of trouble. Sometimes I feel more like a prison officer than a nurse... you know you tell people when to get up... tell them when they've got to have their breakfast. They've got very little scope to do anything they want to do. There's one TV room where they can smoke, there's a garden... but somebody absconded this week so nobody else can go out there from now on. We used to have basketball rings but somebody else used the basketball ring to jump over the fence so that was taken down. We used to have a football but then it got kicked over the fence and never got replaced. So there's nothing for them to do. We just spend the whole day saying no to people mostly, there's very little to say yes to. You just try and encourage them by saying "if you behave yourselves you get out of here quicker". That's the motivation for this place. Staff have got to be motivated to do something and we're so short staffed... lack of input from the other departments like OT... low morale I suppose as well... it's "no I don't want to do anything with you other than what I have to, 'cause I'm just getting so much hassle". So you do what you've got to do really and not a lot else.* CD

This nurse continued, explaining how she felt unable to remain in this environment much longer:

> *You see very little progress 'cause the little bits you see and feel good about just get wiped out the next moment. So staff find it difficult and that's why people don't stay in the job that long. My mum was saying to me, because I was saying "I want to get out now" and she said "they need you 'cause you are prepared to fight for them". But it's like how much can you take? I really can't stand this so in the end you've got to put yourself first haven't you? Before the patients. That's what you end up doing... for your own sanity's sake and your job prospects. Make sure everyone gets out alive at the end of the shift, it comes down to that kind of model.* CD

An over-reliance on medication as the primary, sometimes only, therapeutic tool was also identified by respondents as contributing to an institutionalising, disempowering environment.

Being at the 'sharp end' led some staff to adopt a siege mentality, according to one user-worker:

> *There's a bit of a siege mentality starting to come through that's endemic and perhaps we automatically develop ways of protecting ourselves against the pain of what we experience. Perhaps it is an inevitable process that needs to be recognised and some form of... if not a sabbatical, some sort of change in the working environment just to recognise that there's an automatic process of numbing... and desensitisation which is just part of being human. Particularly in acute mental health services... what happens is that either they become so numbed, so desensitised that they don't even think anymore or it can take a number of more heroic forms. Some will numb themselves to it like everybody's asleep, the nurses are walking zombies and it's difficult to engage with them. They actually turn right off and it must be impossible for the patients when they do that and that is the bulk of the complaints that you hear from the wards... they're not being listened to or they're being ignored. But the other one is the "we're too busy" one which is like an 'ER' response. It's like... everyone is panicky and everything is done in a rush and the reward is that it's a means of getting through the shift and the sense of the reward is the sheer excitement... The feeling you get when you go on those wards - it's as if you've just stepped into the ER programme on TV rather than an actual A & E. It's as if everything is done in little puffed up cameos. I think it's actually more dangerous or certainly as dangerous as the "we've turned off and we're not engaging with ourselves or our patients anymore"... because patients still get ignored but they're rather in awe of these very, very manic people rushing around. Because everything is done at such a pace and in such a way where they feel they can't access the nurses, they don't feel they can be angry with them because they're obviously so hard working. And the nurses themselves are no more approachable about issues of change because at the end of the day they have the perfect reward which is walking away from the shift and falling into the bar. The ER approach often goes with alcohol abuse and that's the comfort and reward, the adrenaline.*
> BA

Menzies' work (1970), described in Chapter two, on the functioning of social systems as a defence against anxiety, can be drawn upon in the analysis of the above passage. Menzies believed that anxieties felt by nurses, primarily because of their relationships withpatients, led to the development of socially structured defence mechanisms appearing as elements in the structure, culture and mode of functioning of an organisation. The quote above by BA, gives Menzies' work a modern makeover. Using the analogy of '*ER*', a furiously-paced TV series set in an American inner-city casualty department, BA provides a way of understanding the link between the stress of working in acute mental health services and the resultant disengaged staff response to service users. The disengagement and detachment of staff from patients described by BA, can be understood using Menzies' (1970) analysis to be a defensive reaction to the stress of working with patients that helps nurses control their feelings of anxiety.Menzies' description of the ways in which the nursing service splits up nurses' contact with patients takes on a new meaning here. In this example, the respondent described staff employing mechanisms that deliberately sought to minimise time spent with any one patient. This is achieved by disengaging from the patients completely and turning into 'walking zombies', or by constructing a fantasy environment for themselves where they are too busy to engage with patients.

Another writer helpful in continuing this analysis is Lipsky (1980), who writes of the consequences of tensions between capabilities and objectives whereby workers rationalise the discrepancy between service ideals and service provision as the 'modification of the conception of work'. He views workers' attempts to redefine the nature of the job or the nature of clients as coping responses to job stress; where workers modify their objectives to better match their ability to perform. Withdrawal from work is one way of dealing with the tension between capabilities and objectives, either by leaving the service or by psychologically withdrawing, (Lipsky, 1980). The quote by the nurse CD on page 153 could be viewed as an example of somebody suffering from job stress and manifesting signs of withdrawal, due to the "overwhelming and insuperable difficulties of gaining gratification of task processes and achievement" (Lipsky, 1980: 143). Absenteeism, high turnover of staff and general withdrawal from involvement with clients are, for Lipsky, all responses to the pressures of job stress.

Chronic stress, burn out and the general disempowerment of staff means that survival is the mode of operating for some, perhaps many, front-line staff. The demands for user participation becomes yet one more competing demand. Lipsky's (1980) work on ideology and goal orientations helps to understand the source of these competing demands further. He argues that one of the ways in which conceptions of work in public services can be modified is through ideology and milieu. For Lipsky (1980) ideology can serve as a way of disciplining goal orientations when many goals compete:

> By stressing some goals over others, administrators partially solve the problem of what kind of institution they will run (1980: 148).

Objectives are therefore clearer and employees have a better sense of what they are expected to achieve. The medicalisation of social problems is one trend that Lipsky associates with the simplification of goal orientations in public services: it provides a defence against personal responsibility by resting responsibility for clients in their physical or psychological development. The medical model, according to Lipsky (1980), helps workers in public services to solve the problems of goal complexity.

On the basis of the data presented here I would argue that user participation is now one of the 'goal orientations' Lipsky (1980) describes; introduced with the drive towards consumerism in public services. However, this particular goal is contradicted by other goal orientations that exist within mental health services. The medicalisation of social problems described above, and the social control associated with the non-voluntary nature of most mental health and psychiatric services, are two examples. The contradictory nature of these goal orientations leads to some organisations asserting the primacy of one goal over others. Due to practices that appear to promote user participation and empowerment being associated with the 'moral high ground' described earlier, organisations now assert that user involvement and empowerment is one of their primary concerns. However, the goal of empowerment and the goals of social control and medicalisation, which involve removing power from users of services, could be described as diametrically opposed.

Variations in professional practice and cultures

A central finding from respondent's answers to questions on the barriers to user participation was the view that because mental health services are still dominated by psychiatry and the medical model, any radical changes are very difficult to achieve, for example:

> *The problem is that mental health services are still dominated by psychiatry and there are some people in psychiatry who have some very fixed ideas about things...*
> AC

Another common view was that there are great variations in practice across geographical areas, specialisms, Trusts and professional groups, as one user explained:

> *It depends on the professional, you've got the OT that turns around and says user involvement is brilliant and will actually listen to people and you've got people that are higher up just paying lip service. There are exceptions, some areas are very good and other areas are very bad. So you can't really generalise and say "yes it's good" or "no it's bad" because different people in different areas have given us a different response.* HK

One explanation for these variations lies in the implications and strength of dominant ideologies of mental illness, care and control. This was alluded to by an experienced user-worker who used the term *'different agendas'*, to differentiate between professionals:

> *There are probably different agendas within the professional camp. In my experience it's actually the clinicians, particularly the psychiatrists, who have been*

> *most ignorant about empowerment and involvement issues. I think they feel threatened by it. They feel threatened by a different perspective, a different approach to mental health, they want to hang on to the kind of supremacy of the medical model. So in terms of people who are mentally ill being able to make decisions about their own care you know they're not up for it, end of story.* MG

At this juncture it seems appropriate to address the links between ideology, beliefs and attitudes. Ideology, beliefs, value-systems and structures are all related and interconnected. The next comment blends all these factors together in describing the complexity of the relationship between factors that militate against user participation:

> *Prejudice is the biggest one. A lot of professionals still have a very paternal kind of attitude and they genuinely think that users just won't be able to cope, you know, poor dears, that type of attitude. So prejudice and the traditional culture of the services... the system is based on that kind of prejudice and that's an enormous barrier.* KM

"The traditional culture of the services" is a phrase that usefully illustrates the associated features of system and structure, ideology and beliefs. A realisation that the involvement and empowerment of users requires a change in the culture of services, was recognised by a number of respondents. One manager identified the importance of promoting a culture that was grounded in the experiences of service users, in her definition of user involvement:

> *...creating an environment in the Trust that supports a huge range of initiatives and the involvement of a huge diversity of people who use our services in planning, managing, evaluating, developing our services. I say that because what it definitely isn't, is just a couple of activities or projects or a couple of people or a group of people. It's very much about trying to promote a culture within the Trust where both service users and staff on the ground are supported to be thinking about practice and service delivery in relation to how it's experienced by service users. What we've been able to do successfully is incorporate user empowerment... values, objectives, strategies into the highest management level in the organisation.* NP

However, the 'top-down' approach described here, however genuine, often encounters fundamental problems in reaching the 'front-line' cultures that service users contend with on an everyday basis:

> *Even if senior management are more constructive then you get obstruction further down the line.* YT

To end this discussion on practice and culture I present an extract from an interview with a service user that knits together attitudes and beliefs with specific 'cultures' and the resistance of what he calls a *'canteen culture'*:

> *I'd be surprised if someone entered the mental health world, and they weren't genuine about trying to improve the quality of life of the people they're working with. I'd be surprised if they'd actually bother to walk through that door. I think everyone comes in with that intention. But... what happens is there is a canteen culture before you get through the door to the users. Like the police it's a canteen culture... And it's all very well for the top guy to say 'Oh I believe in user involvement, I want user empowerment', but if the people in the canteen don't believe that, then basically it ain't going to happen on the front-line.* DB

The term *'canteen culture'* is used here, in the same way that *siege mentality* was used earlier in this chapter (BA: 154), to denote a defensive response by a group of people to protect them from the people they have to deal with and the stresses this involves. Borrowing again from Lipsky (1980), workers may also stereotype their clients so as to reduce the tension resulting from their inability to respond to citizens according to ideal service models. The *'canteen culture'* described here could be viewed as illustrative of work described earlier in the thesis by Lipsky (1980), Menzies (1970) and Wardhaugh and Wilding (1993), on routinised, disengaged practices, and staff who depersonalise clients/patients/users in order to manage anxiety caused by the gap between the ideal and the reality of services.

Professional attitudes towards service users

None of the respondents in this study professed a belief that service users should not have more say in their treatment and services, though this was described as not necessarily common among all professionals, as this psychologist indicates:

> *There is a core of people who don't think that it's appropriate that users have more of a voice in the organisation. I guess because people don't like having their practice questioned or they don't like having to change in any way so they find that quite threatening.* WA

For professionals, seeing themselves as unaffected by madness and insanity is part of the ideology of the medical model and an institutional legacy that still pervades. Perceiving users as 'the other' has enabled professionals to distance themselves from madness:

> *There's something about mental health professionals distancing ourselves from madness.... So if we're going to sit in community with madness, if we're going to sit in a round with madness then... we can't be so sure about our own sanity and there's a lot about validating our own sanity by placing the insanity in the Other...* JR

> *There's the larger wider thing about how the community, your family and friends, well society in general, treats users and patients. Mental patients are non-people,*

> *as people to be feared and you take that on anyway whether you are conscious of it or not.* PF

Placing madness in the 'other' is present in wider society and a fear of madness is well documented as one of the main reasons why treatment of the 'mad' or mentally ill has been so severe and punitive in the past (Scull, 1989).

Professional boundaries between work and non-work were also identified as part of the reason why professionals do not always relate to service users as people. A fear of acknowledging one's own distress and vulnerability was one reason suggested for an obsession with boundaries, according to this user-worker:

> *One of the biggest problems is our own fear which gets us back to the issue of disclosure, people's fear... if we compartmentalise our fears of our underbelly, our emotional underbellies where the risk of the gulf between the person that we are at work, the person we* ***present*** *when we are at work, to perhaps the more chaotic and unhappy people we might be away from work or the dissatisfactions in our lives... You'd think it was an environment where it would be easier to talk about relationship problems or your problem with alcohol or the aspirin crunching habit or whatever but in fact it's more difficult. It's actually easier in a commercial office environment than in nursing and it's something about nursing and practice that makes it more difficult. I think there is a feeling that the users in crisis represent to us a lot of what we don't want to know about in ourselves and are frightened of within ourselves.* BA

Another service user suggested that rather than being non-persons, users are treated as 'special' and therefore different:

> *This is a classic case of user involvement - I've been invited to this meeting about opening these two new wards in the borough. Now what they'll say is "well what do people want? What do people want on wards?" and what I might say if I feel like it is "well what would you bloody like if you had a breakdown? Try and think! You're not that alien to the concept of mental ill health", "you've probably had it, you'll probably get it again, God forbid they cart you into hospital, what would you like? How would you like to be treated?" Now if people started thinking in those terms more often rather than you need special little things because you're special little aliens and we can never be part of your world. It's rubbish!* HK

These commentaries have particular relevance as we watch current Labour government proposals to increase restriction on the rights of people with mental health problems (DoH 2000). Here, public policy is directly affected by the 'demonisation' of those experiencing mental distress, and this creates an increased sense of fear towards those society is encouraged to perceive as 'different'. In fact, the evidence presented here suggests that at least some mental health staff do not view service users very differently from the way the general public perceives them. Here a nurse manager is honest about her disappointment in her colleague's beliefs:

> *Unfortunately some of the remarks that you hear from staff are very similar to people who I would say are ignorant i.e. the general public. You would hope that the people who work within the organisation would be a bit more enlightened but I've heard people say "what can you expect, these people are not normal". It's almost like nothing users can say or do will be valid because they have the tag of having mental health problems.* YT

A service user from another Trust offered a similar observation:

> *The view of the person who's mentally ill, is that we're thick, we're not very bright and we're life long, that is that we're going to have this diagnosis forever. We aren't ever going to work again, we probably won't have kids, if we did, it wouldn't be wise. That's the common attitude of a lot of staff that I've come across, that you're not normal, that you're a severe case of schizophrenia or whatever. The majority seem to see us like that, we are not encouraged to get a job or have a life or have an input even in services.* HK

Summary

This section has presented the findings from the study on the barriers and obstacles to user participation in statutory mental health services. According to the data analysed, societal views, changes in social and health policy, organisational structures, the pressures of particular environments, shortages of resources, defensive staff practice and disempowering staff attitudes, all have a role to play in curtailing good practice in relationships between professionals and service users. The barriers to users being more involved in their services can be viewed as being contained within a prevailing ideology that militates against user participation by emphasising the sickness and 'difference' of the service user or patient. The medical model and traditional, institutional 'canteen cultures' can lead to low expectations of service users by staff and a focus on professionals as active agents, by virtue of their assumed sanity and health. Work by Lipsky (1980) and Menzies (1970) has been drawn upon to aid a more detailed analysis and to illustrate the mechanisms that may be preventing change in user-professional relations, despite protestations otherwise.

Conclusions of Chapter

This chapter has set the scene for the later analysis of user-professional and user-organisational power relationships by describing the findings relating to the first of the three main groups of research questions: ***to describe the current policy and practice environment of user involvement in the contexts studied.*** The sub-questions in this section were focused around the meanings, motives, conditions, incentives and obstacles that surround collaborative activities occurring between users and professionals/managers in statutory mental health services.

The material presented elaborates on the literature presented in Chapters one and two. The data presented indicates that user involvement, in terms of increased information and choice as well as increased control, is not widespread in the contexts studied. Although practice varies considerably, between service settings and individual practitioners, the research suggests that the involvement of service users in their care and treatment is not happening in the way suggested by hospital policy or professional/academic rhetoric.

There was no overall consensus amongst respondents in terms of the meaning of user involvement. Although some respondents found the term useful and felt that it reflected a degree of change, others felt that the words 'involvement' and 'participation' were meaningless; giving the impression that things were changing when they were not. The most commonly shared response was one of scepticism towards both the idea, and the practice of, user involvement. Of the professionals and managers interviewed, only the senior manager responsible for user involvement within Trust B talked about involvement and empowerment in non-sceptical ways. Other respondents were wary of speaking against the 'party line', but when they did so, they were generally scathing about the lack of change that was taking place through 'top-down' approaches.

The preoccupation of Trusts with their image, and of 'being seen to be doing' user involvement, demonstrates that some organisations may involve users in order to claim the 'moral high ground'. Indeed, this has been posited as a primary motivation for some Trusts. The scepticism of the majority of the respondents could be said to indicate their belief that the changes that have occurred have, on the whole, been illusory. The claims of user participation and empowerment do indeed ring hollow when set against the responses of the staff that work 'on the front-line' and the users who receive services 'on the front-line'. Throughout this research, mental health services have largely been described as; chaotic, under-resourced, professionally driven, sometimes abusive and often disempowering, for both staff and service users. Additionally, the experiences of many respondents emphasised a disparity between how a service is experienced and how a service describes and perceives itself.

On the subject of what conditions were cited as contributing to a more receptive environment to user participation working; the attitudes of professionals was considered to be the primary factor. Strong leadership and management within an organisation that created policies and codes of conduct to support good practice and challenge bad practice, was also identified. Less pressurised settings, more resources, more staff and the practice of moving staff around, were also mentioned as important factors in creating a supportive environment.

Amongst those professionals that had worked in partnership with service users, many identified rewards that confirmed the value of these activities to them. Although the work was described as very challenging, many said that they would continue to work in these ways. The single most motivating factor for staff was the value accrued from breaking down boundaries between them and the people they provided services for. This breaking down of boundaries, as other writers argue (Menzies, 1970), is a vital prerequisite to wider organisational and cultural change. For service users the rewards related to having an impact on, and making a difference to, service provision. Political and other new experiences were valued as learning opportunities, as were the small payments received for being involved with activities initiated by service agencies.

In terms of the factors that impinge on power sharing processes in mental health services, a variety of factors have been identified in this research: chronic under-funding, stretched services, suspicions about the motives of government and the desire on the part of statutory services to continue their role as providers, all serve to limit the degree of choice and control available to users. One of the most significant contributions of this research has been the way that user involvement has been shown to be limited by the institutional contexts within which it is situated, and by the institutionalised practices of staff working in these contexts. This is a theme that continues through the following chapters. A notable factor limiting the effectiveness of involvement strategies is what is best described generically as user group problems; this subject will be covered in Chapter six on the capacity, power and powerlessness of user groups.

A final word on negative cases is required before moving on. In qualitative research it is important to attend to negative cases in order to make the transition from raw data to analysis transparent. Negative cases are examples from the data that do not fit with emerging patterns. Within this part of the research the only negative case found in the interview responses was a respondent who said:

> *We haven't found many barriers... I can't say there are any barriers... but that's not necessarily true for all user groups and all Trusts.* FN

This negative case does not contradict the findings previously described. No other negative cases were found in the data that are not compared and contrasted in the text.

Chapter Five

Mapping the tensions of participation in practice

The group of research questions addressed here are concerned with mapping the tensions that exist within participatory activities, particularly in relation to power. The presence of significant tensions within participatory contexts has been noted in previous research, as described earlier in the thesis. When analysing the data related to this category, I use some of the theories and models of power and participation described in the literature review earlier, to illuminate tensions within the interview accounts. The chapter is particularly concerned with examples of professional and organisational resistance to the involvement of users, as can be seen from the main subset of questions below:

- What challenges does the sharing of power in mental health services pose to those professionals involved? For example, what examples of conflict can be seen? (Addressed in Part one)
- Can participation in mental health services be understood using the consensus model of involvement or does the conflict model offer a more accurate tool for analysis? (Part two)
- Is there evidence of professional resistance to user participation and power sharing? (Part three)
- If so, how is this resistance manifested in structures and processes? (Part four)

The chapter explores the strategies and tactics used by organisations and professionals to resist increased control by service users, and focuses particularly on the representational model of involvement and the limitations this approach creates for devolving service power. Again, each research sub-question shall be dealt with in turn.

Part One: The Challenges of Participation in Mental Health Services

Unsettling relations: role insecurity and ambiguity

The risks to professionals of sharing power with service users/survivors have been articulated by Church (1995), as involving both professional and personal dimensions. In this study, some professionals admitted to finding the idea of users setting up their own systems of help and support very challenging. This clinical psychologist was honest about her apprehensions:

> *The first thing that jumps into my head is that one of the biggest barriers is the question... if this user involvement is successful does that mean that the rest of us are unemployed?! (laughing). Does it mean that you end up in a few years time without NHS psychiatry? Does it mean that there are no jobs for psychologists? In some of the meetings I go to with users... people are saying rather than fighting against the system we should be trying to set up our own systems and our own services which would mean that there would not be the present psychiatric services and the need for professionals... which is very challenging to us...* WA

This comment addresses the consensus versus conflict theory of change (Ng, 1980; Rees, 1991). As described in Chapter one, a closer look at different calls for user participation reveals conflicts of interest and a split between the consensus and conflict agendas. As this psychologist describes, being part of a reform movement for change is one thing, being told you're no longer needed and that you're actually getting in the way, is quite another:

> *It's easier to think well this is what happens and then criticise and challenge it, trying to prevent abusive practices and try to make them a little bit better... it's quite mind-boggling to actually think it's not about doing any of that but instead trying to create something completely different... it's difficult to get your head round that when you're involved in providing services. There's something about reforming the old system but there's also something about making sure it carries on and everything really stays the same by just changing a little bit to keep up with the times.* WA

The shift from activities to reform the present system, to activities that attempt to undermine the current system and replace it with another, represents a challenge to those who previously saw themselves as change agents. Although motivated by her wish to make improvements in services, WA was uncomfortable when the emphasis changed from reforming to replacing. Her awareness that reformism is an attempt to keep things the same, as much as make sure they change, is probably an enlightened position when compared to other mental health professionals.

Being comfortable with the way things are, and not being prepared to make the extra effort that user involvement requires, was a recurring theme throughout the interviews. This was partly explained as being inevitable given the pressure under which many professionals work, but apathy was also identified as a contributing factor:

> *For professionals it's something very challenging and hard work and for a lot of people they don't want to do that amount of hard work. I think people go to work, tell people what to do a bit you know and go home.* JR

This user-worker refers to the additional energy required if professionals are to develop their practice in line with current ideas, or reflect critically on their practice. Having one's position undermined, where the taken-for-granted roles and expectations are no longer current, requires reflection on how one works. This respondent did not feel many people had the energy or volition to do this and suggests that demands for user participation present a fundamental challenge to the sense of self and role of professionals. These expressions of professional insecurity and role ambiguity reveal the uncertainties that arise when challenges to traditional power structures take place.

Professional disempowerment: what about us?

When asked about professional responses to user participation, the overwhelming view of respondents was that users having more power, or being *perceived* to have more power, compounded professionals' sense of their own disempowerment:

> *There will be some staff that feel "where is our empowerment?" and that's where the tension lies. They feel that maybe users are becoming more articulate and empowered and nobody is actually doing anything for staff.* DB

A user-worker in Trust B agreed that the disempowerment of staff on the acute wards of hospitals was very serious:

> *Staff feel that users are getting everything and they are not being listened to at all.* BA

And a nurse manager in the same Trust stated that her staff felt that:

> *...if another person comes in there is always a little less power for me unless I keep that person powerless.* YT

These quotes demonstrate the 'zero-sum' (Clegg, 1989) conception of power; in which power is assumed to be finite so that being powerful involves the assertion of control and strength over others. This analysis of power has been criticised as naïve and deterministic compared to more recent analysis (Clegg, 1989; Fairclough, 1989; Foucault, 1972, 1973, 1976), however, it is clear from the quote above that the 'zero-sum' model has currency for practitioners.

The nurse manager YT, quoted above, elaborated on her views as to why staff were so sensitive to their power status or lack of power:

> *As I go round and talk to staff they say that patients have more power, they are able to make complaints, make allegations against us and we don't have a leg to stand on, which leads to defensive practice. So people feel more and more disempowered and under stress. At the moment in this Trust in-patient services are coming under a) scrutiny and b) criticism, so it feels that they can't do anything right and that their needs are not being addressed in terms of organisational changes. So you can kick the cat can't you? There will always be someone else that you can slap. If you've got doctors and psychologists saying "you should be doing more of this" and then you've also got the users saying "we want more of this" then you're between a rock and a hard place. People don't want to share power and particularly if their attitudes towards people with mental health problems are not... ...as is presented in the lovely journals, I don't know... maybe people are more comfortable working with service users when they are one peg down, well at least one peg down.* YT

Another manager (a user-worker) within the same Trust echoed these sentiments:

> *There's a sense I get from the wards that "you do too much for users". That if users ask for something they get it, which is not true at all but that's the perception and I think that the language we're using is maybe contributing to that. They are saying "it's right that those things are happening but who's asking us what we feel? Where's our questionnaire? And if there is one will you take it seriously?" There're like "we know it's a good thing... but nobody is asking us what we feel, nobody's taking us seriously".* BA

This manager's analysis; that professionals are feeling disempowered partly because they see users being more empowered than they previously were, is interesting. It can be argued that front-line nursing staff have always been under-paid and under-valued for the work they do. Certainly work on the social organisation of nursing, by Menzies (1970) and others, makes the case that the systematic disempowerment of individual nurses, as well as the profession, is widespread; especially under certain regimes. From the respondents' views presented above, it appears that front-line workers are finding their lack of power increasingly difficult to cope with because the people they previously had most power over, are seen *by them,* as more powerful and more articulate about their rights.

"Whose side are you on?" was an expression that emerged in accounts of staff disempowerment; a phrase also used by Becker (1967). Professionals who positioned themselves as allies of users and user groups sensed that they were viewed suspiciously by their

colleagues and fellow professionals, felt that they risked making enemies within the organisation, and feared that they would be over-looked for promotion. They also felt that they were viewed suspiciously by service users, who were unsure whether they could be trusted.

Unsettling relations: dealing with anger

Being challenged by service users with negative experiences, and dealing with their anger, was viewed by professionals as one of the main challenges presented by processes of user participation. In comparison, the users and user-workers I spoke to were quite matter of fact about this expression of anger:

> *...the first user group itself actually quickly collapsed because it was trying to be a user and professional group and there was too much anger within the users so the professionals stopped coming because they could not deal with the anger.* MG
>
> *Staff sometimes react to user's anger and get upset by it. They can't see the positive side of being angry, that it can be quite liberating. It's quite an English thing to be uncomfortable with anger. They even thought that being angry was part of being insane and in that way dismissed what we were saying.* HK

For the professionals it was a different matter:

> *We've found it challenging in some quite uncomfortable ways... users are often quite provocative and challenging and will say things like "do you really think that continuing to practise as a psychiatrist is compatible with being critical? Aren't you just kidding yourself, aren't you just playing at it?" And I think these are all quite difficult criticisms to deal with. We do our best to be genuinely sympathetic and sometimes I am genuinely shocked at some of the horrible things that have happened to people in the system. But there's also a reaction that's evoked by people who are very angry and very hostile about psychiatry which is the one that's a sort of... gut reaction for psychiatrists which is to say "well actually that's your problem, you're the mad one, you're the one with the disturbed personality, you're the one who's unable to see that we are only doing our best to help". In a sense to rubbish their experience or to deny it because accepting the reality of their negative experiences is very uncomfortable because we feel trapped too. Working as a consultant I was responsible for treating the patients on a ward which I felt was ugly, dirty, squalid, understaffed and not a very conducive place for the treatment of psychiatric patients and what does one do? It doesn't feel like a very meaningful option to say "well I'm just not prepared to work in this sort of environment because it is so unpleasant" but working in it you are laying yourself open to people being extremely angry and distressed and saying "I was on your ward, I was*

> *under your care and I was offered useless, distressing and unpleasant treatment and what are you going to do about it?"* EN

What is interesting about the above comment is how psychiatrists are described as resorting to the illness model in order to justify their positions A response of: *"well actually that's your problem, you're the mad one, you're the one with the disturbed personality, you're the one who's unable to see that we are only doing our best to help",* is typical of what Lipsky (1980) describes as the ability of the medical model to provide a defence against the personal responsibility of the worker. If responsibility is placed on the mental and behavioural characteristics of clients, then the services, and the professionals that work in them, are shielded from having to confront their own failures or the failures of the agency for which they work. The expression of anger, through the increased 'voice' of service users/survivors, seems to be easily dismissed by professionals who blame a user's illness or behavioural characteristics for their 'inappropriate' displays of anger. Another significant feature of this quote is the idea that service users are holding psychiatrists accountable for the practices that go on in the wards. EN seemed to acknowledge that he was unable to account for the dreadful experience that many people have in 'his care'. He also seems to acknowledge this as a legitimate challenge by saying *"and I think these are all quite difficult criticisms to deal with".*

Professional expectations about the 'place' of service users, were clearly violated in examples discovered during this research; especially when users were involved in training professionals. A service user and psychiatrist comment below on the dynamics that this can raise:

> *We can get quite firey, because we know we've only got an hour, we've got an hour within a year, that's the only exposure they will get to users in this way ever! So we do role-plays, workshops, give them loads of handouts, try to get this message across and they're like completely blown away by it and find it a bit aggressive.* HK

> *Junior doctors often do feel in a very uncomfortable position because they feel they are practising... they are doing things they don't always like doing and they don't always feel their knowledge base is secure enough to justify them doing it so they are doing it because they are told to. And then somebody comes along who from their point of view says "what you're doing is outrageous and wrong and it's rubbish" and they feel tremendously attacked by that. They are not in a position to do anything about it and they are supposed to learn that it's all a very good thing and pass exams in it and then there is someone having a go at them over it.* EN

Junior members of staff confronted with dissatisfied service users who have been given some authority over them if only temporarily, can feel insecure and threatened, and in Trust A training of junior doctors by service users was stopped as a result of complaints from doctors about this exposure. One professional spoke about the increased risk of these defensive reactions occurring, especially when users came from different cultures to professionals:

> *It might be easier to have involvement by users who are educated middle-class people who speak the same kind of language as professionals and it might be less easy to have involvement where users... I'm using stereotypes, but it would be harder to imagine a Black service user coming from a drug culture who presents a very different angle... being heard.* WA

Other issues arise when service users are given opportunities to take on roles other than 'patient', through working with professionals on committees or being involved in training. These extended roles can bring added complexities and risks for service users. The instability of some service users' health could result in them being readmitted to acute wards, and treated or nursed by the same professionals they were previously working with or training, for example:

> *Some people do struggle with the idea of working... as equals with users in particular settings when they're well and then having to be back on the wards when people are unwell. I must admit I find that... not difficult in a bad sense but it's a change, of suddenly you're in a different role with somebody. Somebody you've been working with on a committee and suddenly they are on the ward and you get a message to go and see them and they are not particularly well at the time, it is hard to somehow adjust your role. So I think that's something we're all struggling with because we are using... genuine users. When I say genuine I mean some hospitals would have some people who have been unwell a long time ago and have almost become sort of professional users, but we are working with people who do become unwell and are back on wards on sections. If you're a nurse or doctor it can be hard, because that's the person who in a different forum may have been the one teaching you about things and then suddenly you are caring for them. But obviously it's even more difficult for the client themselves, they must find it incredibly hard, to have the status of being a user consultant and then suddenly be back on the ward with very little status.* TB

This insecurity and vulnerability for service users is part of the dynamic of being an active service user within an organisation that also casts users in dependent roles as 'patients'. This vulnerability has been noted by Williams and Lindley (1996) who highlighted the extra stress experienced by users who were involved in trying to change the services they used. Role ambiguity is, therefore, an issue not only for professionals but also one for service users.

Summary

This section has presented a number of comments concerning the role insecurity and ambiguity experienced by professionals. Many of the professional respondents were genuinely in favour of increased service user influence and control, and actively supported initiatives of this ilk. However, hostility and apathy, although not detected in any of their comments, was described by many of the respondents to be reactions of some professionals they knew. A significant finding among professional respondents was the "what about us?" feeling: indeed, the extent of professional disempowerment among front-line workers in high-pressure services was described by respondents as acute. The predominant view was that increased power for service users left professionals with less power; an analysis that assumes the zero sum model of power (Clegg, 1989), and fails to recognise the possibilities of power as relational rather than as 'possessed'. Clegg maintains that power is 'possessed', by individuals, 'only in so far as they are relationally constituted as doing so' (1989: 207). Without doubt, the power issues discussed here are complex and challenging for all concerned. Nevertheless, conceiving power within the zero-sum model does not offer the flexibility required to make sense of the complexity of user-professional relationships, because power is viewed in such an uncompromising and rigid way.

The important question is, therefore; can the destabilisation of power relations in mental health services achieve changes in how power and disempowerment is understood and how it can be 'shared'? As this section has shown, professionals *have* felt the impact of the enhanced status of service users within the organisations in which they work, even if that new status has created little tangible change. Professionals in the study expressed feeling challenged and uncomfortable; appearing to have lost the taken-for-granted status that Lipsky (1980) has described as a feature of workers in public services. From the evidence presented here, user participation has contributed to the destabilisation of the previously static, hierarchical relationships that are still prevalent within most institutional mental health settings. It has been suggested that this loss of professional status, and consequent role insecurity, may be symptomatic of a shift in the status quo within organisations. Wider challenges to medical hegemony through a range of theoretical and policy changes, may add to the professional sensitivity and insecurity that arguably represents this shift in the status quo. The next part of this chapter examines conflict situations more closely, with the aim of distilling the insights they may provide for a further analysis of power in the context of user participation.

Part Two: Analysis of Conflict

The second section of this chapter examines examples of conflict in order to illuminate power in action. It is divided into three sections; conflict defined by professionals, conflict defined by users and user-workers, and evidence of a professional resistance to service user participation in mental health services. Different theories of power (Bachrach and Baratz 1962; Foucault, 1972, 1973, 1974, 1976; Lukes 1974) will be used to inform the analysis. I also make particular use of consensus and conflict theories of social change (Ng, 1980; Rees, 1991) throughout this section.

Conflict according to professionals: what conflict?

An interesting aspect of professional respondents' views of conflict was that none spoke directly about having been in conflict with user groups. However, the concern to 'be seen to be doing' involvement, may have led to professionals putting a rosy gloss on any difficulties encountered and may well explain the reluctance of professionals and managers to talk to me in terms of conflict and power. This should be borne in mind before drawing general conclusions from my analysis. Having said this, I shall, for the purposes of providing propositions about power in action, draw out some of the underlying issues I have interpretated in the data.

When looking for signs of power beneath the surface of the accounts I was given, it was possible to identify a number of factors linked to conflict and control. The first factor was subtle control of service user groups by their 'parent' organisations, and can be discerned in the comment below by a senior manager in a voluntary sector organisation, when asked whether he had experienced any conflict with the user group he had helped get off the ground:

> *We work much more in alliance with the user group than get into conflicts with them... I'm trying to think hard of anything we've ever actually strongly disagreed about and I can't, I really can't think of anything... as I say detail, you know, if they were going to publish something in a newsletter and some of it was a bit strong then I might say well, you need to tone that down a little bit... because you know if you're just completely antagonistic to the statutory people you're probably not going to get as far because there are some very nice people working for statutory services not just nasty people... so when service users have come to us and said what's your advice on the best way to deal with a subject, we were thinking of doing it like this, we might have said "well, perhaps you should try it like this first" so that's not a conflict really that's just saying - can you advise us on what the best techniques to use are 'cause we were thinking of doing it like this so I, I really can't think of anything.* AC

By exposing this comment to critical analysis, it seems to describe a scenario that may be indicative of the many ways that user groups can be influenced/manipulated by other more powerful individuals and groups; albeit often unconsciously and subtly. In the situation described by AC, the manager advised the group on the best way to deal with the statutory sector services and this advice could be described as advocating a consensual rather than conflict model of change (Ng, 1980; Rees, 1991). This may well have been good advice, based on experience in the field of trying to create positive change in mental health services, but is not impartial if the voluntary organisation has an interest in maintaining consensus relationships with statutory services.

Also significant, is the reluctance on the part of groups that are 'under the wing' of voluntary organisations, to speak against their 'parent' groups. The user development worker of the user group referred to by AC previously, describes how she viewed the relationship between her user group and the 'parent' organisation:

> *We're actually closely linked to X since we are a project of theirs. I don't think we've had any run-ins with them. Once or twice they've commented on how we've spent our money. When we first started we were doing a lot of lunches to try to do a lot of networking and found we could talk to people a lot easier over lunch than attending a meeting so we would pick people off from key establishments and get them round a table and have a lunch, and that took quite a bit of funding, so yes it was frowned upon, it wasn't stopped but it was frowned upon, but as a rule we have very good working relationships with other bodies.* BM

This group had received the message from their 'parent' group that having lunches was not an appropriate use of funds because it cost too much, which begs the question; is it only going to meetings that is OK? Professionals often view going to lunch and networking as essential aspects of their business so this suggests there may be different 'rules of the game' (Clegg, 1989) for service user groups than for professionals.

Another example of consensus relations potentially masking conflict was a criticism of user-professional relationships as being too 'cosy'. This was suggested by one respondent when describing his Trusts' methods of user involvement:

> *I think we've got to question aspects of our model... the joint meetings we have that use a traditional model of a meeting may be OK with a lot of our users who know it and feel safe there but for some people the idea of going to the headquarters of the institution that suppressed you and dehumanised you.... I mean there are other users out there who don't feel comfortable with this and are not able to have a cosy rapport with us. I feel sometimes that it's a little bit too cosy. Sometimes there should be more anger and conflict because the bottom line is that we are on*

> *different sides... of the fence. And sometimes at the meetings we all agree about everything... I'm not saying you have to have huge rows all the time but occasionally I would want to be at one of those meetings and somebody, a user, to bang on the table and say "NO this is wrong, here you all are sitting being cosy".*
> TB

If there is a comfortable relationship between professionals/managers and service users potential conflict may be brushed over since it is not seen as being in anyone's interests. Another respondent in the same Trust suggested a reason for this lack of discernible conflict:

> *...you've got an established relationship with a user group whereby certain individuals are feted and paid to attend certain selected committees, not the really powerful ones but the ones that are seen as being OK..* BA

Who gets chosen to represent others and the remit they are given, is a theme that came up in a number of the interviews. A critical analysis of *where* involvement of users is allowed to take place, and *how*, can be facilitated using the work of Lukes (1974) and Gaventa (1980). Lukes' (1974) seminal work on power develops what he terms the 'third dimension of power'; whereby powerful groups influence, shape and determine less powerful groups' wants and needs. It focuses attention on the power processes, meanings and patterns that get 'B to act and believe in a manner in which B otherwise might not, to A's benefit and B's detriment' (Gaventa, 1980:15-16). In this scenario, a lack of overt conflict can occur as a result of B's perceived or actual powerlessness, illustrated here by WA who describes the disempowerment of many of the people she has worked with:

> *...users of mental health services are disempowered to the extent that they only actually ask for things that they might be likely to get so it's quite rare that they'd actually be in complete disagreement or be saying something very different from staff. That probably depends on whether you are working in a service where people are much more able. So if you are working in a service where service users are more likely to hold down jobs and have other resources like self-identity and so on, they are much more likely to say something against staff. But I think it's unlikely in an area where people are much more disabled and that really highlights the power difference.* WA

The dynamic described here, where people only ask for things they might be likely to get, has been described by Friedrich (1937 cited in Clegg, 1989) as the 'rule of anticipated reaction'. This theory describes a scenario where B anticipates A's likely opposition and consequently does not raise an issue. So, as the quote by WA describes, issues might not be raised if they are anticipated to fail. A's power, therefore, extends to formulating the issues to be discussed or seen as important.

A further variation of non-decision-making can occur through the *mobilisation of bias* or the process of the *organising in and out* of certain issues (Bachrach and Baratz, 1962), as was described in Chapter four. What needs to be made explicit here is the potential for latent conflict to exist in user involvement forums even though it may not be apparent to those involved. Although conflict was not named by professionals as an important issue, I suggest that this could be due to the effective *mobilisation of bias* that not only determines whether certain demands come to be expressed, but whether such demands will even cross people's minds.

We are on the same side

Another effective strategy for creating the impression of a consensus between service users and professionals, was one where professionals made comments such as: "*we are on the same side*", and "*we are as frustrated as you about the failings of our services*". A senior manager, responding to a question about conflict, described this thus:

> *It's not so much conflict, it's frustration about the fact that we've made very slow progress towards some of the real important goals. I can't remember a situation where it's been you know we all think this and you all think that. It's more about "look we've told you five hundred times that we want an alternative to hospital admission and you still haven't got it". "We've told you a million times that we want proper out of hours services and we haven't got it yet". But how we've dealt with that is to try and enlist people's help to make joint representations to the Health Authority or whoever but in terms of saying look "these are joint priorities about where we need to go next". So, for instance, some people in the service user groups have written to a whole range of people, the Government and politicians and we would have had a Trust stand on endorsing or supporting that and we very much do share information... it is trying to engage some of that frustration in saying well "who do we talk to about it, we're as frustrated as you".* NP

This manager is being genuine in her concern to work with service users on commonly identified issues of concern, though some interesting phrases emerge in this passage: "*a Trust stand on endorsing and supporting*" and "*enlist people's help to make joint representations*". These appear to communicate a reluctance to assume responsibility and it is important to ask here; what is this manager's role in supporting or denying user group's pleas for change? Moreover, what is her role in justifying, or not, the Trust staff's position and giving it legitimacy or not? The constrained nature of funding for mental health is of course a factor here, and statutory services are clearly under-funded for what they are expected to provide. Lobbying higher level decision-makers may well be a worthwhile goal for 'joint representations' and this is not being contested here, but I do wish to raise questions about the mechanisms by which conflict and disagreement is represented by professionals and managers.

Reconstructing 'the problem'

The next comment is a continuation of the one made previously by NP, and a good example of another dynamic that occurs when discussing conflict between users and professionals; that of the reconstruction or re-presentation of conflict as a problem between individual (or groups of) service users:

> *The conflict I have found most difficult is between service users and over the years there have been different people coming and going and different groups coming and going and the bit I find most stressful and difficult to manage is when people are falling out with each other. Sometimes it gets to big conflict, big arguments and shouting and there's this feeling that somehow I could be an arbitrator... Sometimes people say "I'm not going to be involved anymore if they are" and you sit there and say "well no actually there's space for quite a range of people and different perspectives" and I certainly don't want to get suddenly dragged into making decisions about who's in and who's out and I refuse to do that and I will say "what support can we give to perhaps sit down and talk about this... ".* NP

The key words/phrases here are: *"arbitrator", "dragged into making decisions about who's in and who's out"* and *"comes with the territory"*. Within any group there are individuals with different views, not only about the matter in hand but also about the way change should be brought about. Within the service user/consumer/survivor movement there are differences and divisions which are to be expected. Conflict in user groups and different beliefs about how change should come about can be a big drain on the confidence, energy and ability of groups to function. My intention is not to deny conflict between users but to 'problematise' this manager's account, by drawing attention to the way it places responsibility on 'the other' for the lack of progress caused by infighting and strife.

The same manager follows up on this point and sets out the parameters of these different positions well:

> *The biggest tension for me seems to be between service users and service user groups who are very strong proponents of the partnership, collaboration model, you know wanting to play a full part in identifying the problems and the solutions and working together and those people that feel more comfortable being slightly on the outside and giving some strong messages in, the people who are happy to play the campaigning role and to be really saying it like it is. It's good having people who are comfortable sitting on the outside because they do keep you... make sure you're not getting complacent. But actually what we really need is the people with the skills to help us to find out what we should be doing. But what happens sometimes is people end up deflecting energy amongst each other and then we are*

> *all losing very important input and expertise and energy on things that we can actually change.* NP

Here the key phrases seem to be *"slightly on the outside", "strong messages", "saying it like it is", "complacent"* and *"deflecting energy amongst each other".* There is a sense of frustration that people are not all 'on message' with the Trust, and its views about the 'things we can actually change'. There is a discernible element of blaming users for the loss of 'very important input and expertise and energy'. Use of the word 'arbitrator' (by NP on the page before) denotes that the professional role within these disputes is an active rather than a passive one. The professional here is being called upon, or sees herself as being called upon, to resolve or settle these disputes. She is also being asked to adjudicate on who should stay and who should go, in 'stand off' situations. Importantly, the status of the professional is assured and reaffirmed through the experience, knowledge, or wisdom to deal with the 'problem'. Yet again, service users have become the problem that professionals are required to resolve.

The previous comments from NP also refer to the favour conferred on service users who work alongside the Trust to achieve change, as opposed to the people that work 'slightly on the outside'. What seems to be suggested is that, although it is useful in principal to have people taking different positions in relation to the Trust, what is *really* needed, in practice, is: *"people with the skills to help us to find out what we should be doing".* Although the respondent believes that there is a place for everyone at the table, other comments place this belief in question because she clearly and understandably states a preference for people who *"want to play a full part".* She makes no attempt to hide her frustration at the people sitting on the outside saying it as it is:

> *...actually practically all the people we work with more or less... are in the "well lets see what we can do about it" and I know that's not the case elsewhere and I'd find that really frustrating if the model was very much of people from outside shouting in. I'd be saying "come and help me do it, don't expect me to know what the answer is, I don't expect you to know what the answer is but together we might".* NP

That professionals take care to present the activity of involving mental health service users, in the main as conflict free; certainly in terms of conflict with professionals, is interesting in itself. A manager with a similar responsibility for user participation in a different Trust made a similar comment about his Trust's excellent relationship with its user group. He also took the view that his Trust was lucky to have a user group that worked with them to change things rather than being 'obstreperous and difficult'; a characterisation he made of users in other Trusts. Both these managers described their relationship with their user groups as very good, whilst both also thought that other Trusts geographically near to them had bad relationships with their users. In these cases, articulating positive relationships with users became a key device for claiming the moral high ground (Mullender and Ward, 1991), in order to justify their status as a 'better' organisation.

Views of conflict according to service users/user-workers

Throughout the study, service users and user-workers referred to conflict and confrontations with professionals and their organisations. In comparison to professionals, service users experienced no difficulty naming power disputes and conflict situations. Being the weaker group seemed to make power inequalities and disputes very obvious, and people spoke with passion about situations that had angered and frustrated them. This comment is from the Chair of one user group who was involved on a Police Liaison Committee when an incident involving the police using CS spray occurred within the hospital:

> *The things that have caused conflict have been disastrous things happening. For example, a patient was sprayed in the face with CS spray by the police. I sit on the Police Liaison Committee and the incident happened just before the PLC meeting so we went to it and said we were absolutely appalled that the police sprayed a patient in the hospital. We got no backing from any of the staff, even though I know that many of them were appalled with the police. The police said "if you call us in we do it the way we want to do it". Real bully boys, really quite nasty and we felt that this committee was actually supporting the police's action by not speaking out and not saying anything and not doing anything. They were setting up little sub-groups and meetings to try and prevent it but nothing has really happened and it will happen again. That's when I left it I said I don't want to be part of this committee and I got a nasty letter back from the chair saying we don't condemn CS spray we take it very seriously but it's just all lip service.* HK

In this instance, the professionals were unable or unwilling to collaborate with users to challenge behaviour that could be argued to be legally and morally unacceptable.

This next comment, by a user development worker, concerned the behaviour of professionals who were unhappy at being challenged by users to make a reality of user participation on a day-service management committee:

> *When we went to the first management team meeting the managers were treating it like it was a user forum, they abandoned all their ongoing business and began to treat it as something else. So I kept asking questions like "is this a user forum or are users part of the management team?" And in the end they agreed that users were part of the management team and we had it minuted. And then because there were three management meetings, two without users and one with users, I said "if*

> *they are part of the management team although they're not coming to all the meetings, they must have minutes to the meetings" and there was uproar. They did not want them to have the minutes. There was a real ding-dong. I mean it was outrageous, absolutely outrageous. One of the nurses just completely lost it, and laid in to one of the users, it was just outrageous behaviour. I've never seen a performance like it in my life. But in the end they agreed that this core group of users could have the minutes... So since then we've had all the minutes so when we come to our bit of the meeting we take the minutes and in the matters arising we raise issues from their meetings. They've been ambivalent. Sometimes they've really liked it and sometimes they haven't.* MG

This situation shows service users, with the help of their worker, refusing to be involved in the tokenistic way that the professionals seemed to hope or expect they would be. Rather than involving users as full members, the real business of the meetings went elsewhere; effectively turning the management meetings into a user forum. The users confronted and resisted this strategy of exclusion and overt conflict was the result. Significantly, the users persevered and succeeded in receiving minutes from the other management meetings, allowing them to become fully involved in the decisions that were being made about their centre. This is an example of disagreements as to what is open for negotiation and what is not, and of professionals' desire to control the 'rules of the game' (Clegg, 1989).

Another service user, when asked about examples of conflict, talked in terms of a "*war*":

> *When I work with user groups there is talk of a war of attrition about who can wear the other person down the soonest and you get that impression when you talk to service users. They're just worn out by it. They're just worn out with banging their head against a brick wall.* DB

A text that relates well to this is *The Art of War* by Sun Tzu (1998), a text suggested to me by one of the respondents, who believed the power dynamics that existed in the involvement processes she was part of, were echoed in this book. She explains:

> *Where they* (the staff) *fall down is they don't have a political understanding like the users do, the users have pre-meetings, strategy meetings they think things through very deeply. Staff, in terms of their side of the war, well they are not doing that, they don't even conceptualise it as a war.* MG

The Art of War attaches great importance to politics and diplomacy, advising that strategy lines be devised with the long-term and fundamental interests of the state, not just expediency, in mind. If Sun Tzu's *The Art of War* has validity for those in the front-line of the 'battle' for the struggle for power and for a say in services, this has major implications for how power relations should be understood in participatory contexts. Current understandings are conceived as an 'either-or' dichotomy where either a reform (consensus) or a radical (conflict) model is used to work for change. The model of power used in this analysis remains the zero-sum model where power is seen as being held by individuals or groups. If power is epitomised by strategies and networks, and participation understood as characterised by conflict and struggles for power: with both 'sides' using strategy and deception to further their own ends, the consensus model of involvement then seems at best naive and at worse part of the deception.

Summary

The second part of this chapter has focused on a lack of acknowledgement by professionals of the presence of conflict in their relationships with service users and user groups. In groups started by professional organisations, whether by hospital Trusts or voluntary organisations, these 'parent' organisations still held a considerable amount of control over their 'offspring'. Small user groups are vulnerable to control by larger, more established non-user groups/organisations. There was a focus and a preoccupation with the consensus model of change (Ng, 1980; Rees, 1991), where cosy, comfortable relationships are said to prevail. Conflict is assured when user groups do not accept these 'cosy' relationships. I have described how the dominant groups in user involvement processes, not only create the 'rules of the game' (Clegg, 1989), through stipulating the nature and extent of involvement, but also use strategies such as *securing consent* to ensure that the rules of the game are followed. The issue of what is open for negotiation and what is not was raised, as was the danger that powerful groups may begin to bypass formal mechanisms for decision-making, now that they are expected to 'share' power. For some user and user worker respondents, the practice of user involvement was viewed as a war or game, where strategies and counter-strategies prevailed that aimed to further a particular group's own interests.

The next section identifies the structures, strategies and processes that organisations have adopted to engage with the user participation agenda which, I argue, have served largely to limit the extent of user involvement.

Part Three: Professional and organisational strategies of resistance

Resistance to, or discomfort with, an increased user voice within Trusts, was a consistent feature of the data, as were subtle forms of resistance like stalling tactics. The following three responses followed questions regarding respondents' experiences of resistance and all three describe situations where service users had initiated action based on their own agenda and issues. The first comment, from the user development worker in Trust A, concerned the difficulty of working with what she perceived as massive resistance from the organisation and some of its staff:

> *A few months ago it was just awful, there was this back-lash or resistance... huge, huge massive resistance everywhere. But now it seems to have moved on again. It's not easy, if you turn your back for a minute it's all back to square one. Back to the old custodial... well it is very, very custodial still. Very custodial in attitudes... that's the default position. And you've got to work ever so hard to get out of that position and as soon as you relax it goes back. That's the disheartening thing. And you can put in a lot of energy... and the movement tends to attract a lot of high energy, charismatic people. But as soon as they relax, as soon as they want a break, it all slips back again. Where I see us as trying to push ahead a user agenda, we meet resistance to that in a very big way.* MG

This respondent is clear about the difficulties faced when pursuing a user agenda rather than a Trust agenda, and her view; one shared by many service users and two other professionals, was that the default position was one of 'old custodial attitudes'. She believed that the new agenda of user participation sat uncomfortably for some people working in mental health services, and could be particularly fragile when other dynamics, such as Trust mergers or internal crises, intervened.

A group of staff in a different Trust to those in the study, were concerned by the increased power of service users within it, leading to an interesting development that respondent WA relates:

> *There are probably quite a large number of people who are against the user involvement developments that are happening in our service. There is a group of staff that call themselves the Staff Breakaway Group who are against the users. They think that users should respect staff more and that's quite scary and has made me really aware that there's quite a big element of that even here. There is a document coming out, drawn up by users about how staff should treat users and about staff attitudes and it looks like this is a backlash against that.* WA

This respondent had found out about this 'underground' group by accident, which suggests that there were risks to them being more overt about their agenda, at least at this early stage. The particular Trust this respondent is commenting on was one that had taken comparatively radical steps to change the power dynamics within the hospital, partly due to the influence of a high ranking professional, who identified herself openly as a user of mental health services.

In this next account a different form of resistance is described, where processes of non-action and stalling are used as mechanisms to manage or prevent change:

> *It was generally agreed* (by the user group) *that the nurse managers were worth talking to as a group because they had sufficient kind of formal authority within the organisation to implement any recommendations that might arise 'cause people didn't want to just piss into the wind, they wanted to talk to people who could do something. But what never happened was a dialogue. It was the user members setting the agenda, having a lot to say on the day and the attempts to draw... not only responses but agenda items in their own right from the mangers, didn't really happen. So you had this very asymmetrical set-up. A kind of reversal of the usual thing where the professional sets the agenda and does everything. But this concept that you could have a much more symmetrical, balanced kind of interchange didn't work out. But... even this obvious sense from the managers that we don't like this was never sort of said, it came out in behaviour... staying away and then coming back and sort of looking rather glum and being rather defensive about some of the points coming up and some people clearly feeling very personally attacked. So there was a sense of... much slower progress than I think people had hoped for.* SW

Attempts to resist change and avoid a 'balanced kind of interchange' by 'looking glum', 'staying away', and from the use of silence or non-participation were effective strategies in undermining a situation where users were given a platform to negotiate with nurse managers about their concerns: a rare example of 'non-invited' participation. The managers of these wards were told by a senior manager to meet with the user group to hear and respond to user group concerns, and it is clear from this account that the managers were not happy about this situation. As they were unable to withdraw from the process due to pressure from above, they resisted the users agenda by disengaging with it in the ways described.

Summary

The evidence from this data demonstrates not only that resistance is occurring, but that it takes different forms; with professional power in WA and SW's accounts not being exercised in a traditional overt way. Both situations had a sense of hidden, almost tentative dissent, and while one was verbalised and acted on; the other remained unspoken. While these situations demonstrate defensive behaviour, there is also evidence that some professionals are able to be more flexible with their role and function, and adapt to changes required of them.

Part Four: Structures, Strategies and Processes Used to Resist the Participation Agenda

Throughout this study a number of strategies and processes for blocking or stalling the user participation agenda were identified within statutory mental health organisations. Part four of this chapter makes tentative connections between these strategies and processes, as well as theoretical frameworks of power, to further explore the power dynamics of participation. The data describes different facets of the representational model of user involvement, predominant in the two Trusts studied. An analysis is provided to assess whether this model may itself be a strategy to resist meaningful partnership. Firstly, the role of language in 'naturalising' power relationships and resisting change is considered.

Language and power

Professionals, in this study, were not comfortable talking about user involvement in terms of power, as a service user describes here:

> *We had these two user involvement people in the social services... they do the mental health liaison meetings... and there was something that came up and I was talking about power in a meeting and I said about us having power, having the power to do things and this woman from there said "I don't think in terms of power" or "I don't think we need to think in terms of power"... I actually wrote them a letter after that and said I think only somebody with an investment in the status quo... can talk like that....* JR

As described in Chapter two, the 'invisibility' of power can be described in terms of hegemony (Gramsci, 1971); the process by which ideas that serve the interests of a ruling or dominant group are translated into a certain version of reality. This version then becomes the 'true', 'natural' or dominant explanation making sense of everyday reality, and hence becomes 'common-sense'. A rich example of the ideological use of language within Trusts is contained in this comment by a user-worker:

> *When I think of all the good things that the Trust has done I also think it is quite expert at putting in, very astutely, enough things to convince ourselves, the user groups and others that "oh wow this stuff is good!", when its expertise is more to do with... words, concepts, the key points to be done which I think it's very, very good at. That is a real risk; that some services actually block progress by the use of the very language which we would want to try to describe as a liberation process or an empowerment process.* BA

Using the language of empowerment to block progress can occur in places that are not comfortable with devolving power, but keen to promote the impression that they are.

The tendency of professionals to deny their own power was also a central feature of the data. Respondents gave examples of professionals saying *"but we don't have the power to change that, it's that group over there that holds the power"*, when demands on them were made. A user-worker received this response when training student nurses on user involvement:

> *What I got from them was "we can't do this we're totally powerless it's the psychiatrists who have all the power and we just have to go along with the way things are". There are a lot of professionals particularly in hospital services who feel totally disempowered themselves, and don't see themselves as having any kind of power, not only within their job but in relation to patients on the ward. They wouldn't easily recognise that they have power and that is very difficult.* SH

Similarly a psychiatrist commented that it was the government and the public safety agenda that ultimately frustrated and restricted professionals' attempts to do their jobs better. Another user-worker was cynical about the number of professionals genuinely interested in an increase in service user power:

> *I think with professionals most of them pay lip-service to empowerment and involvement. In fact all of them do, they all do actually.* KM

Using jargon in meetings and documents is one of the obvious ways language may be used by professionals to resist change. According to this user development worker, the use of jargon can restrict the ability of service users to fully participate:

> *A lot of professionals, if they don't want user involvement will use the high-powered words, phrases and comments and a lot of users are frightened to actually say "excuse me but what's that?" They might say it once or twice but if it carries on they'll just shrink back and not take part.* BM

Language can therefore be viewed as one of a number of strategies used by professionals to construct 'the rules of the game' (Clegg, 1989).

Some user group members undertake a 'translating role' [6] within groups or within advocacy/ information/rights services; recognising that power can be exercised over people through a process of obfuscation. A user development worker describes this process well:

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[6] These people are termed 'internal organic intellectuals' by Carmen (1996), developing the term as first used byGramsci (1976). Organic intellectuals are individual members of powerless groups whose conscience and expertise has been raised through active struggle.

> *Part of my role has almost been a translator when it comes to the jargon. It's something I spent a lot of time trying to put into plain English with the users I was out there speaking to and working with. It's bad because I know that language is used unfairly as part of the power that enables the professionals to keep things on their side, you know, to protect their interests but for users who feel comfortable using the terminology and feel able to use it I think that can be a good way of scoring some points. The language and the system and everything else about it needs to change, to be more accessible in a whole variety of ways, but in the short term I think it's been quite useful for us.* KM

Using the language of participation and empowerment to call professionals to account, can also be seen as part of a strategy to reclaim power by service users:

> *Language is changing the whole perspective to do with mental health which is dominated by the reductionist, medical model and I think the language is very much part and parcel of that. We have found it useful in the short term to exploit some of that... we do use language to our own advantage. The language we tend to exploit is the language of involvement and empowerment because that's what the services are supposed to do anyway and to some extent we just remind them of it and say "well this is how you could do it!"* KM

It appears as though the language of consumerism has been well learnt by activists. Certainly the two quotes from BA and KM indicate that exploiting the language of involvement and empowerment, for short-term gain and advantage, is seen as part of the 'game' for both 'sides'. A desire to exploit the language of empowerment and participation, is therefore, not only visible in professionals and organisations, but has also become a strategy for user groups to call service providers to account.

The limitations of the representational approach to user participation

There are many other factors that can be discerned that effectively resist the participation agenda. All of these can be associated with the representative model of participation that was predominant in both Trusts studied. The two Trusts had taken slightly different approaches to the representative model, however, with one using a quarterly consultation forum with user groups, senior managers and senior clinicians, to supplement decision-making committees. Briefly, the representative model places an emphasis on users being represented on decision-making committees at different levels of the Trust, along with other stakeholders. Although this is the dominant model for user involvement and participation in statutory mental health services, the research findings have shown that the representative model presents serious limitations in terms of the practice and outcomes of participation. The themes described are: the limitations of the advisory role, divide and rule, undermining representativeness, non-decision-making power and whose agenda?

Limitations on the advisory role

These two comments came from middle management professionals, employed in different Trusts, and contain many of the central tensions I want to present:

> *User involvement, in terms of upper management and the top level of policy, means more than just having a user or representatives of a user group, sit on a selected number of key committees and groups which are usually very carefully selected. It would be very interesting to look at, with a Trust like this that prides itself on having a high level of user involvement, which are the groups and committees that they allow users on? And more importantly which are the ones that they don't.* TB

> *...because this is a very committee-based kind of structure, you know that's how the processes work here, formal groups meet, they have agendas, they make recommendations, the recommendations are written up in a paper, the paper goes to another committee and is considered and is amended and so on and so forth. So there has been a lot of emphasis on representation which is about a user being in the group somewhere and, certainly in the early days, that led to a lot of resistance around well we can't call it representation because in what sense are any of these people representative? So there was a lot of resistance to the inclusion of users even on that kind of basis.* SW

These quotes highlight some of the fundamental limitations of the representative model of user involvement. As the first comment by TB suggests, there are issues to do with the selection of committees that users attend. The second comment highlights the ways that user representativeness is frequently questioned by professionals. Some respondents proposed that with users only having an advisory role within an organisation, rather than a more formal role such as an employee, this undermined their ability to have a significant influence on Trust decision-making:

> *Part of the problem is, when you're not an employee per se, you are always going to be in an advisory capacity. So even if they were on one of the clinical policy groups and they had two users on that they would also have fourteen professionals as well. So they are always going to be either marginalised or the "yes that's a very interesting point of view but we are not going to go with it" kind of thing. So the limitations I suppose lie in the capacity that they hold.* EN

Being part of a minority entails a constant challenge to be heard. As described in Chapter two however, work concerning the influence of 'active minorities' (Maass and Clark III, 1984;

Moscovici and Mugn, 1985), suggests that social power and social influence are not the same thing.

The capacity of the committee and organisational structure to hear the voices and take account of the views expressed was also questioned by interviewees and the following respondent asks: *"how far are people prepared to let it go?"*:

> *Well I suppose the... stumbling block or the question that arises is: "how far are people prepared to let it go?" Would you allow a majority of users on any Trust committee? Or are there always going to be two or three which is to say... it's tokenism of a different kind. The role that they have may not be a token one, it may be a constructive one, but they are always going to be outvoted and that's that. In the current political climate that is not allowed, it's out of the question... things like risk assessment, and control of public safety and the detention of people perceived to be dangerous, is the institutional medical function that patients will not be allowed to interfere with.* EN

This respondent, a psychiatrist, poses a number of interesting questions: is it possible for user involvement to extend into the realm of, tough, everyday decisions that are made by professionals on behalf of society and the Government? Can user participation ever extend into the really crucial arenas of policy making that ultimately impact most on service users' lives? The answer EN gives to his own question is 'no'; *"it's not allowed, it's out of the question"*.

Representation of user interests occurs in certain committees only and these are ones that appear to be carefully selected by senior managers. Indeed, not only have the committees been selected, sometimes the individual representatives are carefully selected too:

> *The users I observe on the community care policy committee are constructive and committed and everybody works together. Quite how they got to be the users who were selected, and what would have happened if somebody had got selected who was you know er... fundamentally hostile to the existence or the aims of the Trust, I don't know.* EN

The consensus model of change, where everyone works together to achieve mutual goals, appears to be a constructive approach to decision-making in the interests of all. However, as the respondent (EN) suggested: if individuals hostile to the aims of the Trust were selected, this constructive process may be jeopardised and this person goes on to interpret the possible motives behind the selection of certain individuals and certain committees:

> *It is perfectly possible that there are tensions there. I can't speak for the users on the committee so I don't know if they do feel used in a tokenistic way or not. It's not how it looks to me. In a way that's what an intelligent organisation that wanted to*

> *control the user voice would do. It would create a situation where their voice was heard in certain specific areas of the work that was never allowed to challenge the fundamental workings of the Trust. I couldn't say whether that was happening or not.... I have no observations on which I could base that assumption, just a feeling about politics in general, that that's the sort of thing that goes on and it's up to you whether you feel that it's about subverting the hostile aims of the user movement or whether it's about genuinely being constructive.* EN

Is tokenistic involvement then a deliberate ploy by an 'intelligent' organisation in order to avoid substantive change to the organisation?

Similarly, a service user makes clear her view of the danger of appeasement and tokenism:

> *...they don't want us to have power, because once we have that power basically we are a threat to them. They want people who appease them, ideally who fit in with what they want to do because it fits their system perfectly and if we turn around and say we're doing this, they don't like it.* HK

In the representative model of user involvement operating in Trust A, according to this service user respondent, power remains with individuals who are senior within the organisation; doctors, senior managers and Trust board members:

> *The users are quite far down on the list of priorities. Even on the Board, even if you look at Board level, they're nowhere near the Board. There's not even a director to represent us on the Board. I mean it's a top-down approach so users are like an irritant to the staff. It's like fuck off and leave me to do what I'm doing we've got enough pressures without having you lot on our back. So that's why there's resistance. And they're backed by the whole management structure. Generally it's a top down approach and that's the problem, it should be a bottom up approach.* DB

The top-down approach described here can lead to resentment and resistance amongst staff who believe that they have enough to do, and in the view of DB this resistance is supported by the whole management structure.

Divide and rule

The selection of individuals to represent user interests within hospital structures can be defined as a political activity. A related political development described by one service user activist was the creation of an "aristocracy" of service users; those that have access to certain privileges and rewards:

> *They have created an aristocracy of users, which is our group. We are the only ones allowed to use that room. The only ones that can use the phone and the computer. There is a system of key-holders and to be a key-holder is like a prize. It*

> *is clear to me as well as others that when this prize is taken away from you it is a punishment, so there are prizes and punishments operated by the users on themselves.* RW

Privileges, prizes and punishments are an understandable consequence of having individuals selected by the organisational 'establishment' to play roles identified by the 'establishment'. Lipsky (1980) writes that the allocation of psychological rewards and sanctions, associated with clients entering into relationships with them, is one of the principal ways that workers in public services exercise control over clients. This respondent RW was very keen to build links with the front-line staff, including ancillary staff, to prevent them from thinking that service users had become 'lackeys' for the hospital management. A similar dynamic to this was noted by Church (1995), in her research on user/survivor participation. She found that several of the professionals involved in the legislation consultation with users/survivors perceived user participation as evidence of a government bias against service providers. The respondent RW, believed that users were being used by management as a 'battering ram' against staff, which ultimately made the user group's task much more difficult.

RW also felt strongly that the more the user group became involved with the Trust's structures, privileges and rewards, the less it identified with, and therefore advocated for, the in-patients. Another comment, from a manager in Trust B, articulated a discomfort with the limited range of views that are heard by the *"powers that be"*:

> *There's people on the user group who are known to all members of the Board and they get invited to things like the Trust Christmas party and the AGM and all those kinds of things but to me it's the same old faces basically and not many of those either. So, user involvement is working in terms of yes they have the ear of the 'powers that be' but obviously it's a limited range of views that's getting heard. And they are the people who want to be involved so you may be getting a particular type of person. I don't think there's anybody that's under 35 and certainly not anyone from ethnic minorities. So it is quite a narrow view that they are getting even though they are supposed to be representative. How representative can any one person be?* TB

The core of this Trust's user involvement strategy was a small number of individuals who were actively consulted, and the problem identified by this respondent, was the limited and narrow range of views that were heard. The notion of an aristocracy of service users; a small, privileged group of people who have the ear of those with power, therefore has validity in this Trust also.

Undermining representativeness

The observation by TB (page 188), that the majority of 'involved' users had little in common with those on the in-patient wards, bears closer examination. Within the representative model of involvement a major point of contention is who does the representing? Comments from respondents in the previous section were sceptical of the mechanisms by which individuals were chosen as representatives, and of the capacity of these individuals to represent those most vulnerable within the hospital or service system. From this, I now turn to address the issue of representation as it is commonly used in user involvement; as a way of dismissing user views altogether.

Both Trusts in the study expected service users not only to represent their own views, but to represent the views of other service users within the hospital; though there seemed to be no process in place to ensure feedback to those being represented, or to gather their views. This resulted in individuals either representing only a small minority of views, or sometimes only their own, without having effective democratic structures to select, train, resource and support these representatives. Accusations from professionals of unrepresentativeness were therefore a frequent occurrence for the user groups. Other representatives on committees were not grilled so closely about their representativeness. One professional who attended some committees during the early days of user involvement in trust A commented on the discussions that took place over the capability, as well as representativeness, of service users:

> *It came up in various forms and people rarely said well "OK let's look at Dr so and so sitting over there and how representative is he of other doctors"? What was very noticeable was that this was something that was only really looked at with the inclusion of users. And it went hand in hand with this other issue about whether users were kind of mentally capable of...(laughs) you know, fulfilling these roles. There were a number of users who were considered... and sort of rejected. There was a kind of thinking-out-loud sort of discussion that went round the table and they were variously sort of dismissed as being kind of too ill or too fragile and then another name came up and that person was dismissed because they weren't even mentally ill! So it was like (laughter) you couldn't really win... you know it was pretty hard to get past the criteria really. To me it was just a rather transparent kind of... stalling tactic I suppose is what I would call it. A lot of it felt like stalling tactics.* SW

Another example of professional resistance that revolves around the issue of representativeness is the "*gut hostile response*", that can be seen in this comment by a senior psychiatric registrar:

> *One of the reasons why doctors often have a sort of gut hostile response to the concept of organised user involvement is that they say well the whole job is about*

> *talking to individual patients who are users of the service and coming to some kind of negotiation or mutual understanding with them about what the service does for them as patients and I think that is partly justified and partly not you know I'm just putting it as a point of view. As a doctor you are in a position to hear an awful lot of user views about their treatment you have access to so many opinions, experiences, attitudes and beliefs from individuals about their experience of psychiatry, that the organised user involvement... well it's additional to that and it's possible to regard it as a small thing compared to for example if I admit ten people to the ward I will hear from every single one of them about what they think about the ward and whether they wanted to be on it or not so it's a small extra to be told that the user group officially thinks the ward is crap. You will hear enough people who are prepared to tell you in no uncertain terms what they like and don't like about side effects of medication or the decor of the ward or the attitude of the nurses or their experiences of being sectioned or whatever else it may be. That's not to say I don't think there's a role for advocacy I think there's a very important role for advocacy because I think there are a lot of people who do feel very inhibited and they would hesitate to tell their consultant that their experience on the ward was worse than useless. That sounds like a negative view, it's not an attempt to rubbish organised user involvement, although I can see that it could be seen as that, it's just an attempt to explain why there might be a slight ambivalence from most doctors or certainly for me about the concept of organised user involvement because we feel "well who are you representing?", when I hear so much from people who are talking to me direct and unmediated through some kind of body. Let me extend that, there's the sort of feeling that user movements were going to pick up the people most disaffected by the experience and what about all the people who have wonderful experiences, where are they? I think it's perfectly reasonable that organised users should see their main role as constructive criticism. They are not there to tell us what a wonderful job we're doing and I don't see why they should... but it's something that comes into the equation when you're faced with a body which is critical and you want to defend yourselves a little bit and say "well there are lots of people who don't feel like you".* EN

What is interesting about this commentary is the way in which EN uses rhetorical devices to undermine organised user involvement while at the same time distancing himself from this as a personal view: *"I'm just putting it as a point of view"*. His words give precedence to the individual user and negate the idea of collective action, perceiving the user group as a potential distortion of the larger user voice: *"when I hear so much from people who are talking to me direct and unmediated through some kind of body"*. This apparent distrust of service users gathering together to support each other, and collectively campaigning and working for change, seems rather ironic given psychiatry's preoccupation with grouping users/patients together for more benign purposes like social occasions or 'therapeutic' activities. EN's words lend weight to the argument that psychiatry continues to be uncomfortable with the idea of service users gathering together for their own purposes.

The final sentence: *"it's something that comes into the equation when you're faced with a body which is critical and you want to defend yourselves a little bit and say well there are lots of people who don't feel like you"*, reads as vulnerable in tone; given the status of the speaker as a senior registrar. It indicates a sensitivity to image, to how one is seen by others, something with which psychiatry has not had to concern itself in the past. Such professions have traditionally been left to get on with their jobs without much public or professional scrutiny. The push for user participation within health services has been associated with demands for greater citizen and community participatory processes across public services and government. Defensive responses to criticism are, therefore, to be expected from those professionals not used to having their practice scrutinised or criticised.

Non-decision-making power

In this study one of the major criticisms of user involvement in practice was the sense that the decisions that users were allowed to make or influence were small, less crucial ones, as this professional describes:

> *It's quite safe to have users making the small decisions like on the decoration of the ward or such like because it doesn't really matter if it's yellow or if it's black... whereas the business plan for the next five years is important. It reminds me of some of the things I've read about gender relations where women decide what the family will eat whereas the men decide where they will live and what car they are going to have. So you get a situation where a person can be involved in making 90% of the decisions but in actual fact they're not the decisions that actually matter. So service users could choose what kind of paper to use and whether to have flowers on the wards, but not decide whether to use ECT or not. I think the decisions that users are involved in are the minor ones... when you step a little bit past that people start to get very anxious.* WA

This quote highlights the ways that professionals can limit decision-making to less significant areas. Non-decision-making has attracted attention in the literature on power, through the work of Bachrach and Baratz (1962), who state that power can be exercised by confining the scope of decision-making to relatively 'safe' issues. Service users among my respondents provided examples of what had been negotiated by users and user groups: tea and coffee on the wards and access to hot water and clothes cupboards were areas where user groups had achieved success.

Medication practices were not up for discussion however. Indeed, in this study conflict was reported whenever users directly challenged individual psychiatrists about, for example, medication regimes or the need for independent advocacy. Overt conflict also occurred as a result of suggestions from users for access to complimentary therapies. In other words, when service users became concerned with an individual professional's practice or approach to treating a patient, and missed this in user forums, the shutters came down fast.

Non-decision-making power can also be seen in the differences between how things look 'on paper' and how they work out in practice. This user-worker described how issues raised by members of a day centre committee were dropped off the agenda:

> *The day centre looks all very good on paper, there's a member's committee, they have regular monthly meetings and the manager comes to the last half hour of the meeting and it all sounds very democratic. But when it comes down to it there are still issues which the members' committee raise and they just get dropped off the agenda or like complete fob-offs you know, totally and utterly. There was one time that the member's committee actually pulled rank and went over the manager's head to the management committee. But that was a very, very risky thing for those users to do and the staff made it obvious afterwards that they really, really resented it and it should not happen again. So in that situation when it gets to really sensitive issues, or issues the professionals define as sensitive, the committee's hands are tied.* KM

The desire 'to be seen to be doing' involvement, therefore, seems stronger than the desire to actually engage in user involvement.

Under-funding of user involvement activities can also be seen as another form of non-decision-making:

> *I think it* (push for user involvement) *tends to perhaps emanate from our administrative and managerial centre and I'm not sure how successfully it disseminates down through the 'ranks'. So how it actually impinges on practice on the wards... perhaps I would have some reservations. I think if we went and did a straw poll of people on duty today and asked 'well how many of you know about the code of practice?'... I think they get a flavour of it through users participating in the induction days and seeing users about... Maybe we need more resources for user empowerment. We are relying heavily on a few members of staff who are committed to it and a few user consultants who we do expect kind of a lot of.* TB

Other signs that non-decision-making power was limiting the influence of users are evident in comments from users and user-workers that speak of blocking, stalling and delaying:

> *It's more a lack of willingness to actually send certain things forward, things that we felt were important, that they didn't, or that they had a million other things to do.* HK

> *It's just so labour intensive to get anywhere... the organisation tends to block me wherever it can.* MG

> *...and they use delaying tactics like meetings... meetings are delaying tactics. Meeting after meeting after meeting... and nothing happens.* RW

The use of meetings, discussions on representation, lack of resources and a lack of willingness to move things forward, can all be interpreted as tactics used by organisations and staff in organisations to avoid giving up power.

Whose agenda?

Tying user group members into time consuming and slow committee structures was an effective way to keep them busy working on the Trust's business, until users realised that was what was happening:

> *We never set up new things, that's the way I felt. We were continually having to go to meetings, boring fucking meetings, reading minutes, having a load of paperwork. Half the time the staff never turned up to them, it was really boring and soul destroying and I thought fuck it, I'm not doing that anymore. Likewise with the committees, I stuck with them for a long time. I must have been on two different committees for a long time, about one and a half to two years. And I saw* ***no change,*** *and got very frustrated.* HK

Many users and user groups gave their service providers the benefit of the doubt and engaged with them, freely giving their time and energies. Some of the active service users had been 'in the system' long enough to have doubts about the usefulness of sitting on committees, but by the time they realised that change was not forthcoming, they had already been 'involved' for a number of years. Many people were bitter about the amount of time wasted in arenas where their views were undermined or ignored:

> *What have we been empowered to do? What have we been involved to do? I saw my social worker about this the other day and he said to me "I don't like meetings" and I said "yeah nor do I!". So why are we being empowered to go to meetings? I mean their outcomes, their judge of outcomes, is about how many users go to these meetings. That's how they look at things. On my estate they beg people to come to the Tenants Association and it affects their lives, it affects their surroundings and yet people don't give a damn about going along to a meeting.* DB

The meeting culture is, however, heavily ingrained in most mechanisms of user involvement participation, with some user groups being given targets for the number of meetings they are required to attend in order to receive annual funding:

> *The health authority has actually given us targets which is to have a 150 meetings or visits per year and 300 'phone-calls. Last year we answered the 'phone 563 times and that's not including the blank messages on the answer-phone, and went out... had 136 meetings and 135 visits, so we more than met the targets.* BM

These targets form part of a culture that demands measurable outputs in exchange for funding. In this study, opportunities for user involvement often drew people's energies into areas of least interest, as this respondent illustrates:

> *It was just too hospital based OK it is a hospital user group, but like... loads of people in our group don't fucking go into hospital anymore. There is only a small percentage that will continue to go in and out or go in once in a blue moon. It's like we're kind of reflecting funding of mental health if you like, because most money goes into acute wards which is a complete waste of money, instead of like looking at a safe house for women or a refuge, or alternatives to hospitals or decent day care, or a chance to get a job, all that sort of thing.* HK

In both Trusts studied, but particularly Trust A, user involvement was clearly biased towards getting people involved in existing services. Only rarely did service users describe opportunities where they were involved in new initiatives or developments, so while Trusts gained credibility, users gained huge workloads:

> *...we became quite a big entity in that place... largely because we were pushing for things but also because we were having work thrown at us where people sort of cottoned on to the idea "oh we've got a user group that's really good isn't it, let's ask the users"... and we unfortunately responded to them and gave them what they wanted rather than sort of... sitting down ourselves and thinking through what we were capable of doing, what was important and what really needed changing in the hospital rather than just when someone from the Trust said, "can you do this?" and we said "yes, yes we'll do that, we'll get someone to do that"... we really did stretch ourselves.* HK

Working for the Trust also had the effect of limiting the group's energies for other activities, as HK continues:

> *...we kind of lost our sense of who we were really. We just turned into this working machine for the Trust, we never set foot outside the hospital really so we never got involved in what was going on around us because we were inundated with work. It was no one's fault, but I think there was a bit of engineering going on, on their part. We were so bogged down with issues like tea and coffee on the wards that we*

> *forgot that we had talked about smashing up the ECT machines. We kind of lost the political side of it and got bogged down with the practical day to day issues of the wards. That's where we kind of lost it a bit really but we were pushed down that road by the hospital who set up endless groups....* HK

Although most hospital user groups were set up to be consulted precisely in the way described above, the strategy of harnessing the user voice in this way can be interpreted as a means of limiting the effectiveness of groups; who might otherwise express dissent and unhappiness in less controllable ways. Groups set up by statutory agencies to provide 'involvement and consultation' were most vulnerable to having their agenda determined by others:

> *With groups set up specifically by statutory agencies it's about sheer user involvement and that's all, whereas perhaps your typical borough-wide group may be doing other things. It may be doing socials and educational... well keeping its own agenda... I think the fair thing to do is, whatever group you've got, that you should never lose sight of your own agenda 'cause it's so easy to do that if you get into user involvement and it might have half a dozen people going off perhaps full-time with reams of paper and people do this at a national level as well and they are simply responding to... other people's agenda... it simply becomes reactive....* DB

Summary

Although service users could be said to have achieved influence within both the Trusts in this study, there was little evidence that any real change in organisational power relationships had taken place. This chapter has illustrated some of the ways in which language can be used to 'naturalise' power relations and block real change. Some professional respondents in the study seemed unwilling to recognise their own power, or to talk in terms of power, when describing user participation. According to the respondents quoted here, some organisations have become very skilled in using language to give the *impression* of change. Language can, therefore, be viewed as one of a number of strategies used by professionals to create 'the rules of the game' (Clegg, 1989), manipulate agendas and maintain the status quo. A desire to exploit the language of empowerment and participation is not only visible in professionals and organisations but has also become a strategy of user groups, who, by reclaiming the language of empowerment, are calling service providers to account.

The tendency for professionals to judge the success of user participation in terms of the number of users attending meetings, is also indicative of the predominance of the professional and organisational agendas that are served by the representative approach to participation. Organisational agendas were so time-consuming that user groups were described as becoming 'work machines' for the Trusts; leaving no time for them to discuss or act on their own agendas.

So, in this analysis, not only were the meetings that took up most of the user group's time questionable, in terms of giving the group a greater say or influence within the Trusts, they also kept the user group busy on the Trust's agendas rather than working on their own.

The relevance of theories of non-decision-making power, particularly in terms of what was open for negotiation and what was not, was also demonstrated throughout this section. Decision-making was seen to be confined to 'safe' areas that would avoid contention and conflict, and having issues 'dropped off' agendas, was commonplace. Nearly all user involvement consisted of 'invited participation', with the agenda set by the organisation. Conflict took place whenever uninvited participation took place, most obviously when user groups challenged clinical practice. The burn out of user group members was also apparent as frustration gave way to despondency. Blocking, stalling and delaying tactics were noted as less overt forms of resistance to non-invited user participation. It seems then, that the limits of the debate, and the 'rules of the game', are circumscribed by discourses and practices that frame the goals, needs and language of participation.

Conclusions of Chapter

The unsettling relations described by Church (1995) and others were keenly felt by most of the professionals interviewed in this study. Role insecurity and ambiguity has undermined the previous taken-for-granted position held by professionals. Hostility and apathy are two responses to increased user control noted in professional responses in the data, but support of the user involvement agenda was also genuinely expressed and felt by many of those I spoke to. The unsettling relations indicative of professional discomfort could be seen in defensive, personalised responses to anger and criticism. On the whole they were implicitly, rather than explicitly, demonstrated; discerned in instances of 'staying away' and 'not playing the game'.

In assessing the extent to which user participation has provided a forum for social change, questions were asked throughout this thesis about the mechanisms for achieving this in statutory mental health services. Two theories of social change have been suggested; the social conflict model and the social consensus model (Ng, 1980; Rees, 1991), as discussed in Chapters one and two. Professional respondents in the study indicated little acknowledgement of any conflict with users or user groups and were concerned, instead, to emphasise the consensual aspects of these relationships. User participation was most frequently talked about in terms of shared agendas for example. User group members, alternatively, perceived their involvement in statutory mental health organisations as characterised by conflict. Non-decision-making power (Bachrach and Baratz, 1962), offered insights into the power relationships described and became a key mechanism by which professional and organisational responses to users and user groups were interpreted. The 'rules of the game' (Clegg, 1989) that frame user participation remain firmly controlled by statutory agencies; dictating the way participation is defined and structured, meetings are run, and decisions are made. A crucial part of the rules of the game is the issue of what is open for negotiation and what is not. This appeared to be central to the processes of user participation in the contexts studied. When uninvited participation occurred; when a subject was not up for negotiation for example, conflict was inevitably the result.

This chapter has presented evidence that the changes in roles and relationships, described by respondents, represent a noticeable shift in the status quo. Yet again the 'zero-sum' conception of power was seen to be insufficient in explaining these complex relationships. Rose's (1990) suggestion that change can be achieved by a combination of consensus and conflict relations may be the way to overcome the 'either-or' dichotomy of the conflict/consensus model that does not seem to sufficiently embrace the fluid and interchangeable nature of user-professional relationships. I would suggest that the models of power needed to understand the re-negotiation and destabilisation of roles and relationships taking place in mental health services, are ones that see power as fluid; moving between people in practices and discourses (Clegg, 1989; Foucault, 1972, 1973, 1976).

Chapter Six

The Capacity and Empowerment of User Groups

The third and final group of research questions was concerned with documenting user group empowerment. As stated in Chapter three, I wanted to explore whether signs of resistance to professional or organisationally led user involvement could be detected. This chapter therefore assesses the degree to which policies of user involvement and participation have created opportunities for groups and individuals to achieve their own objectives; rather than being used by statutory services purely to comment on services already existing or planned. The strategies employed by user groups to demand power, or to resist being manipulated or used, are also considered in this chapter, as are factors that have limited the effectiveness of user groups in influencing mental health policy and practice. I use theories of power, empowerment and resistance to assess whether user groups or individual service users are more empowered after a decade of being 'involved' in their mental health services. The sub-questions addressed were the following:

- What has been gained by groups and individuals in the process of user involvement? Is there evidence of capacity building within user groups? (Addressed in Part one)
- What strategies and tactics are used by user groups to demand power and create their own agendas for change? (Part two)
- What factors impact on the ability of user groups to create change? (Part three)

In analysing responses to this group of questions a mixture of analytic tools were used, including grounded theory and models of power, consumerism and participation. As with the first category of questions, I approached these questions from a realist perspective, predominantly, because I was dealing in the main with user/survivor accounts.

Part One: What Has Been Gained in the Process of User Participation?

This first section considers the ways in which user groups and individuals have attempted to resist top-down, tokenistic involvement and create opportunities for their agenda to be heard. It also examines the impact of policies and practices of user participation, in facilitating the empowerment of service users/survivors.

Shared experiences and support

The experience of being part of a user group had many positive outcomes for members. Regaining confidence, a sense of self-worth, and finding strength for recovery, were the main benefits of group membership:

> *It gave me a lot of self-confidence quite quickly which I don't think I would have gained without the groups. In one group I sat in a room with thirty people all with the same diagnosis as me and that was very helpful, people with almost parallel stories to mine which was quite alarming but also reassuring.* PF
>
> *I got a lot of strength from the user movement. Without that I don't know how I would have recovered the way I did. It gave me a focus and it brought out my strengths. Maybe the whole experience has brought out my strengths but I think it focused it. Users may not get on all the time but there is a really important value of equality which runs through the user movement. I've had experience of very hierarchical environments and this has been very different.* HK

The equality and democratic environment of many of the groups was valued, as was providing a focus and "*something to do with your time*":

> *I can't underestimate the significance of the group. It gave me a certain amount of confidence. It was a forum where I could express views and where my views were agreed with. It also gave me something to do with my time when time was a huge issue for me.* PF

The personal learning that was gained from attending meetings, watching the involvement processes, accessing resources like computers, and working with other group members, was invaluable. This was especially the case for those people who had had very disempowering experiences leading up to and during their admissions:

> *It gave me an idea about how organisations functioned and was a real eye opener to see how meetings were run and understand the process, get access to a computer and just begin to meet a whole number of different people.* PF

The social aspect of groups was, for some people, the main attraction:

> *I'm on my own you see so it stops me from... it helps me get out and meet people. It's kind of a healing process really, talking to people about various things, about different ways of coping with things.* PH
>
> *I think largely it was a social thing. People like to meet people and chat and... we would get into politics and have meetings about stuff but I think mainly it was having a feeling of support... everyone had been in a similar situation.* KM

The value of shared experience appears to create a sense of community and is a crucial factor in providing strength for the groups and their members. The factors that could be described as therapeutic in the respondents' comments above, can also be described in terms of 'recovery and social support'; words more commonly used by interviewees rather than 'therapeutic'. Because therapy has such negative connotations for many people in user groups, there is a tendency for mental health users/survivors to talk in terms of healing, recovery and support.

Viewing user group membership and activities as therapeutic becomes problematic, however, when the views of professionals are considered. After the data gathering period of this research was formally over, the user group in Trust A went through a period of crisis that brought Trust and user group relations into the spotlight. One of the significant issues that arose from this period, and the subsequent inquiry, was the tendency for clinicians, particularly psychiatrists, to view the membership of the user group and associated activities as; first and foremost, therapeutic. The user group was given the opportunity to formally reply to statements by doctors that their purpose was therapeutic and stated that although mutual support was important, this was not their primary goal; the purpose of their group was definitely *not* a therapeutic one. In their view, the user group was there to provide help to the Trust in developing policy and services; a view that senior management in the Trust endorsed. Due to the confidential nature of these difficulties it is not possible to provide any further details of this situation, but what is illustrated from this brief description, is the fundamental tension between user groups and clinicians on the subject of the purpose and role of hospital-based user groups.

The professional labelling of self-advocacy and collective action for change as 'therapy', could be yet another example of power being exercised through non-decision-making. I propose that the re-labelling of user groups as therapeutic groups can be viewed as an example of power holders:

- limiting the scope of the political process to consideration of only those issues which are *comparatively innocuous to them,* (Bachrach and Baratz, 1962); and
- attempting to influence, shape and determine a less powerful group's wants and needs (Lukes, 1974).

The danger of co-option, is clearly apparent if user groups are viewed in this way. In addition, the benefits of sharing experiences and receiving support may be promoted as the main aim of user groups, by those that feel threatened by what they have to say, in order to undermine the capacity for these groups to challenge the status quo.

Empowerment

Evidence gathered in this study indicates that one of the consequences of user participation may indeed be the empowerment of some service users and user groups. As discussed in Chapter two, the term empowerment holds a variety of meanings depending on the context and academic discipline. The definition of empowerment that I wish to use to analyse the respondent's comments stresses the collective aspect of empowerment, and is offered by Zimmerman and Rappaport:

> Empowerment is a construct that links individual strengths and competencies, natural helping systems, and proactive behaviors to matters of social policy and social change. It is thought to be a process by which individuals gain mastery or control over their lives and democratic participation in the life of their community (1988: 726).

Three comments presented below display a sense of personal and collective power, indicative of the empowerment definition by Zimmerman and Rappaport:

> *Staff can be helpful if you are clear that you are using them for your gain, you are getting something out of it quite concrete. It's knowing what you want out of things.* PF
>
> *Whereas before we would have done things just for the sake of doing them, now I think, is that necessary? Are we actually going to benefit from that? I've learnt to say no basically. If it's not going to be of use to us then we just cut it off the list. Basically if I have to attend a meeting where I'm not listened to and my opinion is ignored, that is not a meeting that we will ever attend again.* BM
>
> *Personally, if I get asked to do anything or if we get asked as a group to do anything, I'll be very cautious about doing it and I'll want to know what, why, what's the purpose and what are we going to get out of it? Not us personally but what fucking benefit are patients going to see at the end of the day and when? We've never really asked those questions, we've just said "yeah, we'll do it".* HK

Active service users, primarily because of bad experiences, are now much more wary of following the user participation agenda without knowing what they are going to get from the process. Being aware of one's sense of power and worth is something that comes with the experience of working independently of professionals, according to one user-worker:

> *You need to build up some confidence away from professionals before you can say "yeah I can work with you" and that's about building a sense of your own power and worth so that you can face people... not several pegs down.* JR

Another by-product of user involvement policies has been the consciousness-raising aspect referred to by a number of respondents in this study:

> *The most powerful and positive real achievement of the last ten years I would see as being consciousness-raising. Because people now very easily and rapidly key into "well actually I'm not a mental patient I'm a user of services and there's a group out there who meet together and want to campaign against ECT". So people might say "what have we achieved over the last ten years?" and I would say "we've done a hell of a lot of consciousness-raising and supporting and meeting other people" and that wasn't there before.* SH

One activist said that the learning process individuals and groups experienced, in working for change, sometimes had an empowering effect. This respondent felt that a user group he knew, who had had a particularly difficult, conflict-ridden, relationship with their local hospital, had in fact become empowered through this process:

> *...we've learnt a lot, we've learnt a hell of a lot. The users there have learnt that they've got a lot of strength about them. They are much more aware of the system because they are up against it.* DB

He also acknowledged that at different times over the past few years the group had also been completely disempowered, through burn out and despair at the lack of impact that they were having. The risks of burn out and low morale in user groups will be discussed later in this chapter. Ensuring empowerment as an outcome of involvement is difficult. As will be described later, one outcome of involvement is often further disempowerment; through the process of fighting against disempowering, tokenistic, top-down models of user involvement. However, the consciousness-raising that accompanies this process *can* lead to empowerment for some:

> *I think we're pretty naive around a lot of user involvement. No one's really worked out the best way of judging the outcomes. Sometimes in the past it's been tokenistic, but users often fought back against that which led on to empowerment. If you are going to involve users it should be an empowering process i.e. they learn something. They learn a lot. On a simple level they might learn a map of their own services and if nothing else they take that away from it.* DB

In this respondent's view, having a concrete gain; such as personal or collective learning, helps to increase the chances of empowerment.

The spaces created for user group involvement not only provide opportunities for learning, they may also offer opportunities to articulate broader demands, as Barnes (1999) observes. One of the user groups in my study provides an interesting example of Barnes' notion of user groups creating new political space. The user group in Trust A, quite early on in their lifetime, became tired of speaking within the limits of 'invited participation' and decided to speak up outside these designated arenas. The group attended the Trust board annual general meeting in force, and took it over; demanding to be heard on certain issues that the Trust management was ignoring and that they felt strongly about. This action displayed a lack of compliance with the normative expectations of 'patient' or service user behaviour that Lipsky (1980) has described. The fact that users and user groups are challenging the power holders, in such direct and uncompromising ways as those described above, suggests that professional control through consent is being undermined. Are user groups breaking the 'rules of the game' by storming board meetings and challenging the superiority of Board members? Disrespect for the rules of the game, and the people that create these rules, must surely be a sign of empowerment; if only through the re-negotiation of identity and position that such action suggests.

Identity beyond that of 'mental patient'

Staying with the theme of identity, one of the sources of strength for user/survivor groups involves the development of a shared identity and a shared perspective. Although fragmentation and division are features of these groups and will be discussed later in this chapter, shared identities and a shared culture also emerged in user groups. A growing articulation of a user or 'Mad' culture was discernible during the time of this study. The person quoted below was one of the main protagonists of a campaign within the user movement to place more importance on developing a unique culture where survivors/users could feel at home:

> *It's about redefining or defining user culture. Maybe that's the way forward - with users feeling comfortable about talking to each other and trusting each other. Like my idea of having a Mad club socially once a month where we don't have to apologise for being mad - where we don't have to hide the fact we're mad. If people don't like it they can go somewhere else. It makes a change, not having to pretend to fit in, feeling inferior.* DB

Being proud to be 'Mad', and being open about this aspect of one's identity, could be seen as an example of an identity politics developing within the user movement. The concept of identity politics can be traced to feminist and other radical analyses by excluded groups, that focus on the oppression experienced by that group, and the socially devalued lives of its members.

For those within the user movement that wish to campaign for better services and the end of stigma, through emphasising 'sameness' rather than 'difference', this radical identity stance can be profoundly challenging. It has gained the interest of the media, however, in a way that other approaches have failed to do (Mulholland, July 2001). The development of a Mad culture could be viewed as a response to a growing awareness that the user movement, up until now, has been a response to the problems *within* psychiatric services, rather than a movement that provides an alternative vision:

> *There's an element of needing to sell yourself to society. Ultimately behind the creation of a Mad culture is creating something that's user controlled. The lunatics are taking over the asylum. Not in big, bold letters but it's already happening. What people want is a culture to go with it. We've got culture, but a lot of the culture we've got we were given. Like the meetings, it's something we didn't really want to do but we had to do it because if we didn't turn up the point wouldn't be said. But I don't see why we should have to go unpaid to meeting after meeting or paid even... I think there is a point where you can say "I've done my meetings... I've achieved that... that's it I'll stop it now".* DB

Disengaging from the meeting culture of top-down involvement, and placing energy into bottom-up initiatives for change, grounded in the agendas of the user groups themselves, heralds a shift in emphasis for many groups. Stepping outside the structures of service-led involvement allows groups to have time to create their own agendas for change, and articulate how they wish to meet these agendas. The strategy described by DB above, places an emphasis on creating a new culture and participating in self-initiated activities.

Summary

The gains for service users and user/survivor groups through involvement in top-down, 'invited participation', are not insignificant. Respondents named the sharing of experiences and being part of a community, as vital in their recovery process. The social aspect of user groups, and the self-confidence and strength that people gained through involvement in these groups, had individual consequences that were hugely important. The personal learning that is gained from participation in organisational structures in the name of user involvement is valued, despite the fact that much of the learning is honed through the experience of challenging and difficult circumstances.

The benefits of participation can mean that user involvement is an end in itself; provided it allows for personal and collective growth. In coming together to participate there is a sharing of knowledge, information and skills that develop the confidence and abilities of individuals, changing them through the experience in immediately beneficial ways; whatever the outcomes within services. There is little doubt, from the evidence presented here, that empowerment is a consequence of involvement for some users. There was a clear sense of service users being able to influence change, albeit sometimes very small changes, within the limitations of the structures they were working in. A sense of personal and collective power is evident in the accounts of service users who articulated a desire to step outside the parameters of 'invited participation', demonstrating the link between participation in community organisations and a sense of empowerment (Zimmerman and Rappaport, 1988). Significantly, the outcome of self-efficacy (Bandura, 1982) or empowerment, is not due to either the design or intention of the involvement mechanisms; but occurs as a result of the difficulties that users and user groups face while participating.

The activities and language of some of the user group members indicates the emergence of a progressive, new political social movement. From the analysis in this section, user groups as communities of identity, are creating their own agendas for change rather than dancing to the tune of the power holders. Through these processes they are gaining confidence and, increasingly, power. More shall be said about this in the discussion in terms of broader literature and the ramifications of these findings.

Part Two: Strategies and Tactics Used by Groups to Demand Power

Play fool to catch wise. Jamaican Slave Proverb[7].

The politics of resistance

Resistance by user groups was evident in a range of forms, including foot-dragging and stalling to exert control:

> *We go slow as possible because I want to make sure the group I'm working with know what's going on. I don't want them going in there, not being sussed and ready for what they're going to get. So we had a six month induction where we never touched a ward, we've gone to the meetings with staff and talked about things and they're begging us to go onto the wards and I'm saying well we're not quite ready yet. You know E's not quite up to it, and I don't want to put too much pressure on D, and I want to make sure it's just right. So we'll stall it a bit longer, which winds them up, they can't understand why. So we're doing the exact opposite, we want a slow process to start and that way staff get to know us, as a group and how we operate.* DB

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[7] From A Diary with Dixie quoted in Orlando Patterson, 'Slavery and Social Death' cited in Scott, 1990.

Knowing that the hospital wanted the user group to start going onto the wards as soon as possible, the group decided to spread its development over a number of months, delaying the process of being actively involved on the wards. Going at their own slow pace kept the group in control, not only of itself but also of the issues with which it engaged. Hospital staff were described as being frustrated with having to move at the user group's pace and this strategy was effective in that it meant the group had more power than if they had given the Trust what they wanted straight away: representation on the wards. Another hospital-based group in the study took a different approach to engagement with their Trust. They made sure their members attended all of the meetings all of the time, in order to prevent professionals pushing through unwanted policies and decisions. This approach had led to burn out and internal conflict because of the volume of work and disenchantment with the lack of change.

Withdrawing involvement was another strategy employed by user groups to resist the dominant agenda they were being pushed to address:

> *What we should be doing is changing the emphasis and stop subordinating to the agenda set up by the Trust. We need to say "we want this subject to be discussed and we want a meeting to solve this problem", not to solve the problems as put forward by them, no, no we want to discuss this instead, **this** is important, **this** is our agenda. Without a proper change in this we shall be seen as part of the Trust. So perhaps the answer is to break away from the hospital and to try to maintain financial support. Break away in the sense that we are an independent group that campaigns for improvements and changes in the hospital and in different areas from a political level right down to a ward level and that would be the solution for the group. Some people in the group are very clear on this. One person suggested in fact that all of us should stop going to the meetings with the hospital. And fight instead for this and this and this you know make a list... and sit and wait.* RW

Exploiting the self-interest and policy and practice preoccupations of senior and middle management, for projects that user groups want to achieve, was a strategy advocated by one user group:

> *It's highly political and if you can put forward a proposal which suits the current climate, the commissioners are far more likely to pick that up. Most of senior and middle management... they're careerists like anyone else, they've got their own interests and obviously they're more likely to work with you if you scratch their back and then they might scratch yours.* KM

Mutual back-scratching was being used successfully by some groups, but many users were too embittered by their experiences of involvement and believed it was time to move out of the system and use more direct, confrontational tactics to achieve what they wanted.

Acknowledgement that very little had changed after all the hard work put into user involvement, was a depressing yet consciousness-raising reality for a number of people:

> *It's probably only dawning on me really... It's outside people looking at it, people that I know in the user movement who did this ten or fifteen years ago, said "well what have you actually achieved from it". We didn't analyse it that much but that's how you've got to look at it at the end of the day. Do they stick to their promises? Like actually what have we bloody achieved? We achieved... a sense that we were a strong user group and that was an achievement and in no way did we fail. Just because things are dying down a bit now there's this like "oh it's falling apart, isn't it terrible, it's failed, everyone's in hospital". But it's not fucking failed! We've been around for four years and badgered that hospital on loads of different issues and stood outside that hospital protesting... not often, not as much as we should. We have tried to tackle a lot of things but most of our energies got sucked into the meetings, the committees and mundane little things, whereas these big issues just get touched on... briefly and then we forget about them.* HK

This respondent, who had been Chair of the Trust A user group, continued:

> *For nearly ten years we've tried co-option, we've gone along, we've been on committees, we've been part of your consultation process, you've thrown your drafts at us, we've set up user groups for you... but it's not making a difference and we don't want to know anymore. My impression is that it's been a painful learning process and user involvement is almost... it's like users are also saying well we've been there, tried that, we're not really interested anymore which might actually be a good thing... that by a learning process we will move on to more confrontational, direct action. There's got to be a meeting of minds for user involvement to work and I can't see a meeting of minds happening from the agency/authority end of things.* HK

User involvement for this individual was understood as a painful learning experience. For many service users/survivors in this study, this way of getting involved was not having an impact, but while some people burned out, gave up and left groups for good, others stayed and proposed a radical shift in emphasis:

> *We will always be partly a support group as well as the campaigning part and that doesn't have to change, but the point is that the political orientation, the aim of the group should be about fighting,* RW

The painful learning process was viewed by some people as a necessary part of the journey towards independence and growth. One user-worker, who viewed this shift in emphasis positively, felt it heralded the empowerment of previously co-opted users and groups, stated:

> *It is also a very exciting time because we've had this great process that has taken a long time but... there have been lots of strong networks and user groups, and users feeling empowered through their work with user groups and joining national organisations who are gradually beginning to realise well we tried co-operation and collaboration and "let's get in there and press for change and meet people on existing terms and dress up for committee meetings"... People are disillusioned so I think we've now got a ready-made base for saying we need to try direct action. We've got to say "what are the ends we are trying to achieve?" It's only a means to an end anyway user involvement, it is only a means as it depends on who owns that process anyway.* SH

A refocusing on the 'ends' that the movement and individual groups are trying to achieve, rather than looking to user participation as the *means* to those ends, does seem a significant shift. Even professional respondents agreed:

> *What service users who have been involved for a long time are more and more doing is saying "we don't need to be involved in telling these statutory people how to run their services, they're sort of beyond hope, we might as well do it ourselves". The benefit of service users coming together isn't really to get involved and participate in statutory services but to get involved and participate in different sorts of services that are actually more able to give them the help and support that they need. They have been banging on to statutory services for donkeys years about what they need and nothing has ever happened.* AC

Disrupting traditional role distinctions

> *...you can't help but have these two takes on it by being in two places.* MG

The increasing number of people working in the mental health system, who have used mental health services, is contributing to a change of culture within statutory and voluntary services. These individuals have the potential to become a powerful weapon in the 'battle' to change the power dynamics of mental health services, primarily through the disruption of the rigid role distinctions of 'helper' and 'helped'. A senior manager in Trust B indicates her commitment to these development, thus:

> *The major strategic drive over the next ten years or so should be developing the role of service users working within mental health services including direct care through to user consultancy. We will never provide services that are acceptable or accessible for people unless we really make use of the fact that a lot of people really know what is helpful, and they are people who have been there. It's really, really important for us to provide the maximum number of opportunities for service users to be employed in the whole range of things but involved in a way where*

> *people can see people being skilled, committed experts, because that's the only way you'll challenge it really.* NP

The employment of people with experience of mental health problems was encouraged in all the Trusts in this study, a fact that compares well to many other Trusts in the UK. Change may happen more subtly through this channel and possibly more effectively, because of the 'official power' that employees have within organisations. Having individual user-workers with 'official power' within organisations may lead to more 'bottom-up' change being made possible.

Roles such as user development worker or advocacy worker often require the worker to withstand high levels of conflict resulting from organisational struggles to gain more power. In this study some user-workers adopted a radical agenda that was explicit about the need for substantial change; while others played a more 'containing' role. As one user-worker who played the radical role explained: *"being on the users side"* is tough. Being a 'high energy, tough person' was identified as crucial to playing a role that attempts to drive forward a radical agenda over the long-term. External supervision, support and a critical perspective were also identified as vital for individuals to sustain these roles. Not having a manager that understands these tensions, nor comes from a user-worker perspective, can also be a source of stress:

> *I've clashed... certainly with my manager, we have seen things very differently and I'm certainly always coming from... a kind of users first perspective and that's not necessarily how other people who are not users see it.* SH

Many tensions underlying the user-worker role were revealed throughout the process of this study and I focus here on three of these tensions in order to locate user-worker experiences within the broader themes of the thesis. The first is described by this user-worker as *"walking a tight-rope":*

> *We're not allowed to have a sense of humour, if you're a service user working in the profession, because it's seen as a sign that you're going manic so... if you have a laugh and joke about something it's "is she just being funny or is she going manic on us" and if you're depressed... you can't just have a hangover from the night before... it's my God she's depressed, she's not well enough to be in work. Everything is medicalised and they all think in terms of you're either well or you're ill. It's very difficult to keep a balance on those. I walk a tight-rope really and I'm not much good at walking tight-ropes.* BM

The medicalisation of one's personality in ways that stereotype people creates real strains for user-workers who felt they were treated differently. This user-worker gave the following account:

> *My main problem is the interference of professionals in personal matters. For example I had a meeting here, a professional meeting with the Chief Executive and*

> *there had been an announcement of cutting funding so some services couldn't be provided. I questioned the validity of this and was told that they had made decisions on the Borough's health on the basis of one visit and I commented "who was it that needed a psychiatrist if decisions of that nature were taken on the basis of one visit". That was then leaked back to my consultant who immediately doubled my medication. I then had a week on high medication and when I rebelled against it spent a couple of days in day-care being assessed and even threatened with sectioning if I refused to take the medication. All on the basis of somebody sort of telling tales after school. I'd made a fairly crass comment admittedly, but with anybody else who wasn't a user it would have just been put to one side. But because I was a user of services and used services locally he had access to my consultant and my consultant increased my medication without even a consultation. I walked into the room and was told "We've got to increase your medication". That I found very hard and I thought long and hard after coming off the medication about how I could cope with that. I thought I had grounds to put in a formal complaint but I then thought that would effect my working relationship with this person and as he's pretty influential in the field that I'm working in, I decided that it wasn't worth taking the risk. All I was going to get if I was lucky was an apology, one in writing if I was really lucky which I could frame or throw darts at, but at the end of the day that would be all that I would get. And it wouldn't really be worth the paper it's written on really. It would be under a 'you do this or else' mentality and I don't want that so I just let it drop although I did actually complain... or did have a chat with his secretary to get them to confirm that he was the one who leaked the information and was told that he hadn't officially spoken to my consultant so in other words he had but he hadn't as far as he was concerned but it had the same impact and that left me very angry for a long time afterwards. I've not actually met him in a meeting since then I think he's been avoiding me.* BM

The abuse of professional power in this account is clear. The implications for this respondent in making a formal complaint meant that the behaviour and actions of professionals went unchallenged.

The following quote relates the difficulties user-workers face when choosing to disclose or not, and symbolises the prejudice they face in the workplace:

> *I come with a number of long-term survivors... who then enter into a caring role where you don't tell people about it, you go through a period where it's something you are very ambiguous about. You just sort of hide it, it's like a secret baggage that kind of hangs round and you don't look at it and you feel that your achievements are in spite of it.* BA

The most extreme problems for user-workers were linked to the fact that they worked and lived in the same area. This brought advantages in terms of seeing the direct consequences of their campaigning, but brought problems regarding boundaries between work and personal life:

> *Because I actually live and work in the same area it's doubly difficult because not only am I a service user, I'm actually using the services I'm trying to get provided, so I'm campaigning for something and then find maybe a few months down the line I actually need to use that service or perhaps I help to review something and I actually end up being in the position of using it. And it can be very difficult for professionals as well because on the one hand they see me one day with one hat on, as a professional, and then on the other hand when I'm not well, seeing me then. And often they have difficulties in actually drawing a line between the two - between me the user and me the professional.* BM

This type of situation is likely to occur more frequently as users become more involved in working alongside professionals within hospital services. The stress that this generates for active service users should not be underestimated.

Summary

This section on strategies and tactics used by user/survivor groups to demand power has shown the politics of resistance (Scott, 1990) in action. Evidence of resistance to the professional/organisational agendas was noted in successful instances of stalling and foot-dragging. Withdrawing involvement was also a successful way of drawing attention to user agendas; although some people seemed reluctant to do this for fear of losing what little voice they had. Changing 'the rules of the game' was gaining popularity with user groups, and new alliances were cautiously being formed with statutory agencies in order to move forward with their own agendas. Campaigning against poor services, and using the media and direct action to appeal to the general public directly, was also becoming increasingly attractive, as user groups became impatient with the slow pace of change associated with 'invited' participation.

The appointment of more users and survivors within psychiatric and mental health services can also be viewed as a strategy having a gradual but significant effect on the culture of services. Some Trusts now have policies to actively encourage the employment of people with experience of using services themselves, and these policies have become a key feature of their expressed desire to create real cultural change. The importance of support for these individuals is crucial to avoid the danger of them becoming isolated and marginalised. There are tensions that result from the disruption of the rigid roles that traditionally separated staff from patients through the maintenance of 'them' from 'us', and good support and supervision is vital to prevent burn out in these workers. Individuals, who occupy both roles, some more overtly than others, are contributing to a change in the culture of mental health services in both statutory and voluntary services.

There have been gains from the 'business as usual' approach to involvement for users and user groups, the biggest reward for users being the ability to have an impact on the services they used. The consciousness-raising and learning that took place in user groups were two other rewards that users mentioned. On an individual level these gains have, for some people, been significant; suggesting that personal empowerment, on a temporary if not permanent basis, has been achieved. The most significant aspect of this empowerment, however, is the fact that it was achieved by service users themselves, rather than through professional or organisational support. Indeed, the empowerment of individual users and user groups was linked by more than one respondent to overcoming the disempowerment and disappointment of 'being involved'.

The gains for groups are less tangible, however, and user groups still seem to be fragile in the face of the strategies described throughout the previous chapters. But community building and user group capacity building *is* taking place through 'top-down', 'business as usual' involvement; despite the problems and tensions. User participation has contributed in significant ways to bringing people together to articulate their anger and frustration with mental health services.

Through gaining confidence and self-assurance, user groups are becoming clearer about the need to work towards their own agendas; rather than those of the services they have used. To create real, lasting change user groups are seeking to transcend invited forms of influence and make changes to the wider social, political and cultural structures that they see to be the main source of the problem. This section of the chapter has argued that addressing the wider social inequalities and injustices, that are often the precipitating factors to becoming involved with the psychiatric system, is another example of the user movement broadening its engagement from services into the wider public sphere. The final part of the chapter presents evidence demonstrating the struggle that the movement will have to accomplish these aims.

Part Three: Factors that Reduce User Group/User Movement Effectiveness

This last section considers factors that limit the effectiveness of user groups and the user/survivor movement in achieving a greater impact on service provision. Some of these factors can be linked to the resistance of organisations and professionals to user participation and therefore build on Chapters five and six, while others relate to the internal dynamics of user groups, or the difficulties arising from the stress associated with enduring mental health problems.

Burn out and low morale

> *I see people in the user group getting tired as well and that is quite normal. People get unwell and burnt out through feeling manipulated and that's another aspect of the user movement, we are not supermen and superwomen, we get tired.* PF
>
> *I have this overwhelming feeling of wanting to give up because it was all so awful.* MG

A number of users/survivors spoke of the lack of recognition by their Trust of the time and energy their group and its members contributed to working on Trust business. At the end of the data gathering phase of this research, one of the user groups was experiencing low motivation and high levels of burn out amongst key individuals:

> *The problem is that we can say that we have had some success in some areas of the running of the hospital, for example some improvements in some wards of the hospital, but they are always cosmetic and maybe they would happen anyway without our involvement maybe later on. But you know there are very, very few things that we can say were as result of our actions.* RW

At this time, the Trust mergers were imminent and many people were feeling the stress of these proposed changes. One service user told of his anger and frustration when the Chief Executive from one of the Trusts due to merge, approached the user group for support:

> *We were approached the other day by the Chief Executive of one of the hospitals that will be merging with this Trust, who is losing his job because of the merger, and he was coming to us to ask us to support his campaign because he was applying for a job, I mean to me it was completely incredible no? Bloody hell no? I mean we cannot accept a meeting with a person who is fighting to keep his job, no, no. I mean this is an example of using the users for their own purposes, for their own careers, which OK they will but we cannot accept that. There are a number of people in the hospital at the moment who are very, very worried about their future, and perhaps they are going to use the fact that they are involved with users for their job prospects, their future and that is manipulation.* RW

The time considerations of user participation within an expanding organisation was also a factor identified by users as contributing to their stress and burn out. The task of sitting on many of the hospital committees can fall to just a few people. One person spoke of the difficulty of finding new members for their user group to take on some of the workload. Lack of infrastructure and support available to user groups combines with this overloading to leave them even more vulnerable:

> *User organisations themselves have been through a very difficult yearning, growing, emerging process, which has sometimes been quite difficult and painful. There hasn't been the infrastructure to support user organisations or people getting resources to give themselves support so there has been a lot of conflict within user organisations which has held back a lot of the political campaigning and a lot of the hands on work that could have been done to lobby at a local, regional and national level.* SH

The link between the conflict within user groups, and the lack of infrastructure and support highlighted by the respondent SH, is a critical feature that I turn to next.

Different agendas and polarised approaches to change

A number of respondents referred to differences and conflict within user groups, because of the wide variety of different views and experiences of mental health services people have. These differences led to tensions between people with contrasting views on what is wrong with services and what should be done about it. The following comments consider how these tensions affect user groups and the movement as a whole:

> *We are still struggling to find workable ways of achieving our aims. The power conflicts that are expressed in different ways come out in personal hostility, which isn't necessarily warranted, it's just a means of expressing it.* SH

> *The difficulty we've got is there's no uniting aims it's not like we want the age of consent lowered or anything. People have their own views so there's no uniting ten commandments for us.* DB

> *There's something about how user groups... how functional they manage to become really. I think there's a lot of possibilities if people can get themselves together sufficiently but all the infighting isn't going to do it.* KM

The diversity of people attracted to the user movement and to user groups helps to explain the difficulty of achieving consensus and the persistence of conflicting interests. People come to user groups with very different experiences of life, as this respondent graphically described:

> *You've got people coming in from completely different positions. You've got people from diverse places in life, coming together, they've been knocked and told they don't fit in... It doesn't work... they get rowdy, they give you outbursts, they interrupt, they are bad tempered. Some people aren't sleeping very well... people aren't eating very well. And you've got people that come in from different positions... in life. We're coming in from different employment positions, training*

> *positions, education. So you've got people who don't want to listen to certain other people or they've had different training backgrounds. And plus we've been damaged before we came together as a powerful group, I mean there's nothing like empowering the disempowered, sometimes it's more dangerous because until they find their feet they can be really destructive... It's a real power field... it's a real power territory.* LG

A particular tension appears to be between those service users who align themselves with the service providers, and those who position themselves as more 'anti' professional and 'anti' medical intervention:

> *With the management group itself it's difficult, a lot of it seems to revolve around splits and polarisation between these positions of aligning oneself with the services and then having a more radical take on it.* PF
>
> *Some people do take quite an anti stance to the professional services and then there are other people who really don't understand that saying well "what's wrong with psychiatrists?" There's people who have had really awful experiences and there are some people who haven't. I get the feeling that there's a lot of people who... who have got the more anti view that have been kind of sidelined and pushed out.* JR

Conflict can be encouraged by the internalisation of negative images from the press and elsewhere. In the face of many problems and few resources, mutual blame easily becomes part of group culture. In this study, a number of respondents acknowledged that user groups have, at times, further marginalised some individuals who were, perhaps, the most in need of support and empowerment:

> *I think to a certain extent the user movement can ostracise people who are less articulate and more damaged by their experiences and they can be marginalised further.* WA

The marginalisation of some members can be seen as a characteristic of disempowered groups, particularly when agendas are subject to strong external influences, as the feminist movement has shown (Harding, 1991). The 'meeting-culture' of many user groups also probably does not help to attract those who are less confident and self-assured. The need to build the capacity of groups through improved infrastructure, increased resources and independent support will feature in the conclusions and recommendations of this thesis.

Representing diversity

One of the main issues faced by the user movement and user groups is accusations of unrepresentativeness. The user groups in the study acknowledged the lack of people from Black and minority ethnic groups and were taking steps to address this under-representation. However, some professionals interviewed believed that user groups were not doing enough to hear the 'different voice' of Black users. Some Black user groups are now setting up alongside their white counterparts in order to represent the interests of Black and minority ethnic users. A Black service user interviewed saw separate groups as the way forward for the time being at least. She also spoke about why some Black people are reluctant to get involved in user groups:

> *...I think that the white folks have got used to their own company, that's point one, but there's also a new Black user group and some people are quite heavily involved in trying to pick that off the ground. I think that as far as Black users are concerned there's a lot of apathy because like they've been on the brunt... the negative end you know like if anybody's going to be termed with a negative term and given the most medication it's usually going to be a Black person. So I think it's that... apathy and a misunderstanding of culture. Some people don't want to have anything to do with it 'cause the memories and the thought of it were so traumatising and invasive that they couldn't like begin to get over it let alone admit to their own community, which is another tight community, admit to their own community that they've been in such a place.* LG

Another Black service user felt he had been badly treated by the user group. He had not felt listened to, and believed that the mostly white user group was as equally dismissive of what he had to say as hospital staff had been. Engaging with the views of Black users is vital if user groups are to avoid accusations of their own exclusionary practices.

Gender is another important issue for user groups. Despite the fact that, in the user groups in the study, women held powerful positions and were often the main motivating force in their groups, a number of women activists were concerned with what they considered to be a very male bias in the user movement as a whole:

> *One of the most pressing problems the user movement has to deal with is the gender problem... problem because it's not being openly acknowledged and recognised. It might be something to do with how males operate generally which is different to the way women... I do think there are differences. Most user organisations have got men doing things mostly or taking the up-front spokesperson roles and you know a lot of women do feel excluded and angry and disempowered by men just driving things through all the time and that is a lot to do with different ways of operating. (...) We're all struggling to be so co-operative and mutually supportive and non-*

> *hierarchical... there's a power vacuum and it's more in men's nature to want to fill the gap.* SH

In common with other social movements the user movement tends to represent the interests of those who are most powerful within the 'oppressed' social group. Hence struggles around power inequalities are played out within the user movement as they are in other social context; with race and gender being particular important divisions. Beresford and Campbell (1994) bring a helpful perspective to the discussion of representation by pointing out that, while an inclusive approach to involvement demands that groups challenge their own sexism, racism, heterosexism and ageism, they also face problems arising from inadequate resources. Inclusive user participation requires not only clear strategies and anti-discriminatory attitudes, but also resources to which user groups often have very little access.

Lack of continuity

Another factor that limits the ability of user groups to be effective change agents, is lack of continuity:

> *The biggest problem is lack of continuity... people not being able to function on a level so they have to take time out.* RM

> *It's such a fraught and emotionally tense process of surviving... one day you might feel a bit on the edge and another day you may feel OK, you have good times and other times when you feel more fragile. That does not fit with an everyday common or garden organisation so we are struggling with multiple difficulties.* SH

User groups are characterised by the central involvement of a small number of key members. This leaves groups vulnerable when these key people become unwell, burn out or leave. This problem is well recognised by some of the professionals I interviewed. One senior manager lamented the huge obstacles presented to partnership working by the fluctuation in health of key individuals:

> *People using services do have very real difficulties. The nature of mental health problems is a huge obstacle and barrier. When people really are very disabled by their mental health problems, and find it really difficult to communicate for all sorts of reasons, when they have very frequent bouts of very ill health and distress I mean these are very obvious barriers! Also I think it is the fluctuation... people have good days, bad days, good months, bad months, good years and bad years and that's a real frustration for continuity 'cause by definition so many of our initiatives are long term goals. And there's nothing more frustrating than working with folks that really care about a particular initiative, really want to be involved but have to dip*

> *in and out because they are having bad times and you really miss their contribution for that time. NP*

Views on Change and the Future

To draw this chapter to a close, I wish to briefly attend to the question of change and how respondents saw participation in mental health services developing over the next few years. To follow is a brief selection of interviewee responses that give an indication of the range of views on this question:

> *Yeah, the word's getting through to people on the front-line... that you can't treat us like second class citizens. You can tell, well not everywhere, but in some places it's got through.* LG
>
> *Some changes have taken place because of user involvement but these changes are often fragile and may be revoked as soon as anything goes wrong. You've really got to have a critical mass of people to make a significant lasting change and I don't think we're there by any means.* MG
>
> *There's too much pressure now for things to slip back to the way they were.* DB
>
> *Unless there is continuing pressure on the Trust I could feel despondent about the future.* SW
>
> *I see bad things coming, very bad things and more oppression so I'm more impatient.* RW
>
> *I see the time and opportunity and window for real change as having gone because the structures that were in place are being superseded and other priorities are moving in. Now the worry is about safety and budgets and seamless services. The official momentum has been lost.* HK
>
> *There is scope and potential for an awful lot of change for the good but the current political climate is so difficult and hostile, this is not a good time for even a strong, established well-run, well-financed group. So power in ownership of services and provision for users is still pretty distant.* SH
>
> *I'm always reminding myself that at the end of the day we're looking at quite a large cultural shift which is going to take years. It's not going to happen in one year, two years, three years and you have to remind yourself of that or you just get pissed off and you go home and give up. The goals are very long-term goals, the*

> *problems and issues that we are trying to address are really complex. There aren't any simple solutions. How do you keep going? How do you keep resources going? How do you keep the energy going? Although it's really hard work I think it's worth it at the end of the day... we are making changes now, even though we don't always realise it.* NP

When asked about change some interviewees said that they thought things were improving but slowly, while others felt that things were getting worse, primarily due to the government preoccupation with cutting costs and public safety. There was general agreement that change in the organisational cultures of mental health services was a long-term and complex task, that would take years to accomplish. The overriding view was that an official commitment from government to the goals of partnership working was needed in order to continue the progress made to date.

Summary

The last part of this chapter set out to address the question: what factors limit the effectiveness of user groups in achieving change? One feature of the data was an organisational resistance that limited the effectiveness of user groups by overwhelming groups with top-down agendas, and not providing them with the levels of support required to build capacity and avoid burn out. A high level of despondency was detected from some service users/survivors, who described feeling manipulated by their Trusts. This resulted in users leaving the group, and some people ended up back in hospital when relationships got particularly bad. Taking on leadership roles within groups or within the movement is a stress to health for those that do it: not least because of the limited support available for the task. Indeed, users pay a substantial personal cost for their involvement, as has been highlighted in the literature in earlier chapters. When some users drop out, due to frustration with lack of change, more work is left for fewer people, which leaves the group vulnerable to collapse. An important area, therefore, is clarity that users will continue to have access to services when they require them, since access to services can be jeopardised by relationships breaking down between individuals and their hospital or service. The development of crisis plans, where users plan and convey what they want to happen should they get unwell during their involvement with the group; can also be helpful. In this way user groups, together with clinicians, then have a mandate to take action to support members who become unwell. The general importance of infrastructure and support is key to maintaining the capacity of user groups to be involved in statutory services.

The second key area that limits the effectiveness and capacity of user groups is that of different agendas and polarised views on the most appropriate mechanisms for change. Diversity is important and must be embraced and channelled appropriately to avoid splits in user groups that can then be exploited by those with power. The conflicts of interest that arise within user groups should, therefore, be seen as inevitable and predictable. Anticipation of difficulties may lead to greater clarity about how conflicts can best be handled and managed, to prevent fragmentation and division. It is also important to acknowledge that problems of limited effectiveness; arising from differences, tension and conflict within user groups, tend to be exacerbated by under-resourcing. With insufficient resources to broaden the base for representation of user concerns, and to appeal to a wider range of potential activists; user groups, are likely to continue to be characterised by tension and conflict. There was little evidence of alliances with other user groups and other disability groups in this research, or collaboration on potentially common issues. An exception was one user group's collaborative campaign with local disability groups to reinstate free bus-passes.

Conclusions of Chapter

There is evidence in this study that the dialogue between user groups and service purchasers and providers, *has* opened up discussion about the processes, practices and outcomes of services, and has called providers to account. The changes that appear to be most beneficial to users are the increased consciousness-raising that forums such as user groups have helped to bring about. Providing alternative spaces and alternative roles for people who have had bad experiences in the mental health system to re-engage, is a vital benefit. The shared experiences and support gained through attending user groups, and the empowerment that some individuals have attained, even temporarily until their next set back; are not insignificant. For the user group members in the study, the membership of their user group had contributed to their recovery and stability when they were most fragile. Being able to use their negative experiences of the system in a positive way, through involvement and perhaps change, gave people a role and value until they were able to pick up their lives again. For some, it helped them to be successful outside of the user group, having a new confidence in themselves, and they then became less involved with their group. For others their involvement became their life.

Chapter Seven

Discussion of relevance of findings to theory and practice and an agenda for change

The central thesis proposed at the start of this work, and reiterated throughout, was that participation will not succeed as a strategy to improve services, or to change relationships between service users and service providers, if it is disengaged from an understanding of power and its effects. The four main aims of the research were to:

- Document the practices of user participation within the psychiatric/mental health system from a critical perspective;
- Identify and describe the barriers to user involvement;
- Provide an account of the 'unsettling relations' (Church, 1995) of participation; and
- Develop our understanding of, and build on theories about, the experience of participation and any resulting changes in power relationships.

The research aimed to contribute to the growing body of literature (Baistow, 1995; Barnes, *et al.*, 1999; Church, 1995, 1996; Croft and Beresford, 1992, 1995; Wadsworth and Epstein, 1998) that has sought to explicate the power relationships, conflicts of interest, ambiguities and tensions within participation; both in theory and in practice. This chapter aims to demonstrate the ways in which the background literature on user participation, described in Chapters one and two, is extended or challenged by my research findings. In this chapter I shall discuss the findings of the research within their wider context, drawing on literature both from health and social care settings and from the field of community participation in urban regeneration and overseas development. The rationale for drawing on research and theoretical work from such a wide context is a belief that the issues that have been detailed in this research resonate with other contexts where participation takes place in situations of power inequality. The chapter aims to outline the wider implications of the findings for theory, policy and practice; and includes an explicit agenda for change. It also provides a discussion of the lessons learned from the conduct of the research and outlines further research that might follow from these findings.

Implications for the Theory of User Participation in Statutory Mental Health Services

Limitations of the 'business as usual' approach to user participation

Forms of participation have multiplied over the past few years with users becoming more and more involved in mainstream statutory service consultation and decision-making processes. The findings of this research indicate that while there have indeed been some gains for users and user groups, there is no evidence that the 'cultural-revolution', required to transform power relations in public services and organisations (Barnes and Walker, 1996), has taken place in the settings studied. The findings suggest, instead, that services have not visibly progressed, either in terms of increased information and choice in people's care and treatment, or in terms of control and influence over service development and delivery. User participation appears to have failed to concede many opportunities for real change in the quality of services or in user-professional relationships.

Although services have been 'opened up' to scrutiny; in a way previously unknown in the NHS, professionals still decide where, when and how user participation takes place. Accordingly, the 'rules of engagement' or 'rules of the game' (Clegg, 1989), concerning the nature, form and organisation of participation, remain firmly controlled by statutory service partners. These rules of the game influence the way decisions are made, what is on and off the agenda, what is open for negotiation and what is not. Overall, user involvement rarely extended to setting agendas and provided few opportunities to alter the form decision-making took.

I have described the way that political expediency, the result of government pressure on Trusts to involve users/consumers, has led to an emphasis on 'being seen to be doing' involvement; rather than on laying the foundations for real substantive change. I propose that many of the tensions and conflicts of user involvement, documented in this study, can be associated with the uncritical adoption of the consumerist approach which has resulted in a 'business as usual' (Cornwall, 2000b) model of participation in practice. The findings of this research therefore support the writings of Beresford (1997), Brandon (1991) and Croft and Beresford (1995) that suggest that because the market-driven approach to participation has been constructed in terms of services, and in the interests of the service system; gains for service users have been severely limited.

According to Beresford and Campbell (1994), most arrangements for user participation in mental health services are linked with *administrative* rather than *political* structures, because this is where most of the user consultation/participation forums are located. This study elaborates on the ways in which a concern with redesigning only the administrative structures of service systems leaves the formal and informal political structures where power lies, untouched. In doing so it has highlighted the severe limitations of the representative model of democracy that most consumerist involvement adopts. Conventional representative forms of participation do not seem sufficiently attentive to power inequalities to enable those who have previously been relatively powerless within a system, to be heard and valued. I suggest that the practice of placing the emphasis on redesigning the administrative structures of service systems does little to change the institutional, political and cultural structures and systems, or the 'networking of relations' (Clegg, 1989), within which power is located.

In terms of the form participation took in the contexts studied, decision-making was confined to 'safe' areas; with users' own issues described as 'dropping off' agendas. The types of involvement described by respondents included *informing, consultation* and *placation,* but did not extend to the higher rungs on Arnstein's 'ladder of participation' (1969: See page 39). The findings suggest that the level of user involvement, in the contexts studied, remained within the rungs of non-participation and tokenism; rather than indicating any real gains in user power. This is not a surprising finding given the predominance of the consumerist approach to involvement which is concerned with having 'a say' rather than renegotiating relations of power. The lack of real gains in power and influence led to burn out and internal conflict within one of the user groups. This was primarily because of the volume of work required by them in order to deliver the required 'involvement', but it was also a result of a general disenchantment with a lack of acknowledgement of their role and a lack of discernible change. The finding echos David Reville's comment on the overloading of consumer representatives from the late 1980's in Canada:

> We get consumer representation on our committees and boards and then snow them under with bureaucratic paper and administrivia. We burn them right out and then we cluck sadly and whisper that they weren't really up to it after all. Their medication needs adjusting, we say, and we are really so damn sympathetic (Reville in Church and Reville, 1988:27).

Users and user groups tended to get involved with issues and attending committees in order to prevent something that they disagreed with from taking place; rather than engaging for more positive reasons. White (1996) has written about a similar dynamic in participation in overseas development where:

> People often participate for negative reasons: they do not have the confidence that their interests will be represented unless they are physically there (1996: 11).

Similarly, using Cornwall's typology of participatory approaches (2000a, based on White's model, 1996) displayed in Table 7.1, most forms of user involvement could be described as being situated within either the *nominal* or *instrumental* forms of participation.

Table 7.1. Cornwall's adaptation of White's typology of participatory approaches

Form	**What 'participation means to the implementing agency**	**What 'participation' means for those on the receiving end**	**What 'participation' is for**
Nominal	Legitimation to show they are doing something	Inclusion to retain some access to potential benefits	Display
Instrumental	Efficiency to limit funders' input, draw on community contributions and make projects more cost effective	Cost of time spent on project related labour and other activities	As a means of achieving cost effectiveness and local facilities
Representative	Sustainability to avoid creating dependency	Leverage to influence the shape the project takes and its management	To give people a voice in determining their own development
Transformative	Empowerment to strengthen people's capabilities to take decisions and act for themselves	Empowerment to be able to decide and act for themselves	Both as a means and an end, a continuing dynamic

Source: Cornwall (2000a: 9) adapted from White (1996: 7-9).

There were very few examples of representative or transformative involvement (Cornwall, 2001a; White, 1996), despite a few genuine attempts by some senior managers to create more opportunities for this. All but a few examples of involvement were 'invited' and 'top-down': often with uncertain or weak connections to organisational decision-making processes. For some interviewees their scepticism indicated a frustration with participatory activities that were, to their mind, purely about legitimation and display: to show they were doing something. The form designated by the term representative is used differently within the typology to the way I have used it in this thesis. In White/Cornwall's typology, representative is used to indicate the top-down motive of creating sustainability, and is about giving people a genuine voice. In this thesis I have used the term representative to designate the representative model of participation, demonstrated through user membership of Trust decision-making committees. Although there were examples in the data of genuine attempts by professionals to create forms of participation that did give people a voice and the opportunity to empower themselves, these had not seemed to be able to create significant changes at the 'front-line' of service provision. There was, therefore, little evidence of either the representative or the transformative forms of participation, according to the analysis provided by use of this typology. The findings concur therefore, with Potter's (1988) analysis that:

> Consumerism is fine as far as it goes, but it does not go far enough to effect a radical shift in the distribution of power (157).

Participation as a strategy to resist change and support the status quo

Another contribution of this thesis, in theorising user participation in mental health services, has been the exploration of user participation as a strategy for legitimation and display; a possibility raised by analysing the data in relation to Cornwall/White's (2000a/1996) typology. The findings presented suggest that the representative or 'business as usual' model of involvement, is not only inadequate as an effective mechanism for change within services, but appears to operate as a mechanism to maintain and legitimate the status quo. Respondents in this study expressed the view that some Trusts, and some individual professionals, had approached the task of user involvement by following what they described as a 'winning formula': by saying the right things at the right time to the right people in the right places. Because of the need to 'be seen to be doing' involvement, organisations wishing to claim the 'moral high ground' in a competitive climate did this, in part, by demonstrating their activities to involve service users. Even individual managers were described as seeking to make use of their connection with the local user group to furnish their careers. This finding indicates the pertinence of Croft and Beresford's (1995) suggestion that managers (in their case social services managers) may use consultation merely to legitimate their own ends.

Harrison and Mort's (1998) work on strategies of legitimation used by managers in health services to 'play the user card' exposes the danger that the gathering of user views may be a politically expedient mechanism to legitimise managers' own policy and practice decisions/positions when it suits them. The data presented here suggests their analysis to be valid and offers a powerful lesson for the analysis of power relations in mental health services: that user involvement may have become a tool for organisations/professionals, rather than a mechanism for service users to have more say and control over the services they receive.

On the basis of the data presented it is possible to suggest that users' voices may be being selectively incorporated into decision-making processes in order to sustain existing structures. Interestingly, these findings mirror Carmen's warning that participation in international development has been an attempt to 'neutralise' true participation:

> It would appear indeed, that recent moves towards the 'promotion' or 'mobilisation' of people's movements, or other initiatives aimed at 'reaching the grassroots', are part of an attempt to neutralise people's creative genius and thirst for true democracy and true participation (Carmen, 1996: 207).

Carmen is obviously sceptical about the extent to which partnership and participation can really create changes in ingrained power relationships within situations of longstanding inequality and oppression. Other critics have similar views, arguing that participation and involvement initiatives have the potential to co-opt opposition and 'ride out change' (Marsh and Rhodes, 1992): diverting attention away from the more exploitative structures of power in society (Stewart and Taylor, 1995). Cornwall (2000b) offers the reminder that participation was first used in colonial countries to fashion 'good citizens'. She emphasises the early pragmatism of participatory initiatives in overseas countries in the 1950's and 1960's that aimed to realise the goals of cost-effectiveness, compliance and sustainability; rather than the empowerment of the people. Cornwall (2000b) suggests that the adoption of participation by mainstream development agencies, provided support for orthodox development solutions that side-stepped relations of power and kept people poor. The co-option described by Carmen (1996) and Cornwall (2000b) has been demonstrated to also be a danger in participatory contexts in mental health services.

Various theories of power were drawn upon in order to illuminate the ways in which user participation had become limited to safe areas and selectively incorporated into some areas and not others. The theory of non-decision-making power (Bachrach and Baratz, 1962) was one of the most useful tools for this analysis. This theory proposes that power can be exercised by confining the scope of decision-making to relatively 'safe' issues through practices that limit discussion to consideration of only those issues that are comparatively innocuous to the dominant group. This is achieved through the organising in and out of certain issues and the mobilisation of bias.

There were examples of non-decision-making being played out in some of the findings presented. For instance, service users provided examples of gains that they had negotiated: the achievements of gaining access to hot water for tea and coffee on the wards and access to clothes cupboards, were areas where user groups had achieved most success. However, by both user and professional admission, subjects such as medication practices were not up for discussion. Indeed, conflict was reported whenever users directly challenged the practice of individual practitioners. This was particularly the case with issues users wanted to raise with individual psychiatrists about medication regimes, the desire for access to non-medical complimentary therapies, or the need for independent advocacy. When service user comments were concerned with an individual professional's practice or approach to treating a patient; the shutters were described as coming down fast. Conflict was generally reported to take place whenever users initiated non-invited participation. This finding is reflected in a quote by Sang (1989):

> ...from beginning to end patients' advocacy is run to suit the interests of institutions which are being forced to change in the face of new policies. The fact that it appears progressive is a reflection of the power of the controlling forces which exist within psychiatric services and which come openly into play as soon as 'clinical judgement' and other professional rights are challenged (Sang, 1989: 204).

Another mechanism suggested in the findings, that could be considered to be an example of the 'mobilisation of bias', was the practice of describing user-professional relations in consensus terms. Professionals interviewed were reluctant to talk in terms of power; preferring to talk of shared agendas. One manager viewed his Trust as creating an overly cosy or comfortable relationship with the user group; something he disagreed with because he felt it un-helpfully masked the conflict he believed to be inherent in relations between users and professionals. This view was unusual and for most other professionals there was a distinct preoccupation with conceiving relationships as operating within a consensus model (Ng, 1980; Rees, 1991).

For groups that did not allow professionals the comfort of these consenting relationships; conflict was assured. Overall, the description of user-professional and user group-organisational relationships as consensual, served to deny the day to day experience faced by users and user groups, which they described as painful and conflict ridden. Hastings, MacArthur and MacGregor (1996) suggest, however, that conflict may be a sign that partnership is actually working. Their research on community involvement in regeneration suggests that smooth working relationships in partnership environments may, in fact, reflect weak community partners. And according to Clegg (1989), the suppression of certain kinds of conflict and exploitation of other kinds, is part of all forms of political organisation. Professional descriptions of the presence or absence of conflict, and of comfortable and consenting relationships between user groups and organisations were, therefore, looked at with considerable interest.

As described in Chapter two of the thesis, Hugman (1991) draws attention to the way in which professional discourse constructs patients as 'difficult' and 'uncooperative'; through general conversational rules. He poses the question of whether 'co-operation' only describes situations where service user actions are in agreement with the expectations of professionals. Hugman (1991) is using Foucault's ideas that emphasise the operation of power through professional practices that construct, not only the content of interactions with clients, but also the relationships with clients, the rules that govern these interactions and relationships, and the role each party plays. The question posed in the literature review was whether participatory practices merely replicate dominant understandings of the 'professional' and the 'client/patient/user', or whether they have the capacity to resist these and present alternative understandings of the client, their role and relationships/interactions with care-givers. The findings of this research suggest that in the majority of participatory activities that users were involved in, dominant understandings of the client/patient/user prevailed. For example, most forms of 'invited' participation continued to construct the organisation and its workers as knowing best, and as working in the best interests of the client/patient/user; despite comments of users to the contrary.

Another example of the construction of user interests by the dominant group, described in the research, was that of user groups that had been started by professional organisations, whether by hospital Trusts or voluntary organisations, to represent the user voice. It was apparent that the 'parent' organisations held a considerable amount of control over their 'offspring'. It seemed that small user groups were highly vulnerable to control by larger, more established non-user groups/organisations. This finding substantiates Atkinson's (1999) view that participation merely reinforces existing relations of control and domination, by discursively setting the limits of what is possible and thereby constructing the demands that can be made. In his analysis, more powerful organisations use a combination of political and bureaucratic authority to control a less powerful organisation's objectives; a point that was demonstrated in Chapter five (page172) when the user group was 'advised' on the best method of engagement with the Trust to achieve their goals. This could be seen as an example of the mobilisation of bias, where user groups are hindered in raising issues that may be detrimental to 'parent' group preferences. BothLukes and Foucault agree that power is most effective when it is operating unnoticed through the creation of the 'normal' and 'natural' order: through hegemonic practices. Using these ideas to extend the analysis above, I would suggest that participation, as a form of power, may be particularly effective because people enter into the process willingly, a fact that Foucault saw as an essential aspect of the operation of power:

> Power is tolerable only on condition that it mask a substantial part of itself. Its success is proportional to its ability to hide its own mechanisms' (Foucault, 1976: 86).

So, has user participation merely been a coping strategy to lessen the impact of the user/survivor movement? Trivedi wrote of her involvement in the National Service Framework for Mental Health, as a Black service user, in the Openmind journal recently:

> ...the whole experience left me feeling battered and bruised and certainly in poorer mental health (2001: 19).

She describes the process of involvement, in developing this piece of policy, as marginalising and devaluing: with a lack of proper attention paid to issues of 'race' and culture. All the issues raised by Trivedi (2001) have featured in this piece of research: being in a minority, divide and rule, rushed time-frames, accusations of unrepresentativeness and lack of support. This experience led Trivedi to state that she will never be involved in such a disempowering and damaging consultation again. That this was an experience had at the hands of the government itself is a depressing warning that participation is tough to do well at the top of organisational hierarchies, let alone at the bottom. To summarise, there are, therefore, great limitations on the 'loyalty' and 'voice' aspects of Hirschman's (1970) three strategies of influence described in Chapter one. The findings agree with the work of Harrison and Mort (1998) and Marsh and Rhodes (1992), in concluding that user participation is highly vulnerable to manipulation by statutory organisations wishing to create the illusion of change.

The constraints created by institutionalised contexts and staff practices

One of the aims of this thesis was to document the 'unsettling relations' of participation within a UK context, in reference to the work of Church (1995) in Canada, and Wadsworth and Epstein (1998) in Australia. By describing evidence of unsettling relations the study makes a significant contribution to theory on the nature of organisational and professional resistance to change.

Many ideological, cultural and organisational barriers to increased user influence in statutory mental health services, were described in this study. Some of these barriers combined to create what was described by one user respondent as a 'canteen culture'. Chronic under-funding, stretched services, suspicions about the motives of government, and a desire on the part of statutory services to continue their role as providers, were all factors that seemed to operate against organisations becoming more receptive to the ideas of joint working and user involvement. As could be detected from the findings presented in Chapter four on being at the 'sharp end', statutory psychiatric environments in the late 1990's can be very challenging places to work; with an emphasis on survival and getting by. Evidence presented by respondents working at the 'sharp end' of services illuminates just how much pressure the mental health/psychiatric system is under, after years of chronic under-funding.

A recent report by Mind (2000) on patient's views of conditions on psychiatric wards supports the findings presented here. The survey paints a grim picture of life on many psychiatric wards:

> ...a depressing environment, unsafe, dirty, with illegal drugs easily available, minimal contact with staff, not enough to do and not enough access to food, drink, bathing facilities, interpreters if needed, telephones and fresh air' (2000: 31).

There can be no doubt that working in such conditions can curtail the commitment of staff to what has been described as 'the icing on the cake'; user involvement policies handed down from management. In addition, comments from respondents in both Trusts studied, suggested that user groups were used by Trust management as a 'battering ram' against front-line staff, as part of an effort to create management-initiated change. This left front-line staff feeling attacked from all sides.

It was proposed that contradictory and opposing goal or service orientations (Lipsky, 1980) have led to acute anxiety and frustration for those on the 'front-line' of mental health organisations. The findings suggest that the tensions arising from these contradictory and contrary goals are most acutely felt on the 'front-line' of mental health organisations; since it is there that the rhetoric of these goals need to be translated into action. Front-line workers are faced with the unenviable task of managing and negotiating these multiple goals in their day to day work. The failure to manage to do this is, therefore, less the fault of individual workers and more the result of the inability of organisations to reduce the opposing nature of the goal orientations set. As senior managers have described in this research, the goals their organisations are charged with setting are not necessarily ones desired by those who work in that organisation. Society has set the goal of social control and psychiatric services are charged with determining the limits and boundaries of normality and deviance, and acting on its behalf to manage these boundaries. Through the efforts of the medial establishment and the collusion and support of society, the medicalisation of social problems is fully entrenched in most of our public services, most obviously in the mental health/psychiatric service. Even under the leadership of charismatic and conscientious leaders, some of whom I had the pleasure of meeting during this research, creating unity out of these seemingly incompatible aims can seem unrealisable.

In pressurised environments staff were described as withdrawing from patients and adopting a 'siege mentality'. Practice becomes 'standard' and regimental severely effecting the capacity of service providers to attend to user's needs respectfully and effectively. Work on the corruption of care by Wardhaugh and Wilding (1993), described in Chapter two, addresses the link between the pressures of particular kinds of work and neglectful and abusive treatment. According to Wardhaugh and Wilding (1993), a lack of resources exacerbates the way the moral legitimacy of the work: 'is undermined by the gap which separates the rhetoric of policy from the sharp reality of practice' (16). Poor working conditions, inadequate resources, little or no support or supervision, badly designed wards, and not feeling safe or valued, does not bode well for good practice; let alone for genuine user involvement.

One of the contributions of this work was the way that it documented the strength of organisational and professional resistance to change. Menzies' (1970) work was used to shed light on why change may be so difficult in mental health services. In her observation of the nursing profession, the defensive techniques she interpreted as meaningful included an obsession with avoiding change at all costs. The nursing service, according to Menzies, tries to avoid change wherever possible; clinging to the familiar even when it has become irrelevant and unhelpful. The impending sense of crisis referred to by Menzies (1970), resulting from the organisational relations of nursing and chronic under-resourcing, undermines the ability of staff to look beyond survival on a day-to-day basis. Menzies' (1970) analysis of the professional boundaries between 'them' and 'us' highlights the strength of defensive responses and the importance of dismantling role boundaries as a prerequisite to organisational and professional change. Drawing on psychoanalytic theory, she suggests that reluctance to change can be best understood as the resistance of groups unconsciously clinging to existing institutions because change threatens defences developed to manage professional and organisational anxiety. That a profession may become less flexible and more restrictive in the face of change has important lessons for user participation initiatives.

Using Menzies' (1970) analysis, the demands for user participation, and the consequent challenges to the role of professionals, can therefore be seen as creating considerable anxiety and as presenting a fundamental threat to existing structures. My analysis proposes that processes of user participation have served to undermine and destabilise previously static conceptions of user-professional roles and relationships. The findings showed that roles are no longer clear cut and boundaries between 'them' and 'us' can no longer be assumed. I believe that these changes in roles and relationships represent tangible shifts in the status quo and have implications for policy and practice that will be considered in the next part of this chapter.

Viewing the resistant behaviour of staff working at the sharp end of services as meaningful, as a way of managing the anxiety that results from the challenges of working closely with people in distress; is important for a number of reasons. There is a crucial need to recognise the stress of workers in under-resourced, challenging care environments, if steps to address power imbalances are to succeed. Chronic stress and disempowerment of staff is not conducive to good user-professional relationships. Related to this was a tendency amongst staff respondents to see power as a 'zero-sum' phenomenon (Clegg 1989): a cake that everyone wants a bigger slice of. In this analysis the idea that service users should have more power is threatening to staff members who believe they have little enough power themselves. My analysis suggests, alternatively, that the models of power required to understand the re-negotiation and destabilisation of roles and relationships, taking place in mental health services, are ones that understand power as fluid; moving between people in networks, cultures, practices and discourses (Clegg, 1989; Foucault, 1972, 1973, 1976).

The study found that many of the professionals interviewed were genuinely in favour of increased service user influence and control, with some actively supporting initiatives of this ilk. It must be noted however that the professionals interviewed were recommended or chosen largely because of their involvement with users and I was unable to access many ward level staff to interview. Hostility and apathy, though not detected in any of the professional respondent's comments, was described by most of them to be reactions of some mental health staff to increased user influence. Although no hostility or apathy was detected in the professional commentaries presented here, a sense of ambivalence was perceived in the analysis of some of them. It appears that this ambivalence may indicate a hesitation to adopt a position of genuine equality with users, because of the loss of expert status this may involve. Professionals described feeling uncomfortable and defensive in situations of conflict or situations where they felt personally attacked by users, and this also seemed to the cause of some of the ambivalence. Role insecurity and ambiguity were thus seen to undermine the previous taken-for-granted position held by professionals.

Resistance on behalf of staff, towards increased user influence and involvement, was evident from the data. This resistance was mostly implicitly rather than explicitly demonstrated, through professionals 'staying away' from user-initiated forums and not 'playing the game'; as well as through organised 'underground' activities that opposed Trust user involvement policies. Analysis indicated that blocking, stalling and delaying tactics were also used to undermine user initiated suggestions or demands for change. Unfortunately it was not possible to assess to what extent this was unconscious or by design. The findings also illustrated some of the ways in which language can be used to 'naturalise' power relations and block real change. The use of meetings, discussions on representation, lack of resources and a lack of willingness to move things forward, were all interpreted as tactics used by organisations and staff in organisations to avoid giving up power, using Clegg's (1989) analysis of power:

> ...if demands do get onto the political agenda they may be effectively sequestered via endless committees, enquiries or co-option' (77).

Croft and Beresford (1992) write of these kinds of stalling tactics as deliberate mechanisms to render user participation ineffectual. Williams and Lindley (1996), in their work on collaboration with users, also refer to the powerful dynamics supporting the status quo. Many of the mechanisms they describe used to 'keep people down'; such as controlling the agenda, talking in jargon, ensuring that users are an obvious minority and questioning their representativeness, have also been features of the data presented here. The reluctance of professionals to acknowledge the collective user voice; preferring to label user group activity as 'therapeutic', was another such example.

User participation as a window of opportunity

The fourth principal contribution of this research was the finding that, despite the problems of tokenism and incorporation, substantial individual and collective gains have been accrued by service users. This thesis suggests that user participation can therefore be viewed as an end in itself; allowing service users and user groups to exploit the windows and cracks in the system (Tarrow, 1994). In both Trusts service users had taken advantage of the space created by top-down user involvement to organise and create their own agenda for change. Consequently, the consumerist drive to involve users in services, despite the flaws described above, appeared to have significantly contributed to the mobilisation of user issues by bringing people together. Nationally this process of coming together has given the user movement the boost of numbers and energy needed to create what some have described (Emerick, 1991) as a new social movement; by providing opportunities for users to share experiences and collectively articulate their anger and frustration. These findings are similar to those of Church (1995), who also found that users/survivors had taken top-down Government-led consultation exercises as opportunities to organise. She comments on the Canadian experience thus:

> This seems to be the general character of systemic and organisational change where survivors are concerned. They make gains but not necessarily in the time, place or direction of their own choosing. Theirs is the art of rising to circumstance (1995: 122).

If user involvement in its present form cannot deliver the 'cultural revolution' required in services, perhaps it could be usefully viewed as an opportunity for users to organise and construct their own agendas for change. This suggestion will be explored in the next section on recommendations for practice and policy.

User groups in this study employed different strategies of resistance to try to exert some control over the participatory processes in which they were involved. As Church (1995) proposes, user/survivor disempowerment can be perceived as a lack of resistance, which steadily reduces through active methods of resisting top-down involvement agendas. Withdrawing involvement and 'foot-dragging' were two strategies identified as most effective. For some user respondents involvement was viewed as a war or game, where strategies and counter-strategies devised to further the group's own interests.

The findings showed that participation in user groups gives people a voice and a valued role, providing safe environments in which to recover and rebuild fragile identities and shattered confidence, overcome stigma, and develop new skills and competencies. This study has shown that a transformation of norms and values has taken place through the construction and explication of non-psychiatric identities; with survivors/users re-labelling themselves as 'Mad and proud'. By reclaiming and renegotiating the previously ill-fated identity of madness, and creating new forms of positive imagery, some individuals and groups are challenging professional and organisational constraints. One strategy for change, described by some of the respondents in the study, placed an emphasis on creating a new culture and participating in self-initiated activities to address their continued sense of marginalisation and frustration. This finding can be linked to work by Rucht (1990) that describes some social movement strategies to be 'identity-orientated' by virtue of their concern to change cultural codes by practising alternative lifestyles, or what he calls their 'counter cultural challenges'.

According to Emerick, in his research on the politics of psychiatric self-help, the promotion of empowered, positive and non-psychiatric identities through self-help group activities, involves the shedding of: 'sticky ex-deviant labels', and the development of a 're-labelling movement' (1991: 1122). The primary goal of new social or grassroots movements, according to Wittig (1996), is the desire to change power relationships through local organising. Through membership of social and grassroots movements the self-efficacy and self-esteem of individuals may improve, new identities may be formed, skills and resources may be acquired, and attitudes towards the political system may be altered (Wittig, 1996). The evidence presented in this section indicates that, for some people in some groups, these positive consequences have indeed been achieved. The activism expressed by the users in this section may demonstrate a 'transformation of norms and values and the social shaping of knowledge at the cultural level' (Wittig, 1996:5) that is associated with social movements in general.

The user movement is therefore reclaiming the right to self-definition and increasing its influence in the public sphere as 'makers and shapers' (Cornwall and Gaventa, 2000), rather than as passive recipients of services: a finding that supports the work of Barnes and Shardlow (1996). Collective action, by making broader demands on services and through the movement towards self-help and self-provisioning, is contributing towards the creation of identities of service users/survivors and user groups as political actors, rather than just consumers (Barnes and Shardlow, 1997; Cornwall and Gaventa, 2000). With this politicisation comes a broader engagement in the public sphere that not only gives a platform for articulating rights but also for 'recasting responsibilities and rights' (Cornwall and Gaventa, 2000). User groups, in this analysis, do not simply seek a voice within services but seek social justice for their members by taking action against exclusionary practices that affect them. This awareness and action constitutes the breaking of what Lister (1998) has described as the 'chains of victimhood'. Some user groups are using the legal system to seek redress, recognition and changes to the law, to protect their human and civil rights. The use of art, poetry and music concerts, to get important messages into the public domain, are also examples of this wider activity.

By gaining confidence and self-assurance, user groups appear to be becoming clearer about the need to work towards their own agendas and forfeit the ambivalent position of 'peripheral insider' (Maloney, Jordan and McLaughlin, 1994); in the hope of gaining increased power and influence. Addressing the wider social inequalities and injustices that often precipitate people becoming involved with the psychiatric system (Williams, 1999), was another example, where the movement has broadened its engagement from services provided into the wider public sphere. A survivor activist sums up the importance of breaking away from the existing structures thus:

> *Probably the biggest downside of user involvement within mental health services is it keeps you pinned to what's going on at the day hospital and how the hospital is run. It ties you to current existing structures...* SH

The importance of creating infrastructure to support these changes is visible in new support group networks created to encourage group stability and longevity. A growing awareness that the strategy of withdrawing from top-down involvement processes can be more powerful than staying in them, has bolstered confidence in 'stepping outside' the structures of 'invited participation'. In these situations a greater emphasis on social action, on the support of members, on advocacy, campaigning and direct action has taken place.

So were users empowered through the process of involvement? If we use Zimmerman and Rappaport's (1988) and McWhirter's (1991) analysis, then the answer is 'yes'. From the findings detailed in Chapter six I would like to suggest that empowerment has indeed been achieved by some individuals and groups. Empowerment at the group and community level involves a politicisation process that takes place within individuals as they move towards having a greater awareness of the wider social and political issues that influence their condition or status. A sense of personal and collective power is evident in the accounts of service users who articulated a desire to step outside of the parameters of 'invited participation'. This demonstrates the link between participation in community organisations and a sense of empowerment

(Zimmerman and Rappaport, 1988). Significantly, the outcome of self-efficacy (Bandura, 1982) or empowerment was found not to be due to either the design or intention of the involvement mechanisms, but occurs as a result of the difficulties that users and user groups face while participating. Richardson (1983) agrees on this point suggesting that despite the rhetoric of participation being largely deceptive it can, however, provide opportunities for the politicisation of those involved, encourage new forms of political involvement and thereby create political empowerment for some people.

User groups have enabled people to link into 'matters of social policy and social change' (Zimmerman and Rappaport, 1988), helping them to be more aware of the power dynamics at work in their life context. User groups and opportunities for involvement have provided contexts for people, some who have previously been marginalised from or disinterested in such activities, to exercise democratic participation in the life of their community. Individuals, through their comments in this research, have emphasised the importance of their user group in helping them to regain, or exert for the first time sometimes, a sense of control over their lives. User groups were described as helping people to realise their strengths and feel confident in their skills and capabilities again. There is evidence in the findings that user groups can help to build individual capacity, although it was also noted that some people have found their membership of user groups very difficult. The pressures faced by groups to meet the workload now required of them can lead to burn out and individual and group collapse. Barnes (1999) has written of the tensions and dilemmas faced by user groups in enhancing the citizenship of their members, while also providing feedback and input into service systems. This overloading of users' energies is a common finding in work on partnership in the community and voluntary sectors (Taylor, 2000a). It is important, therefore, not to romanticise the effects that participation in user groups can have because of the tendencies described in Chapter six for groups to become preoccupied with conflicts spurred by individual differences in strategy and agenda, and to become victims of low morale and burn out.

Barnes' (1999) suggestion that collective action amongst service users can provide the avenues through which citizenship can be expressed, is helpful to analyse this activity further. She suggests that this can be achieved through:

- Seeking to achieve social rights associated with the *status* of citizenship;
- Providing a forum from which excluded individuals can contribute to the *practice* of citizenship; and
- Enhancing the *accountability* of public services to their citizen users (1999: 82).

Evidence from this study has indicated that collective action can indeed be viewed as being constructive in gaining citizenship status for some users involved in user-led initiatives. The example of the user group storming the Boardroom to demand that their criticisms were acknowledged and attended to, illustrates Barnes's (1999) third point; that citizenship can be expressed through enhancing the accountability of public services to their users. By calling the Trust Board members to account for the services that this user group believed to be substandard and dangerous, the group was seeking to enhance the accountability of public service to the users of those services. So, not only were the user group acting in their own interests and those of their fellow patients on the wards, they were also acting in the public interest.

Although user group capacity building does seem to be taking place as part of 'business as usual' involvement, the study found that user groups are still fragile in the face of various strategies used to deny them genuine power. The finding that the empowerment gained has primarily been the result of users engaging in disempowering processes of top-down involvement, was highly significant. Building and supporting the infrastructure of user groups is vital if these small steps forward are to continue both within and outside of statutory mental health services. The appointment of more service users as workers within the system was also considered to be a powerful mechanism to create change from within.

The importance of looking for political openings is a lesson that is well described in the social movement literature (Tarrow, 1994). As Tarrow describes (1994) change is rarely achieved without an opening on the side of the power holders. Taylor (2000a) writes about the importance of voluntary and community organisations exploiting these openings and opportunities: the windows and cracks that arise through changes in organisational and political structures. She talks of the need to 'develop the skills to spot opportunities, widen cracks in the system, build alliances and generate new forms of governance with allies across the sectors' (2000a: 104).

This research has suggested that user participation can offer such windows of opportunity. Certainly some professionals and managers have managed to exploit the cracks for their own personal and professional benefit. But will it only be the powerful that manage to exploit the opportunities in the changing systems of health and social care? It seems that the main beneficiaries of participation in mental health services have so far been the organisations and some of the senior staff, through 'being seen to be doing' and by some individuals 'climbing on the bandwagon' to further their own careers. The task ahead for user groups and the user movement is therefore to become increasingly sophisticated at 'rewriting the rules' and resisting co-option, through these self-initiated activities and through a politics of presence (Phillips, 1995). I shall describe some of the ways that they may be able to do this most effectively in the next section.

Implications for Policy and Practice – An Agenda for Change

The implications for social action, policy and practice, suggested from the findings of this study, are many and varied. This section draws on the findings of the thesis to develop eight key recommendations and within these to provide an explicit agenda for change for government, service organisations and the user movement. These eight recommendations are to:

1. Replace the established structures and cultures of professional organisation with a person-centred orientation;
2. Provide support for mental health workers to work in new ways;
3. Provide clear 'hands-on' leadership;
4. Place an emphasis on participatory rather than representational forms of involvement;
5. Removing barriers to the employment of people with experience of services
6. Provide resources for user group infrastructure to help build capacity;
7. Create opportunities for user groups and the user movement to engage as citizens rather than as consumers;
8. Create a broad base for participation that reflects diversity and difference.

These recommendations are discussed next, in no particular order of importance, because they are all seen to be essential to the agenda for change.

Replacement of the established structures and cultures of professional organisation with a person-centred orientation

Many of the barriers to user involvement presented in this research were connected to the pressures that reside in acute mental health services; poor standards of practice, out-dated modes of professional organisation and stressful working conditions for staff. Here lies the challenge: the findings of this research suggest that the problems and tensions of participation are so deeply embedded in cultures and practices that effective change will require nothing less than a complete reconstruction of organisational and professional cultures. This means completely replacing the established structures and cultures with a system that puts users first; where they are treated as human beings and have their need for help and support acknowledged without being negatively labelled or stereotyped.

User involvement costs time and resources: it cannot work as an optional extra that can be 'tacked' on to existing systems. User involvement should in fact be viewed as something that requires considerable investment. This means resources not only for user involvement per se, but also to change mental health services into less chaotic, pressured, routinised and interventionist environments. This obviously represents a massive cultural shift that will take a long time to achieve and will require a substantial investment of resources, time and effort.

One of the main priorities of this shift should be to place a higher value on the work of front-line staff and to make a commitment to improve their day to day working conditions since it is at the front-line that these policies are implemented. Lipsky's (1980) work on public service organisations emphasises the need for whole organisations to change if power relations are to shift. He argues that the determinants of practice are deeply rooted in the *structure of the work* that public organisations do. Key to Lipsky's analysis is the connection between the coping responses of workers/professionals to opposing goal or service orientations, and the *patterns of practice* that these coping responses support. Significantly reducing the stress of the job for these workers would help them to make closer connections between the different 'goal orientations' (Lipsky, 1980) that guide their practice. This argument may hold the key to reform if organisations are able to acknowledge the binding relationships between staff attitudes, working conditions and practice; and the decisive, radical action needed to change them.

Support for mental health workers to work in new ways

Church stresses how consumer participation has the potential to call professionals to account:

> ...not just for how we do our work but for who we are. We should expect this process to be painful and conflictual (Church, 1995: 74).

The findings presented in this thesis have demonstrated that the unsettling relations created by participation in mental health services are an inevitability that should be prepared for, rather than denied and ignored. That anger will be part of the dynamics of participation should, according to my research and that of Church (1995, 1996) and Wadsworth and Epstein (1998), suggest the importance of anticipating these 'unsettling relations' and being prepared for them. For professionals to acknowledge the presence of conflict and tensions between their interests and those of the users in their service, would be a courageous first step. To begin to understand their empowerment as needing to happen *alongside* users' empowerment, rather than at the expense of it, would, I believe, bring further rewards.

In this research professional attitudes were seen to be a key factor in supporting or undermining user participation. The knowledge base of professionals was another relevant factor: staff that were able to think beyond the restrictive roles and boundaries of bio-medical, interventionist approaches, were seen by respondents as more supportive of partnership and enabling practice. Service user respondents also appreciated those staff who had a high self-awareness and the ability to behave reciprocally towards them. On the basis of these findings there is, therefore, a need to recognise new forms of knowledge that may not be considered to be 'professional knowledge'. New skills and new ways of working are required throughout organisations if user involvement, in terms of increased power, influence, choice and information, is to be effective. According to Church, the active involvement of users/survivors in decision-making means both a decrease and a qualitative change in professionals' involvement in decisions. This report supports her suggestion that a professional deconstruction and reconstruction is needed to help professionals to unlearn many of the ways they have been taught to relate to people, in order to work with users/survivors 'across difference'. One suggestion to address this need to unlearn and relearn is the creation of safe spaces for professionals to work through these feelings of loss of control and status, have these recognised and be able to move forward. When I was nursing there were not even any safe spaces to receive and give peer support. Wadsworth and Epstein (1998) also recommend that supportive, non-decision-making forums should be created for staff members to surface the 'undiscussables' that staff might feel when interacting with users in participatory environments.

Another recommendation that may support workers to work in new ways would be to incentivise partnership working and the creation of alliances across professional and user boundaries. Close alliances between professionals and service users, brought together in an attempt to create changes in services that serve their mutual interests, was cited as a source of motivation in this study. Lipsky (1980) suggests that the attitudes and behaviour of front-line staff may be effectively challenged if incentives and sanctions are put in place within structures of the workplace to encourage change. Currently there are few incentives for front-line workers in mental health services to perform in ways that are supportive of greater user choice and power. Promotion opportunities and increased salaries that reflect the difficulty and value of partnership work with users, would be two such incentives. Other incentives could include providing supportive environments for staff growth and development and establishing ongoing mechanisms for supportive criticism and reflective. For workers unable or unwilling to make the needed changes to their practice, a tough line should be taken by management to ensure these workers leave the service.

Clear 'hands-on' leadership

Another factor cited in this research that helped to create an environment receptive to increased user influence and user control, was clear leadership throughout an organisation. Clear leadership can serve to ensure effective implementation of policies and assert the importance of partnership and involvement. Equal opportunities policies, user involvement policies and user employment policies were viewed by respondents as important supports to developing a user-friendly culture in mental health services.

One of the complaints of front-line staff in this research was the lack of management efforts to support staff to tell them *how to* involve users more fully. Responsibility, it was argued, lay with management as well as front-line workers, in making sure that involvement became achievable in practice. Staff felt that user involvement policies needed to be translated into real workable practices; rather than issued from the top down. Effective, hands-on, ward level leadership is therefore vital to support good practice on the wards and provide the crucial resources to make this possible. From Lipsky's (1980) analysis, it would also be important for management to recognise the contradictory requirements front-line staff face that encroach upon on their ability to meet the goals of user participation. A suggestion wouldbe for organisational management to try to reduce some of the contradictions that their staff had to work within, where these are within the organisation's control. Although this will not always be possible due to the demands coming from society and legislation, more *recognition* of these conflicting demands would be supportive of staff who currently feel frustrated, angry and under attack.

That managers in mental health institutions were also restricted in their roles as change agents must also be acknowledged. As one senior manager explained, there is an urgent need for government to adequately resource statutory mental health services to allow them to meet the variety of service and goal orientations required of them. If user participation is to be a realistic goal for mental health services, more resources must be made available to enable organisations and user groups to work together in partnership, and create the improvements in services across the board that the first recommendation addresses.

Placing an emphasis on participatory rather than representational forms of involvement

Most partnership initiatives in mental health services, as with partnerships in most other public forums, are built upon a representational model of democracy and decision-making. This model assumes equal access to rational and consensual processes, rather than acknowledging power differentials between groups and the presence of conflict in achieving genuine change. In partnership processes that assume equality it is easy for those with access to more resources and knowledge to reinforce relationships that maintain exclusion and injustice. This thesis is suggesting a reappraisal of the aims and practices of participation, and a shift from using predominantly representative models of participation to using models based on participatory democracy. Participatory or deliberative democracy is about developing dialogue between gatekeepers and those previously excluded from decision-making. This is particularly important in mental health where service users have been excluded from citizenship.

There also needs to be an acknowledgement that though formal structures of decision-making are important, often more crucial are the informal, 'behind the scenes' relationships where bargaining and negotiation of deals takes place (Hastings, MacArthur and MacGregor, 1996). There is a danger that users participating in formal organisational structures will force power holders to increasingly rely on informal networks and alliances to make decisions, while creating the illusion of power sharing. There are no simple answers to this problem, though mechanisms like those raised by Stewart (1997) that draw on deliberative democracy principals; community visioning, citizens juries, round tables, citizen appraisal and community planning conferences, provide ideas about how to revitalise traditional decision making structures.

Removing barriers to the employment of people with experience of services

The findings have shown that people who have experiences of psychiatric services becoming workers/professionals within the system is a very effective mechanism for change. Although these positions can be highly stressful for the individuals who do this I suggest that this is one of the most effective ways to create meaningful change. There is a move within some Trusts and organisations to employ people with mental health problems because of their experience rather than despite it, with the idea that the experience of mental illness can be valuable rather than only disabling. The NHSE/DoH have launched a publication called *Looking Beyond Labels* (2000) recommending that the NHS take positive steps to recruit people with disabilities; including people with mental health problems. Across the country some Trusts that have developed policies on employment of people with experience of mental health problems have demonstrated that this can be a very successful mechanism for positive change, both for individuals and for organisations. I recommend that mental health Trusts develop fully inclusive policies that allow people who have experienced mental health problems to apply for professional positions; with full disclosure at the point of application. It is also important that appropriate support and tenure arrangements be made that allow people to return to work without penalty after an episode of illness.

Capacity building for user groups – the development of infrastructure

The need for a more supportive infrastructure, both for organisations and for user groups, has been a key finding in this research as it has been in other research on public participation (DoH/KPMH, 1992; Wistow, 1992). The funding of service user groups has thus far been predominantly tied to top-down involvement and even this, in the main, has been inadequate and insecure. One of the ways that statutory services can support the development of infrastructure is through funding independent user group self-organisation, as Barnes *et al.* (1999) describe. The presence of groups set up specifically to build a support infrastructure for user groups, to help maintain existing groups and facilitate new ones, is fortunately becoming more familiar. An example is the Network 2000 initiative in Wakefield that is user-led and receives support in terms of information and funding from the statutory sector. The aim of the network is to become stable and sustainable and provide a 'support group' for support groups, helping them to network with each other and support user involvement. The significance of this particular development is that the network's aims of building infrastructure and providing support are being funded by statutory sources.

Engagement as citizens rather than consumers

> ...there is development, where people and their communities – whatever the space and timespan – act as subjects and are not acted upon as objects; assert their autonomy, self-reliance and self-confidence when they set up and carry out projects. To develop is to be, or to become, not to have (Nerfin, 1981: 73).

The findings of this study provide a basis for recommending that the revitalisation of notions of civil rights, citizenship and deliberative democracy within mental health service systems, may provide a way out of the quagmire in which user/professional/organisational relationships have found themselves. The failure of forty years of user/community participation to alter established power structures within public sector services (Stewart and Taylor, 1995), suggests that the continued lack of structural power held by mental health service users and marginalised communities needs to be addressed before change can be a realistic alternative. The findings have emphasised the costs of participation in mainstream services and this needs to be taken into account by groups if they are to stay in control of their involvement.

Basing its engagement in service systems on models of citizenship, rather than models of consumerism, may help to move the user movement forward from its present position as 'peripheral insider' (Maloney, Jordan and McLaughlin, 1994). Maloney, Jordan and McLaughlin (1994) describe user groups as 'peripheral insiders' if they are included in policy consultation mechanisms but still viewed by the power holders as marginal. On the basis of their research and experience, Beresford and Campbell (1994) have concluded that it makes more sense for user groups to spend their time and energies participating in their own activities and initiatives, rather than 'being represented' in service systems. Moving strategic position from being 'peripheral insiders' to being 'outsiders by choice', is a choice some groups have already made. Their strategy is to remain outside of the policy process and exert pressure through appeals to the public, using the media, for example. Although making an impact on policy and practice is never as simple as this formula suggests, with groups and organisations commonly using both insider and outsider strategies concurrently, or at different times in their life spans, this concept still has utility here. During the period of this research, user groups I was aware of, not only those from Trust A and B, were becoming disenchanted with the role of peripheral insider. Realising that the position of peripheral insiders was not achieving any substantial change; a number of groups in the city had decided to move to a more overt outsider role, using campaigning and direct action to try to achieve their goals.

User groups, and the user movement as a whole, therefore needs to make choices about whether to maintain a 'peripheral insider' status (Maloney, Jordan and McLaughlin, 1994), if gains from top-down involvement are not forthcoming, or whether to move over to being outside of statutory services. They need to negotiate the tensions between influence and independence. Maloney, Jordan and McLaughlin (1994) have suggested that a combination of outsider and insider strategies may be the most effective way forward in terms of changing public policy as this gives groups the ability to switch back and forth between protest and more conventional means of policy influence. User groups must be aware of the implications of making choices between self-organisation to meet their own goals, and meeting the goals of service organisations; who often pay the bills and provide the office space. Independent funding was seen to be important to kick-start new initiatives and its absence is noticeable to users, as this respondent describes:

> *Having independent funding so that you can have user involvement that's not about changing services but which is about starting something that is completely different that challenges the way we think.* RM

Moving from oppositional action to action to develop new forms of institutions will require changes in the nature of the movement itself, as one of the respondents in the research described:

> *User organisations need to get themselves better equipped in all sorts of senses - emotional resources, running well in whatever way we find works whether it's as a formal co-operative or whatever. We've got to keep trying to develop the structures that suit users. Whether that's an underground network or a more formal way of doing things it's hard to say but I think we need to say user involvement is all very well but where is it going to get us? And is that where we want to go?* SH

Although some of the same skills will be required to those of being involved in invited participation, new skills will be needed if the movement is to successfully lobby in the wider public sphere: skills such as working with the media, fundraising, public speaking, and skills in campaigning and organising.

Another related point is the importance of users and user groups developing their own visions for change and being supported to do so by service organisations and government. Freire warned that people can be led into inauthentic types of organisations, thus postponing or diverting the '...threatening alternative: the true organisations of emerged and emerging people' (1972: 117). Although I am not suggesting that hospital or statutory supported user groups are inauthentic types of organisations, clearly there is a need for user groups to develop their own visions and their own agendas, more than they have been able to do thus far. If no time is allowed for this development then power will remain with those who know the rules; the professionals and organisations initiating the involvement. The requirement that public services should create participation opportunities has produced extra resources and openings, and potential alliances and realignments that, according to Tarrow (1994), are capable of bringing new groups to power.

Up until now it seems as though the main beneficiaries of user involvement have been the organisations themselves and some senior staff who have 'climbed on the bandwagon' of participation to further their own interests. It is crucial that user groups also learn to take advantage of the 'windows and cracks' (Tarrow, 1994; Taylor, 2000a) that result from public sector reorganisation. As Cornwall (2000b) suggests, user groups and user/survivors, as citizens, need to define their own entry points into systems and structures and devise their own strategies for change:

> Enhancing citizenship participation requires more than inviting or inducing people to participate, through incentives or by offering them spaces to speak. It requires an active engagement in nurturing voice, building critical consciousness, advocating for the inclusion of women, children, illiterate, poor and excluded people, levering open chinks to widen spaces for involvement in decision-making, and building the political capabilities for democratic engagement. Through this, people come to create their own spaces and enact their own strategies for change (77).

The importance of creating new alliances with other movements is also highlighted in the social movement literature. Fostering connections with other larger movements to solve collective problems has been found to be useful by user movements in other countries (Church, 1995) and is something that has, up until now, been rare in the UK (Barnes and Bowl, 2001). While this study found evidence of the mental health survivor movement drawing parallels with the Gay Pride movement and the Black civil rights movement, there was little mention of links with user movements of disabled people, people with learning difficulties or older people. Although there is uncertainty amongst the user/survivor movement about closely identifying themselves with these movements because of some notable differences between their approaches and strategies, I suggest that this may be a useful strategy to consider in order to consolidate gains made thus far and extend these even further.

The need to create a broad base of participation that reflects diversity

Although the core work of partnership is likely to be confined to the few, there is a need to resource groups sufficiently for them to strengthen links with a wider body of service users. It is necessary to involve users/survivors from groups who experience discrimination within society, to counterbalance the tendency for user participation to attract a narrow section of service users. Attention should also be paid to methods of supporting user groups to build the capacity of more vulnerable, marginalised groups, for example those with serious and enduring mental health problems, women and ethnic minorities.

Lessons learned: Strengths and limitations of the study

One of the major strengths of this piece of work is the quality of the research data that, I believe, enabled an analysis of considerable validity to be offered. Another is the contribution the research has made to further developing the theory regarding the tensions and power dynamics of participation in situations of inequality. The findings have a broad relevance to participatory contexts both within and outside of the health and social care field, and can be drawn upon to better understand problems encountered and potential solutions. One of the key strengths has been the way that the practical implications of the research findings for policy and practice, have been highlighted. The agenda for change offers a challenge to those who wish to engage with the requirement to 'do user involvement' by adopting a half-hearted approach; where user voices are 'bolted on' to existing structures in the hope of remedying a whole host of intransigent issues. As I have shown, participation in the context of inequalities of power requires a massive reconceptualisation of the nature of the 'problem' and its solution.

This piece of research aimed to bring together academic research and activism as Mias (1993) proposes. Although I was not able to complete a participatory project I believe that I was able to make this research inclusive, ethical and reciprocal for those who took part, and believe it was well grounded in the concerns of those I knew who were working for change. The following comment by one of the interviewees, a user-worker, illustrates his view on the utility and wider relevance of this research:

> *Yeah until we can map where we are... we need some way... yeah we need help on this... on what is behind some of the blocks that staff feel and users feel. So it's good stuff... it's good that's it happening.* BA

The transformative nature of the personal learning experiences I gained was immensely valuable in terms of the research training received through having the opportunity to try out so many different approaches and techniques. I learned the validity of Greenwood *et al.'s* (1993) assertion that considerable effort is often required to involve marginal groups in research. I learned that without resources to equalise the research relationships, participatory activities may be purely tokenistic, as the research itself found. Another valuable thing learned was that participation and collaboration is rarely carried out with collectives, but rather with individuals, who are likely to have different ideas about what could and should be done, and how. I learned that collaboration entails complicated power plays and difficult negotiations, since responsibility and accountability to different stakeholders, for example funders, research participants and supervisors, may be in conflict.

Although collaboration with participants in research is a worthwhile activity, the time implications of using these kinds of approaches need to be carefully considered before undertaking research of this nature. The extended nature of this particular piece of research was costly in many ways: not least in terms of not being able to disseminate the research findings to those that took part within a reasonable amount of time. This was one of my biggest regrets and one of the major limitations of a study that was, in some ways, too ambitious. Dissemination is now taking place to user, professional and academic audiences and has become a priority for this final phase of the research process. With hindsight, the attempt to create a collaborative project using video was overly ambitious in a project such as this. Although the process proved immensely valuable in accessing the key informants, interviewees and the co-supervisor, and allowed the user group in Trust A to trust me enough to agree to be involved; an enormous amount of energy and time was used going down what essentially became a blind alley. Learning that research involves compromise, this time in the form of reciprocity with participants and the user co-supervisor, was an important learning curve for me because of my desire to only do something if I could do it well. Compromising one's values and aims can, of course, go too far; but I think this research achieved a balance between 'getting the job done' and doing a piece of work I could be proud of.

The originality of study, in terms of its methodological approach, lies in this use of a user/survivor co-supervisor role and its use of a diverse range of analytic and conceptual tools for the analysis. As far as I am aware the approach of having a user as research supervisor has only been used by Church (1995), in her Canadian research on user participation. This role was built into the research to ensure, as far as was possible, that user/survivor concerns were represented and that the research was accountable, in some way, to the community of interest I was researching. The use of a user/survivor co-supervisor benefited the study in many ways, but particularly in providing an 'extra pair of eyes' from an 'insider' perspective which provided a validity checking function: it challenged my 'outsider' assumptions, biases and blind spots. Perhaps most significantly, it provided an opportunity for reciprocity and friendship and the opportunity to 'work together across difference' (Church, 1995). It is important to note that the role of user/survivor co-supervisor supplemented rather than replaced the traditional support and supervision received from academic supervisors. By building in a role for an 'insider', I was able to engage with some of the goals of a collaborative project; while becoming proficient at working with the difficulties and challenges. This additional role helped to emphasise the contradictions and disagreements that are generated through research accounts and interpretations, by acknowledging the existence of diverse vantage-points. Having a user/survivor as co-supervisor made it possible, even within the considerable limitations of a postgraduate research project, to address at least some of the difficult power dynamics raised when doing research in an area where one is an 'outsider'.

A few words need to be said about the usefulness of the research design and methods. I think overall that the research design enabled the construction of interesting research questions that were meaningful to those who participated. Spending time identifying key informants and potential interviewees also contributed to the production of rich and valid data. As described in Chapter three, the use of a range of different conceptual and analytical tools provided challenges in negotiating different epistemological paradigms, but they were also an invaluable tool to help me subject the data to an intensive analysis. Because of the evolving nature of the research, a feature of the collaborative efforts made, the research design was not as tightly focused as it could have been. However, most qualitative research texts suggest that this is to some extent a feature of qualitative research that seeks to achieve an iterative and cyclical process of knowledge production (Silverman, 2000).

One of the problems the research encountered was not being able to access many front-line staff and managers for interview, because of their reluctance to talk about issues of user involvement at a time of intense pressure for them. Although this was out of my control to a large extent, I could have been more forceful about trying to access people, rather than feel guilty for even asking people. Doing a piece of doctoral research is an exposing experience in many ways and one that involves feeling isolated and unsure of oneself for much of the time. This impacted most on the research by making me less keen to make demands on people who I needed to help me. If I were to do the research again I would be far more assertive about the demands required of others and less preoccupied with the potential negative consequences of the research. This reflects an acknowledgement that my over-protection was sometimes misplaced because the people I met were in the main very well able to protect their own interests. One of the limitations this produced for the study was not being able to create a sample from both Trusts that would allow me to make comparisons.

With hindsight, something that would have helped me to feel more confident about the demands of the research and would also have contributed to the wider ownership of the research, would have been the use of a stakeholder approach. This would have been most useful in the form of an advisory group made up of users and professionals/service providers that could provide guidance on the research aims and process. Although I had an informal group of people; the key informants, to provide this guidance, and my co-supervisor, there would have been further benefits to the study if this arrangement had been more formalised.

At the very start of the research I had hoped to use a formal discourse analysis approach to undertake in-depth analysis of naturally occurring talk between professionals and service users in participation contexts. However, due to constraints of access amongst other problems that the research suffered, a systematic approach using a discourse analysis technique was not possible. Situations that could have been used to gather naturally occurring conversations of the type appropriate to discourse analysis, within the institutions studied (such as meetings between ward/nurse managers and the user group in one Trust), were unfortunately not accessible to me as an outsider. Should I have had a role within the institution this may have been possible. Access to the institutions to gather data became problematic enough without requesting to sit in on politically sensitive meetings between professionals and users, who in one Trust at least, were in conflict much of the time. Instead I used an active interviewing technique where interviewees produced cultural stories that were interpreted with an awareness of the productive and facilitative role of language and links made to theories of power. Although not a limitation of the study, I would however strongly recommend adopting a more comprehensive discourse methodology in further studies of this subject. With more time and resources and fewer access problems, this would have lent additional interpretations of the more subtle power and language relationships in the data.

Further research

There have been well-evidenced theoretical and empirical links made to experiences of participation in overseas development and UK urban regeneration, as well as to health and social care settings throughout this work. These links and commonalities lead me to suggest that the findings of this thesis are consistent with existing work on the tensions of participation and joint-working between public organisations and people demanding change in power relationships. This leads me to suggest that this research has generalisability and relevance to similar environments to the ones studied here. I suggest that a starting place for future research would be to see whether the findings of this research can be replicated in other settings. The metropolitan environment of this study had a number of features not common to smaller urban and rural environments. It would also be useful to engage in a similar piece of research, focusing on the voluntary sector and on social work, to see whether similar findings emerge or whether the majority of the findings detailed here are specific features of institutional mental health settings. An investigation into the relationship between the presence of conflict in user groups and the strategies by which services 'manage' or undermine the user voice, would also be a natural extension of this work. Lastly, I would recommend undertaking a comparative study across a range of 'participatory settings', to identify what resources and conditions make a difference to the tensions and difficulties raised in this research; and which are able to support change. This could be explored with reference to both users and service providers.

Concluding Comments

User participation has been described as 'putting the pain back into the system' (Jowell, 1990). For many users and professionals the experience of user participation itself has been a demanding and painful process. Despite more than a decade of user participation, within the statutory services studied here, the user voice remains marginal and fragmented. This thesis suggests that significant change in mental health services will not be achieved as a result of a 'business as usual' approach to user participation. The research findings have confirmed my original thesis that user participation will fail to concede any genuine change unless it is based on an understanding of power and its effects. This piece of work has documented the ways in which user participation can be better linked to power, powerlessness and empowerment, in order to emphasise the complexity of this task.

Like many new policy developments in health, user participation is in danger of being squeezed into existing structures, systems and practices. *Feathers and Thorns* provides a wealth of new material highlighting the inadequacies of this approach. Because user participation presents such substantial challenges to the status quo, especially in its non-invited forms, many forces can and do conspire against it. Therefore, an emphasis needs to be placed on other mechanisms that can support progressive change in mental health services: user participation should not be considered a remedy for all ills. In fact its vulnerability requires the support of other developments, such as clinical governance, staff training on inequalities, quality in audit programs and non-discriminatory employment policies, for it to have a chance of success. And while *Feathers and Thorns* has demonstrated achievements and gains for those involved in user participation; it has also made clear how much remains to be done.

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Appendices

Appendix A: Proposal for Participatory Video Project and Initial Research Questions, July 1997

CHANGING THE SUBJECT -
PARTICIPATORY ACTION RESEARCH: A VIDEO PROJECT ON POWER, POWERLESSNESS & EMPOWERMENT IN THE MENTAL HEALTH SYSTEM

Project Organiser: Tessa Parkes, Ph.D. Student, The Tizard Centre, University of Kent

Introduction

Although the concept of empowerment is frequently discussed in the health and social care literature few writers actually deal with the relationship between empowerment and the notion of power itself. Notions of empowerment are fraught with ambiguity due to its under-conceptualisation. However to espouse practice as empowering is currently to take the moral high ground, according to Mullender and Ward (1991) as it seems to act 'as a social 'aerosol', covering up the disturbing smell of conflict and conceptual division'. The concept of empowerment is now in vogue in both the practice and theory of mental health care and is used to justify a range of practices that belong to varying ideological positions. The day to day reality of practice however, as documented by both professionals (Susko, 1994, Glenister, 1997, Hopton, 1995, Potier, 1993) and people who have used mental health services (Lawson, 1991, Brandon, 1991, Deegan, 1990) suggests a challenge to this rhetoric. This challenge presents evidence of abuse, powerlessness and oppression of service users.

The project shall examine these and other obstacles to empowerment of mental health service users at both the institutional and the personal level. One of the main aims is to draw connections between language and power. This may involve investigating the possibility that discourses of empowerment within the mental health system work ideologically to mask conflicts of interests between service users and providers (by re-naming the inter-group relationships as ones of partnership and reciprocity for example). There is a need to be aware of the power relationships of the new political and therapeutic climate given moves into alternative environments of care with new models and theories of treatment and support, and different power relationships and strategies of control.

Research Possibilities

Views of people who have been diagnosed as having a mental illness can be invalidated, especially those views that are critical of services. Although not always the case, user and survivor experiences of consultation and partnership exercises have often been described as tokenistic where nothing seems to change leading to disillusionment and scepticism (Department of Health, 1996). These experiences have unsurprisingly led to groups being reluctant to waste their time taking part in research exercises and refusing to get involved due to a suspicion of government, professionals and researchers.

Creating lasting change is difficult for oppressed groups to do on their own due to the massive material and structural power inequalities that exist to prevent changes taking place. Change will take longer and have less impact if people who do have power to recreate understandings i.e. researchers, stay quiet or disinterested. I do believe, therefore, that productive alliances can be and should be made between user and survivor groups and researchers concerned to work for social change. Unless there already have been substantial changes in power relations, getting people to listen can be a frustrating process. Using mainstream channels such as academic research or the media can help to give credibility to a movement that otherwise would be easy to appropriate or dismiss.

Participatory Research

Participatory research is now a well-established approach for investigating social issues and problems. The underlying motivation for participatory research is a commitment to social change and transformation, to people whose lives are in struggle and to promoting people's control over their situations. It believes there to be a need to 'transform our idea of research from mere data gathering into a consciousness raising, transformative technique' (Friere, 1972: 135). Within most models of participatory research a vision of knowledge as power is proposed where power can be kept, shared or given away. Participatory research attempts to decentralise knowledge and the power it contains by putting knowledge in the hands of the oppressed. Gaining access to such 'expert' knowledge allows people to function autonomously instead of relying on others for that information. This is an attempt to reverse the exploitation of people caused by the monopoly of knowledge by the powerful through a realisation that knowledge is increasingly concentrated in the hands of 'experts' and the elite classes they represent.

Proposed Project - Purpose & Aims

To explore the mechanisms of power and resulting powerlessness or empowerment in the current mental health system through a video research project.

The project has as its central aims:

- to add to existing knowledge new understandings about power, powerlessness and empowerment
- to create a methodology for empowering practice from within a 'survivor frame'
- to produce a tool for the dissemination of this research i.e. training video

The analysis of power will focus on

- local forms of decision-making (in institutional and community settings) and the techniques involved
- the language practices that take place between users and professionals
- showing how individuals are vehicles of power
- the relationship between people and organisational structures.

The Process - Using Video

> 'Video also generates change by providing a means for the group to communicate their needs to those with decision-making power' (Shaw and Robertson, 1997:172).
>
> 'With the help of VTR equipment in the hands of native social animators, information can be rapidly disseminated, exchange of views with and between the communities aided and awareness of problems and possible solutions can be accelerated' (Hopkins *et al,* 1972:37).

Potentials of video:

- group-based - brings people together
- way of shifting balance of power - transfer of responsibility
- democratises access to the media
- people can generate their own knowledge
- effective way of voicing opinion or telling a story
- develops participants abilities in technicalities of video and social and creative skills
- opens up channels of communication for under-represented people
- takes the debate to a wider audience

For this project participatory research will be the process used with video being the tool. Time will be spent in a variety of settings both hospital and community to collect information, views and experiences. This information or 'data' will be collected on video and edited later in ways decided by the group as the ideas about the final product evolve throughout the project. One idea is to create layers of dialogue and talk on the issues through interviews with a range of different people - service users and professionals. The group could also record it's own discussions to follow the process of development and to see what changes the group itself goes through as ideas develop. The core group introduce others to the process as participants through a key informant process. Responses to the collected material could also be used as data as the emerging issues are debated and analysed. The project has a dual purpose of:

- process - group activism created through the project has potential benefits to members in various ways
- product - to create a piece of work that can be used to raise awareness of the issues concerned, to educate and inform through dissemination .

Group Membership of Project - Structure of Involvement

- Core group - will share responsibility (with project co-ordinator) of conducting the research and producing the video
- Project co-ordinator - consultation, planning and administration
- Key informants
- Project advisors
- Contributors who give information, interviews, stories etc.

Possible Project Structure and Timescales

Setting Up or Pre-Production (Jan-March)

1. Creating the Project - developing original idea, research and consultation, assessing project viability
2. Setting up the Group - bring together interested people and agree the aims of the project (these may differ from original idea through shared agenda setting)
3. Deciding on the Project Structure - making decisions about membership of the group, number and frequency of sessions etc.
4. Learning Video Skills and Devising the Script - structure and content of material to be gathered
5. Casting and 'Recce'- finding contributors and places to film
6. Finalising Locations and Script

Production (April-May)

Shooting footage: interviews, discussions, events...

Post-Production (June-July)

Editing & Creation of final product

Distribution (Aug-Sept.)

Screening and Distribution

Examples of Videos with Similar Aims

Our Lives (1993) by the Bedworth Video Group - A Framework/Bedworth CPU Project

A View from Inside - Experiences of the Mental Health System (199?) Lamb St. Centre, Coventry

Finding the Edge: A positive view of mental health (1996) One Lung Productions, Croydon Mental Health Users Group

Visible Memories - A film about self-injury (1997) One Lung Productions, Croydon Mental Health Users Group

We're not Mad we're Angry (1984) Channel Four

References Removed

Proposed Research Project – Supporting Statement

Through my work with people who have spent considerable lengths of time in hospital and who are now living in the community I have become aware of a variety of challenges to the notion that, 'care in the community' resembles a major transformation in the way mental health care is provided. Although there have been major changes in the way services are now organised, developed and paid for, I have encountered a number of situations that have caused me to question the presumed effect that this re-location of care has had on the individual relationships that are at the heart of service provision, those between service users and workers.

It seems to me that all too often workers are refusing or unable to give up their old ways of working with people, unwilling to embrace the new ideals of partnership and participation, investing instead in keeping old dependencies and power relations alive. I an interested in looking at why this may be happening, why so many relationships and presumptions remain undisturbed and unchanged and why this is commonly seen as acceptable or goes unrecognised. I would hope to look at how the ideological shifts that are taking place within health and social care impact on the individuals involved: how these processes interface with the personal.

I am interested specifically in the transformation of values, beliefs and attitudes workers from traditional care settings can experience in new environments and how this transformative process can be encouraged, developed and sustained. The aim of my research would be to help workers and professionals to transcend old frameworks for practice and take on the personal challenge of developing participative and empowering ways of being with people. I would hope to provide guidance to organisations and agencies that would help to bridge the gap between people and process leading to the development of more creative and liberating practices and policies.

The areas of relevant thinking and research that I would see as providing a basis and context for this study would be the writings and discourses on social movements and ideologiesthe 'anti-psychiatry' debate, normalisation and social exclusion, therapeutic communities and the democratisation of mental health services, power and control in therapeutic relationships, the new consumerism of health and social care, user involvement and participation, language and social construction, medical sociology - professions, knowledge and power and community development and empowerment.

Due to my aim being to help bridge the gap between the conceptual and the personal I believe that a research approach needs to be adopted that can effectively 'unveil' social processes and sensitive issues such as attitudes and values in such a way that maintains the social context and complexity of the information gathered. I would propose using a discourse-analytic approach since this appears to offer the above while also providing through it's application opportunities for reflexive analysis, re-construction and change. Discourse analysis can produce insight and understandings that are relevant to practitioners and policy makers alike.

Appendix C: Guidelines for Co-supervision Sessions

Aims, Guidance and Practicalities for Co-Supervision Sessions

Aims

The aim of these sessions is to provide the research with a commentary from a user/survivor frame. Commentaries and guidance will be sought on the following key areas:

- the way the information or 'data' is gathered
- on the information itself as it is gathered from the interviews
- gaps in the research
- on the analysis that I develop from the data and emerging themes generated
- a separate analysis from within a 'survivor frame' on the data gathered
- on the emerging theory that develops and contribution to the emerging theory
- on any group-work built into the research process
- direction on dissemination and feedback to participants

Where and When?

The sessions will take place every 4-6 weeks for two hours each time. The meetings shall take place in X. A record shall be kept recording the discussion and decisions made and will be agreed during the meeting and typed up by Tessa with a copy being held by both * and Tessa.

Payment

Payment for these sessions shall be made directly to *'s user group from the research funds held for this project at the Tizard Centre. A sum of £40 will be paid per session. This fee will include reading some material relating to the research between meetings. If much reading is required than a further payment will be made to compensate for this extra work.

Confidentiality

It is important that the information discussed at these meetings is kept confidential. Material or information gathered must not be discussed outside of the meetings in order to protect the individuals who have given accounts. Due to the nature of the 'small-world' of user-groups and institutions we need to be very careful that confidentiality is not broken by mistake since individuals accounts may be recognisable to others. Confidentiality will be broken only when one of us feels that we must due to the seriousness of what we have heard. We need to discuss this with each other and discuss the actions needing to be taken.

Appendix D: Comments on Interviews by Co-supervisor

These comments have been decontextualised. These were comments on the interviews themselves rather than on my analysis. All the main themes raised by the co-supervisor as important have been noted here. They are reproduced to demonstrate the commonalties between the user co-supervisor's interpretation of the transcripts and their meanings and my own for triangulation and validity purposes. In most instances we both picked up on the same significant themes and points. When there were some that either of us had picked up on and the other had not I used this disparity to interrogate my own analysis to see whether I had been biased. The co-supervisor comments are comments on the interviews from the standpoint of somebody who has a leadership role within the user movement. They are therefore also about how the interviewee's comments fit with his own understanding of the main issues. The comments are listed below in no particular order:

- Professional attitudes are the main problem and therefore the main solution.
- Confidentiality – tool professionals use against users.
- Trust between users and professionals important.
- Silent majority – key term
- Why do staff collude with the crap?
- For many staff collaboration is a new concept.
- Control issue – there is a backlash from staff
- Medication is used coercively.
- Importance of defining user involvement – if you can not define involvement how do you know if it works?
- Relevance of boundary issues if somebody uses services and works in the same place.
- Power to withdraw credibility.
- How user groups tend to define themselves by the meetings they go to - shame. They are simply responding to other people's agenda! User movement dictated by professional agenda and professional paternalism.
- We need to create our own agenda.
- Black users need to develop their own voice
- Professionals seem oblivious to the power they have.
- The need to be adversarial
- Need a staff attitude that does not focus on disability and weakness all the time.
- Nurses have a false consciousness – they have their heads in the sand. They are 'falling between stools' and need to reclaim a sense of identity themselves.
- When staff feel isolated it is easier to be custodial.
- Users are saying they want warm friendly services.

- Dangerousness issues have become an excuse.
- There has been bureaucratic rather than real change - Empowerment is superficial
- There is statutory disempowerment in the mental health system but the mental health act give you more rights.
- Nurses can operate the medical model more rigidly than doctors.
- Staff as ignorant as Jo Public
- No meaningful process to get black users on board.
- Interviews show 'warts and all' inner city bin. Institutions are worse since community care.
- No clear vision where they should be going and nursing has a lot to answer for.
- User involvement policies have stayed at the top and not transmitted down to the frontline which is where they should be.
- Hospital wards are abusive places to work too.
- Training is needed to change attitudes.
- Top down – if vision is not shared by majority of staff it doesn't happen. It does make inroads as can be seen in these interviews but more needs to be done. Top-down strategy effects change in organisational culture but this does not impact on bottom-level at the user-professional interface in acute wards. These are neglected in many ways.
- Political decision what users get paid for and what they don't. Why do users not get paid for meeting the Trust on issues that are their own agenda?
- Re the lack of conflict - 'They don't even see it as a war' is a crucial comment. Colonials never do.
- Are user groups only doing things for perks?
- Service providers go to groups that collude with them rather than challenge them.
- Some groups are in a state of denial about conflict.
- Cynical about independence of voluntary sector
- Psychiatry has 'lost the plot!'
- The lack of conflict described by professionals is very interesting as user groups by their very nature should be confrontational so if this one is not – what is going on?
- User involvement means different things to different people.
- Users and staff have different expectations of involvement.
- 'The criticism of the user movement is that it disowns the truly disempowered! It is too mainstream and has lost its idealism! Interesting that the most 'anti' people have been sidelines in the movement according to one interviewee.
- Representation is a key issue – professionals say well you are different which is an obvious way to discredit you and indicates the low expectations of users.
- Advocacy has been diverted into complaints.

Appendix E - Trust A User Involvement Policy

(N.B. This document has been scanned in full, all names replaced with ***********)

Introduction

*********************** NHS Trust supports the principle of involving service users in a meaningful way in the planning and delivery of services. The philosophy behind this approach is that in order to provide a high quality service that meets individual needs, it is vital that the views and perceptions of people on the receiving end of services are taken account of, valued and acted upon. In this way the Trust will pursue a NHS Executive's medium term priority of 'Giving greater voice and influence to users of NHS services and their carers in their own care, the development and definition of standards set for NHS services locally and the development of NHS policy both locally and nationally" (Priorities and Planning Guidelines 1996/97 EL(95)68).

This policy sets out ways in which users are invited to become involved in the operation of the Trust in a way that empowers them and leads to an organisational culture in which users have a central place. It is written in such a way as to set out obligations and a code of behaviour on both sides, including avenues to take if the relationship breaks down.

Definitions:

For the purposes of this document the following terms will be defined

User: A user is someone who uses or has previously used the services of the Trust.

Local Representatives: This is someone who represents the views of users and carers in the local area but are not users themselves of the Trust's services, e.g. representatives from CHCs, voluntary groups, cultural organisations or advocacy projects.

Carer: A carer is someone who is substantially involved in the care of a user of the Trust's services. It is recognised that users may also be carers and vice versa.

User/Carer Involvement: Involvement is a general term for either consultation or participation.

User/Carer Consultation: This involves Trust representatives giving information on proposed changes in services, or proposals for new service delivery to users/carers (and their representatives) who are potentially affected by such changes and developments. The views of users/carers and representatives will be sought.

User/Carer Participation: This involves Trust representatives inviting users and carers to be active participants in groups contributing to the decision making processes of the Trust.

1. **Decision-making and development of users' groups and forums**
   A critical aspect of user involvement is decision-making. Decision-making takes place at a range of levels within the Trust covering both strategic and day to day issues. Effective user/carer involvement at any level, necessitates representatives from the Trust giving full and current information on proposed changes in service delivery to users and carers, within a time-span which makes consultation or participation feasible.

   User/carer participation in decision making can be done at the level of individual services or at an organisational level. Users' and carers' voices will be heard in this way and will contribute to final outcomes, along with other "stakeholders" (i.e. their voices alone will not determine the final outcomes). If users and carers are involved on planning groups at service or organisational levels then the Code of Practice (see below) detailing obligations on both sides, becomes operational.

   In order to facilitate effective involvement of users in decision-making at all levels within the organisation, the Trust will encourage and support the development of a variety of user groups.

2. **Present situation**:
   There are two main user forums at present in existence for the Trust:

   1) ************* A user forum for users and professional allies based at ****************

   2) *****************************

   Both these groups discuss Trust-wide issues and issues of more local concern, particularly acute adult services.

   More locally there is a Patients Council at ************ covering in-patient issues.

   There are some Hospital/Community Mental Health Centre Groups covering local department issues e.g. the Methadone Maintenance Clinic has a very new group.

   Ad hoc Groups arise from time to time covering specific issues (e.g. occupational therapy support, specific threats to certain services etc.).

   It is recognised that particular named groups may change over time or may go out of existence, nevertheless the principle of encouraging main and local forums will continue.

   It is recognised that users have a unique perspective as a result of being on the receiving end of services provided. It is also recognised that user groups change over time and people step in an out as they feel able, and that at times, the work we are asking users to participate in can be very demanding. Where possible users who join committees will represent a larger group of users and will be accountable to that group and responsible for collecting views within the group and reporting back to fellow members. If this is not possible at any one moment in time, the Trust will seek the views of a number of individual users (bearing in mind that they are speaking as individuals) and form an overall picture from this mosaic of views.

Each directorate will be expected to demonstrate a level of user involvement. Where there is a slow turnover of the patient population ideally clinical areas and directorates will develop close relations with users and users will participate in all planning and development forums. Where there is a rapid turnover of users, or users are Outpatients, some creative way should be found to incorporate their views into service planning and quality initiatives. This might have to be done in survey form.

Staff members will be asked to make clear in any document related to changes, i) that they have consulted users and carers (stating how they were consulted or how users and carers participated in the decision making) and the results of that consultation or participation ii) who it was they consulted (or who participated) and who those users and carers represented iii) if users and carers are consulted as individuals, it must be made clear that a range of users/carers were consulted and some conclusion made of a general picture.

Each directorate will nominate a staff member to "lead" on issues of user involvement covering issues about setting up user groups/forums in their directorate, users being involved in quality assurance, staff training etc. Each lead person will be able to draw on the support and resources of the user development worker who will organise regular forums with the "lead" staff to devise training packages, talk about issues of common concern etc.

It is recognised that users' groups also provide a forum for mutual support for users and this is a feature which the Trust acknowledges and wishes to encourage. The Trust does not see its role as organising users' groups but is keen to facilitate their development by the provision of suitable meeting places, transport or transport costs, and the provision of tea and coffee etc. it will also supply back-up administrative facilities where necessary, and a personnel resource in the form of the user development worker and a half-time administrator. (As this work develops resource implications will be kept under review.) A budget will be available to provide training for users in skills in committee work, skills in training and interviewing skills. A budget will also be available to pay users for time spent in consultation about Trust issues.

The Trust aims to work with **************** and help establish users' groups throughout the organisation. Trust staff will be expected to support the development of users' groups and to make attendance at users' group meetings a high priority if they are invited. They will also be expected to encourage users who may wish to attend, to go to meetings.

Proposals for major changes in the way services are configured or delivered will be discussed with users involved in those services. Proposals for the introduction of new services or the closure or existing ones will not be implemented without consultation with the two main user forums or with the relevant user forums and the relevant CHC and other relevant user/carer groups.

3. Information

In order to involve users in a meaningful way in the planning and delivery of services, it is extremely important that they are kept up to date with changes and development in the Trust. In order to facilitate good information flow the Trust will produce quarterly newsletters. Staff at all levels within the organisation will be expected to give a high priority to updating users with clear information. Every effort will be made to provide information to people who have language, literacy and other difficulties.

4. Quality Assurance

In order to ensure that the provision of services by the Trust meets the required standard, a number of quality assurance systems are in place, or being established to monitor the services provided. It is recognised that the perception of users regarding the quality of services that they receive, is an extremely important indicator and the involvement of users within the Trust's Quality Assurance programme is seen as being of critical importance. This involvement will take place both by seeking the views of users through questionnaires and interviews and also by asking users to participate in routine monitoring visits. Also the Trust will move towards including users in the Quality, Audit and Effectiveness Strategy Group which is the setting where quality assurance systems are planned and reviewed including the system for dealing with complaints. At a local level Directorates will set out how they involve users in Quality Assurance and submit this information on a yearly basis to the Fair Access Advisory Committee.

5. Staff Training

In order for user involvement in the Trust to work successfully it is critical that the staff understand and support the principles underpinning user involvement. In order to achieve this a training programme will be developed by the Trust in partnership with the two main user forums or other relevant user groups or individual users. All new staff will be expected to participate in the course during their induction and existing staff will be expected to participate in regular refresher courses.

6. Staff Recruitment

The key aspect in the provision of a high quality service is the recruitment of high calibre staff. The Trust values the views of users in its recruitment and every effort will be made to involve users at all levels in the recruitment processes. This will include the provision of training for users in recruitment and selection skills, particularly in the area of confidentiality. (A separate policy on User Involvement in Recruitment is under development).

7. Equal Opportunities

The Trust opposes all forms of discrimination and will ensure that equal opportunities principles are adhered to in the involvement of users in all areas of its work. The Trust will encourage representation from users from a range of backgrounds that reflect the population it serves (ref. Trusts Equal Opportunities statement in Fair Access to Services Strategy and Trust's User's Charter).

8 Evaluation

As part of its commitment to user involvement, the Trust will evaluate the most effective methods of obtaining user views, using those views to influence professional practice. Organisation and cultural constraints on user participation will be identified.

Code of Practice for Professionals and Users on User Involvement in Trust meetings.

When involving mental health service users in Trust meetings the following points of good practice should be followed:

1. Trust staff should recognise how daunting it may be to users and carers to participate in Trust committees, planning meetings etc. They should be offered preparation, training in committee skills etc. Users and carers should always be invited to attend meetings in pairs.

2. The chair of the group should in advance indicate what kind of experience, representativeness, contacts etc. would be of most help to its work, so that appropriate nominees can be generated

3. A fee should be paid to cover the user's time, over and above travel expenses.

4. The background to the group needs to be explained to the users, organisational systems and technical terms should be explained, and the meeting should be kept as free from jargon as possible.

5. The chair of the group should explicitly invite the users to speak at intervals if they have not otherwise been drawn into the discussion.

6. If users are on groups with senior Trust managers, thought should be given to inviting representatives from front line staff so the representation is more evenly spread and that real issues that arise in clinical situations can be discussed.

7. Users are to be seen as representing main or local user forums as relevant, the local CHC and other relevant user groups or voluntary bodies the users will feedback to their respective groups. If this is not possible a range of views should be sought from individual users and carers. In reports the method and range of consultation should be stated with a rationale.

8. Where appropriate on Trust-wide issues, the 2 representatives should be one from ************* and one from *************.

9. Users and carers, along with everyone else in the group, should respect patient confidentiality absolutely.

10. Users should abide by the terms of the group as to its general confidentiality or otherwise (this will vary) and abide by the Openness Policy of the Trust.

11. Users' and carers' conduct should be appropriate to the occasion as guided by the chair. Nevertheless, the chair must recognise that at times the User perspective is outside of (and sometimes a critique of) usual professional discourse and therefore the group should not be surprised if users talk about areas seen as "taboo" or usually silenced by professional discourse.

12. In the event of difficulties occurring and relations breaking down between Trust staff and user/carer nominees, the user liaison and support worker should be approached and asked to mediate. If mediation is not successful the user or carer will report back to the user group and a user group decision will be made as whether to provide a replacement or whether to withdraw their support from the group.

Appendix F: Trust B User Empowerment Policy and Terms of Reference

(N.B. This document has been scanned in full, all names replaced with ***********)

USER EMPOWERMENT

"We aim to enable and support individual service settings to involve service users in the planning and day to day management of existing and new services. We also aim to support the development of a range of generic and specialist services which enable service users to make real choices in line with their own priorities."

USER EMPOWERMENT - POINTS FOR SERVICE USERS & STAFF

The Trust aims to:

Treat you with dignity and respect, acknowledging and responding to your individual needs, regardless of your ethnic origin and cultural background, religion, gender, sexuality, disability, age or social class.

Promote and support your involvement in identifying and planning your own care and treatment, and also in the planning, running and evaluation of services generally.

Provide you with all relevant information, in an accessible form which will enable you to make informed choices about your treatment and care, and to be aware of your rights under the Mental Health Act.

Offer structured activities so as to ensure there are meaningful choices about how to spend your day.

Encourage staff to give and invite feedback on services and treatment. To regard your complaints as valuable and ensure that you are aware of mechanisms and procedures to enable your comments to be heard without fear of victimisation.

Take the time to listen to your anxieties and concerns, and to regard supportive listening as a key component of the service it offers.

Encourage and support you to read your records and to participate in writing them, within the constraints of legislation.

Explain to you, all those individuals and bodies who have right of access to your notes, and to undertake not to disclose information about you to anyone else without your formal consent.

Encourage you to speak up for yourself and/or choose anyone you trust to speak on your behalf. This person need not be a relative.

Provide an environment in which you feel safe, and free from physical or verbal mistreatment and from any discriminatory practice.

Maximise your sense of control over your life and enhance your self-esteem.

TERMS OF REFERENCE

- To co-ordinate the strategic work of the Trust on user empowerment
- To provide a regular forum where service user representatives and key Trust staff may discuss important service delivery issues with a view to identifying development and improvement areas
- Specifically, to identify ways of maximising opportunities for service users to be involved in the planning and day to day management of existing and new services across the Trust.

MEMBERSHIP

********* Users Forum

******** Mental Health Support Group (African Caribbean mental health organisation)

******** Centre

******** Advocacy Training Network

******** Users Group

******** Residential Services User Group

Advocacy Strategy Group

Trust Chair

Chief Executive

Director for Rehabilitation (lead manager for user empowerment)

Director for Service Development/Nursing

Director for Adult Mental Health

Medical Director/Consultant representative

Associate Director of Adult Mental Health

Adult Mental Health Borough Managers

Fair Access Manager

Quality Development Manager

Advocacy Services Manager

Mental Health Act Administration manager

Staff representative of Joint Staff Consultative Group

Appendix G: Demographic Information on Interviewees by Characteristics

1. Gender of Interviewee

	No of interviewees	Percentage
Women	12	50%
Men	12	50%
Total	24	100%

2. Ethnicity of Interviewee

	No of interviewees	Percentage
White UK	16	66.7%
Black UK	4	16.7%
Other	2	8.3%
Irish	2	8.3%
Total	24	100%

3. Age of Interviewee

	No of interviewees	Percentage
20 - 35	7	29.2%
36 - 55	16	66.7%
56 - 65	1	4.2%
Total	24	100%

4. Are you a user of mental health services?

	No of interviewees	Percentage
No	7	29.2%
Yes	17	70.8%
Total	24	100%

5. If so, how would you describe yourself?

	No of interviewees	Percentage
Not user	7	29.2%
Survivor	6	25%
User	6	25%
User/Survivor	5	20.8%
Total	24	100%

6. Do you consider yourself to have a disability? (other than a mental health disability)

	No of interviewees	Percentage
No	20	83.3%
Yes	4	16.7%
Total	24	100%

7. Do you work in mental health services? (Work here means paid and unpaid)

	No of interviewees	Percentage
No	1	4.2%
Yes	23	95.8%
Total	24	100%

8. If so, where do you work and in what capacity?

	No of interviewees	Percentage
Not a Worker	1	4.2%
Statutory Services - Paid	9	37.5%
Statutory Services - Unpaid	4	16.7%
User Led Group - Paid	5	20.8%
User Led Group - Unpaid	3	12.5%
Voluntary Organisations - Paid	1	4.2%
Voluntary Organisations - Unpaid	1	4.2%
Total	24	100%

9. Is there anything else relevant about yourself that you'd like to mention? (class, sexuality etc)

	No of interviewees	Percentage
Not applicable	21	87.5%
London Working Class	2	8.3%
Working Class	1	4.2%
Total	24	100%

Appendix H: Demographic Information on Interviewees by Person

(N.B. Interviewee's initials have been changed)

Information on Interviewees	**AC**	**PH**	**BA**	**YT**	**RM**	**NP**
Gender	Male	Female	Male	Female	Male	Female
Ethnicity	White UK	Other	White UK	Black UK	White UK	White UK
Age	36-55	36-55	36-55	20-35	36-55	36-55
User of services?	No	Yes	Yes	No	Yes	No
Self-Definition	Not User	Survivor	User/ Survivor	Not User	Survivor	Not User
Disability?	No	Yes	Yes	No	No	No
Do you work in MH Services?	Yes	Not a worker	Yes	Yes	Yes	Yes
If so where? Is this work paid?	Vol. Org. Paid	Not a Worker	Statutory Services Paid	Statutory Services Paid	User Led Group Paid	Statutory Services Paid
Professional group?	Manager Voluntary Org.	N/A	Advocacy Worker	Nurse	User Development Worker	Manager Statutory Services
Anything else?	N/A	N/A	N/A	London Working Class	N/A	N/A
Setting	Other	Trust B	Trust B	Trust B	Other	Trust B

Information on Interviewees	**TB**	**MG**	**SW**	**CD**	**PF**	**JR**
Gender	Male	Female	Male	Female	Female	Male
Ethnicity	White UK	White UK	White UK	Black UK	White UK	White UK
Age	36-55	36-55	36-55	20-35	20-35	36-55
User of services?	Yes	Yes	No	No	Yes	Yes
Self-Definition	User	User	Not User	Not User	User/ Survivor	Survivor
Disability?	No	No	No	No	No	No
Do you work in MH services?	Yes	Yes	Yes	Yes	Yes	Yes
If so where? Is this work paid?	Statutory Services Paid	Statutory Services Paid	Statutory Services Paid	Statutory Services Paid	User Led Group Unpaid	User Led Group Paid
Professional group?	Manager Statutory Services	User Development Worker	Education/ Nursing Background	Nurse	N/A	User Development Worker
Anything else?	N/A	N/A	N/A	N/A	N/A	N/A
Setting	Trust B	Trust A	Trust A	Trust B	Trust A	Other

Information on Interviewees	**EN**	**RW**	**DB**	**LG**	**HK**	**WA**
Gender	Male	Male	Male	Female	Female	Female
Ethnicity	White UK	Other	Irish	Black UK	Irish	White UK
Age	36-55	36-55	36-55	36-55	20-35	20-35
User of services?	No	Yes	Yes	Yes	Yes	No
Self-Definition	Not User	Survivor	User	User	User/ Survivor	Not User
Disability?	No	No	Yes	No	No	No
Do you work in MH services?	Yes	Yes	Yes	Yes	Yes	Yes
If so where? Is this work paid?	Statutory Services Paid	Statutory Services Unpaid	Statutory Services Unpaid	Statutory Services Unpaid	Statutory Services Unpaid	Statutory Services Paid
Professional group?	Psychiatrist	N/A	N/A	N/A	N/A	Clinical Psychologist
Anything else?	N/A	N/A	London Working Class	N/A	N/A	N/A
Setting	Trust A	Trust A	Trust B	Trust A	Trust A	Other

Information on Interviewees	**SH**	**KM**	**FN**	**BM**	**MB**	**GC**
Gender	Female	Female	Male	Female	Male	Male
Ethnicity	White UK	White UK	White UK	White UK	Black UK	White UK
Age	36-55	20-35	36-55	36-55	20-35	56-65
User of services?	Yes	Yes	Yes	Yes	Yes	Yes
Self-Definition	User/ Survivor	Survivor	User	User	Survivor	User/ Survivor
Disability?	No	No	Yes	No	Yes	No
Do you work in MH services?	Yes	Yes	Yes	Yes	Yes	Yes
If so where? Is this work paid	User Led Group Paid	User Led Group Paid	Vol. Org. Unpaid	User Led Group Paid	User Led Group Unpaid	User Led Group Unpaid
Professional group?	Manager Vol. org	User Development Worker	N/A	User Development Worker	N/A	N/A
Anything else?	N/A	N/A	N/A	N/A	N/A	Working Class
Setting	Other	Other	Other	Trust A	Trust A	Trust B

Appendix I: Background Profile Questionnaire for Interviewees

Questionnaire

This questionnaire aims to provide a profile of the people I am interviewing for the purposes of ensuring that a range of views and experiences are gathered and represented in the research.

I would be very grateful if you could tick the boxes that you feel apply to you. This information will only be used for this research and will be kept confidential to this project. There are questions on both sides of this paper. If you don't want to answer a question please just leave the question blank. Many thanks.

1. **Gender** ☐ Male ☐ Female

2. **Ethnicity**

How would you describe your ethnicity or racial group *

Black UK ____________________ African ____________________

Caribbean ____________________ Indian ____________________

Pakistani ____________________ Bangladeshi ____________________

Cypriot Greek ____________________ Cypriot Turkish ____________________

Chinese ____________________ Vietnamese ____________________

White UK ____________________ European ____________________

Irish ____________________ Mixed race ____________________

Other ____________________ (please specify)

* These classifications are as recommended by the Commission for Racial Equality

3. **Age** Please indicate which age group you are in.

16-19	20-35	36-55	56-65	66+

4. **Would you describe yourself as a user/ survivor of mental health services?**

Yes	No

Which of the terms do you prefer? E.g. user, survivor, other please specify below...

5. **Do you consider yourself to have a disability? (other than mental health)**

Yes	No

6. **Do you work in mental health/psychiatric services in some way?**

Yes	No

If yes, can you describe the nature of this work and what professional group you belong to?

Nature of work

Job Title/Prof. Group

7. Do you have any other comments regarding your **background, class, level of education, sexuality** or **any other information** you wish to make known or feel is relevant?

Appendix J: Advert for Interviewees for Research in User Group Newsletter

WANTED!

Users/Survivors willing to be interviewed as part of a research project on USER INVOLVEMENT.

Do you have views on...

⇒ Working with professionals?

⇒ Your experiences of being involved in either your treatment or in the running of your services?

If so read on...

- The research is being carried out by a post-graduate researcher at the **Tizard Centre, University of Kent.**
- The interview usually takes about **an hour.**
- The information you give is completely **confidential** to the research and will not be used for anything else.
- A **payment of £10 will be made in cash** on the day of the interview.
- You will **receive a copy of the research findings** at the end of the project.

Interested?

Call Tessa Parkes on **xxxxxxxxx and leave a message with your name and a contact number** or write to me at The Tizard Centre, University of Kent at Canterbury, Canterbury, Kent, CT27LZ

Appendix K: Correspondence Regarding Access and Interviewees

13th July 1998

Dear *,

Thank you for your interest in my Ph.D. research. * from the * Advocacy Project has contacted me regarding a request I made that she raise the issue of research access at the Fair Access Committee. She mentioned you were interested in knowing more about the research problems I am encountering, perhaps for the purposes of wider discussion, and I enclose a copy of my research outline for you to look at along with some information about my background.

To briefly summarise, I wish to interview eight or ten professionals working in different capacities within the Trust, for an hour to an hour and a half. I shall be asking people about their views on user involvement, relationships between professionals and user groups, what helps or hinders user involvement and the risks and rewards of user involvement. As described in my research outline, all information given will be confidential and the participants anonymous. I am aware of the work your Trust has been doing involving users more centrally and am therefore very interested in speaking to staff members within it. I am also making arrangements to speak to staff within other hospitals to ensure a cross-section of responses.

The main difficulty I am encountering is with the rules of access to the ethics committee that deals with research proposals. Since I am not an employee of the * Trust I cannot put forward my project to the ethics committee without first getting a consultant or senior lecturer to take responsibility. I do not know any consultants or people of senior lecture status within the Trust although I do know quite a few people within it who support my project. It is unlikely that a consultant or senior lecturer would take my study on without wanting some control themselves or to perhaps wish a publication from it. I have asked a senior registrar I know for advice on this issue and was told that this route would indeed have ramifications for my project in terms of ownership.

I understand the need to be cautious of researchers and research and naturally realise that many problems can result from unethical practices. My research is not intrusive or invasive however since it consists of a small number of interviews which people will have to fully consent to. I am aware of the ethical concerns of research as I have already had it passed through the Tizard Centre's ethics committee which * herself sits on. This committee commented on how well thought through the ethical considerations were and were particularly pleased with the level of involvement of service users in the research process.

The research is being properly supervised and overseen at the Tizard Centre where I am a full-time PhD student. My supervisor is Dr. Jennie Williams, senior lecturer and clinical psychologist and it was my initial hope that she would be seen as a sufficient enough authority to take responsibility for the project. It seems this is not the case, the rules clearly state that the 'Principal Investigator' needs to be a * consultant or senior lecturer. Unfortunately without such a person I cannot submit my application to the ethics committee to be discussed or approved. I'm afraid I do not have an extra copy of the ethics committee forms at hand to send you with this information clearly stated.

* mentioned the possibility of an honorary contract with the * for myself or my supervisor, to be given for the duration of the project, an idea initially suggested by * in Personnel and I will be writing to the ethics committee chairs to see if they might consider this. Another option would be for them to accept someone else's authority within the * who isn't either a consultant or a senior lecturer though it appears they are unlikely to budge on this point.

I would be extremely grateful for any advice you might give me on this matter and thank you again for taking an interest.

Yours sincerely,

Ms Tessa Parkes

PhD Researcher, Tizard Centre, University of Kent at Canterbury.

TIZARD
UNIVERSITY OF KENT
AT CANTERBURY

The Tizard Centre

Dr Glynis Murphy
Reader in Applied Psychology of Learning Disability

Dialling code for Canterbury:
01227 (UK) or +44 1227 (International)
Tel: 764000 switchboard (ext.7989)
Fax: 827248
Email: G.H.Murphy@tizard.ukc.ac.uk

23 July 1998

Dear

Re: Ethics Committee

I am writing to you for some advice about submission of a proposal to the above Ethics Committee, which I understand you now co-chair.

We have a very impressive PhD student, Tessa Parkes, here at the Tizard Centre who is doing a PhD in mental health, under Dr Jennie Williams' supervision. Her topic is the empowerment of service user groups in mental health services and she has developed links with service user group. She would like to do some research with them and is uncertain how to proceed in relation to the Ethics Committee.

As we understand it, you have to be employed by to apply to the Ethics Committee and of course neither the service users nor Tess herself are employed. I said I could not believe that the foremost hospital for mental health (!) would not be able to find a way to allow its own service users to do a research project but I am not sure what the best way forward would be. Could I act as the proposer, assuming I am still an honorary SL?

We would be most grateful for your advice.

With very best wishes.

Yours sincerely

Glyn

Dr Glynis Murphy
Deputy Director

PS: I find myself wondering which is harder: one of your days in Bosnia or one of your Ethics Committee days?

Beverley Farm
University of Kent at Canterbury
Canterbury, Kent CT2 7LZ. UK

4th August 1998

Ref: AB/EB/3860/MAN447

Tessa Parkes

CHIEF EXECUTIVE'S DEPARTMENT
Direct Line:
Direct Fax:

Dear Tessa,

You wrote to . on the 13th July with difficulties around approval or in someway involvement through our Ethical Committee for research projects. That's a body that concerns itself with staff and outsiders that wish to gain access to patients in our care at some point. It does not relate in any way to the conduct of pieces of management research around policies and practices in the manner you lay them out.

So there is no need to involve an Ethical Committee in any way and I would be happy for you to interview eight or ten voluntary professionals working in different capacities within the Trust assuming that they wish to participate. We have a called who is based at the She might be helpful in advising you who best to approach. If you have any difficulties please let or I know but I would have thought that an open letter to explain what you have in mind would hopefully engender sufficient response to meet your needs.

Please let me know if I can help in any other way.

Yours sincerely

Chief Executive

Cc:

A Network For Mutual Support & Positive Change In Mental Health Services

11/8/98

Dear Tessa,

have all read your research proposal thoroughly. We think that it is a very worthwhile and relevant study for both Users and staff. We fully support your research and are willing to take part in interviews. Please keep us informed of your progress.

Yours sincerely.

24th August 1998

Dear *,

Thank you for your time last week I really enjoyed meeting you and hearing about the progress of user involvement and empowerment within the Trust. I am very pleased that you feel that you'd like to be involved with my research and I hope that our partnership will be valuable to you also.

As we discussed last week I have given some more thought to the people within the Trust that I would like to interview. I think it would be most useful to speak to about 8 staff (including yourself and *) and 4 service users. This disparity is because I have more interviews with users than staff at the moment within the general sample. Also I would like to contact some * users directly, perhaps through the * who are not so heavily involved, for a variety of experiences. * suggested that an advert in * newsletter may attract some people who are not the people who are most active within the local user movement. I have placed an advert in the September issue and will try to arrange a visit to the * in September. Please could you include * on the list of people you send letters to I could then contact him regarding visiting *.

The names we drew up last Wednesday sounded like a very good starting point with * perhaps suggesting ward staff if he is willing to be involved. Would it be worth generally sending more invitations than 10-12 at this stage in case some people are too busy, not interested etc. or shall we wait and see. The main thing is to ensure a variety of views and perspectives. In the * I shall be trying to interview professionals within different locations, with different roles i.e. nurses, doctors, social workers, psychologists, managers and different places in the hierarchy/levels of responsibility.

I am also attempting to address issues of representation in this research and therefore am trying to interview a good number of staff and users from ethnic minorities (my aim is for around 20% of interviewees). I would be very grateful if you could give this some thought in relation to the people that you initially think of to contact. As we discussed the * contact would be excellent. Are there also front line Trust staff you can think of? * suggested someone who may be good to talk to called * (doesn't remember second name) who he has met recently who has just joined the Trust, working in Safety he thinks? Do you know who this may be?

I have also enclosed a copy of an A4 double-sided information sheet for those people you decide to send letters to so that they have more information about the research project generally. I hope it contains all the information you feel is necessary. One slight problem is that I am rarely at the Canterbury, Tizard number because I mostly work from home in *. I have put that number on the form because I am reluctant to put my home number on the sheet as it is against Tizard personal safety guidance. It shouldn't be too much of a problem because I share a 'phone line with six other colleagues who are excellent message takers! However it may also be helpful for people to contact you in the first instance. How do you feel about this? If this complicated matters or involves more work for you then the message taking I'm sure will be fine.

If * is free before you come back from holiday I will be able to meet him from the 21st September. He can contact me on *. Please feel free to contact me on this number for any reason. Meanwhile have a wonderful break,

Kind regards,

Tessa Parkes

Ph.D. Researcher, The Tizard Centre, University of Kent at Canterbury

26th August 1998

Dear *,

Thank you for responding to my letter sent to * last month outlining my difficulties with access to the * Ethics Committee. As I told * on the telephone last week, I was advised by the secretary of the committee that I would have to go through the Ethics committee even though my research did not involve in-patients. However I had presumed initially that this would not need to be the case in the way you advised in your letter.

I therefore accept your kind invitation to interview staff members of the hospital for this piece of research. This will speed up what has until now become a rather drawn out process so I really appreciate your intervention in this matter. I shall be contacting * as you suggest with a view to approaching staff who wish to take part. As the outline I sent to * details, the interviews are entirely voluntary and will only involve approximately an hour and a half of their time.

Thank you again for your help on this matter,

Yours sincerely,

Tessa Parkes

Ph.D. Researcher, The Tizard Centre, University of Kent at Canterbury.

12th April 1999

Dear *,

I wrote to you just under a year ago concerning gaining access to * to do some research on the subject of user involvement. I have enclosed a copy of my research outline and the letter sent to me by * to place this letter in context. I have now almost finished the interviews and they have all gone very well. I only interviewed a small number of people at * in the end because I broadened out the geographical area the research covered. I very much appreciated the openness you and * showed me last year and wanted to thank you again for that. It certainly speeded up the process of the research at that time and saved me valuable time.

I am now writing to invite you to be interviewed for the research since by all accounts I have heard you have been central to the policy and practice of involving service users within the Trust. I have also interviewed other managers in other Trusts in * who have been responsible for user involvement policies. If you are interested in being interviewed it will take about an hour. I transcribe the interview afterwards and give you a copy where you are able to make amendments to it if you want to before it gets used for the research. I realise however that with the recent merger you must be extremely busy and understand if you are unable to find the time. Please contact me at the above address if you are interested and have the time and we can arrange a time that's most convenient for you,

Yours sincerely,

Tessa Parkes

Ph.D. Researcher, The Tizard Centre, University of Kent at Canterbury

Appendix L: Information Sheet for User/survivor Interviewees

Research on Power and User Involvement in Mental Health Services

Purpose and Aims of the Research

The purpose of this research is to find out more about how user involvement is working, or not working, at a local level. I am exploring different opinions on partnership and power-sharing in the mental health system. One of the main aims is to try to identify the barriers to meaningful involvement in order to be clearer about how to overcome them. I hope to use the material gathered to develop training material used to improve awareness of power issues in this area.

You will have the opportunity to comment on the way your interview is written up and interpreted and your comments will be given a central place in the research. I will make sure that the findings of the research are fed back to you by sending you a copy of the final report. I shall publish the research in magazines and journals read by professionals and users/survivors as well as more academic ones to ensure that the knowledge gathered gets widely read.

The Interview

The interview shall take between an hour and an hour and a half depending on your time and answers. It will be recorded on audio-tape and written up later by myself. We can do the interview wherever is most convenient for you. The tape-recorder can be turned off at any time if you wish.

Questions

The areas I would like to discuss with you are

- views on user involvement
- relationships between user groups and professionals, the hospital or Trust
- understandings about conflict
- what helps or hinders power-sharing

Confidentiality

All information shall be given confidentially. The audio tapes will be numbered and will not contain any names or personal information that can be identified and will not be used for any other purpose than this research. The tapes and information gathered will be kept locked up for safety.

Consent

I shall answer any questions you have about the research so that you feel able to decide whether you want to participate. You are free to withdraw from the project at any time without giving any reason. If you want to take part you shall be asked to sign a consent form which explains also your rights.

Payment

A payment of £10 will be made to all user group members who are interviewed as a thank you. This will be paid in cash on the day of the interview.

Please get in touch with me if you have any other questions or want to discuss things further:

Tessa Parkes
🖂 The Tizard Centre
University of Kent at Canterbury
Canterbury
Kent
CT2 7LZ
☎ (01227) 827269

Appendix M: Consent Form for Interviewees

Consent Form for Research Project on User Involvement

Thank you for agreeing to be interviewed. I really appreciate you giving your time to be involved. Please read the statement below and then sign and date the bottom.

I have read the information given to me by Tessa Parkes on the research project on **Power and User Involvement in Mental Health Services**.

- I have been able to ask questions and now understand the purpose and aims of this research.
- I understand that the interviews are anonymous and confidential so that I shall not be identifiable to others.
- I realise that the interview that I give will be kept safe and will only be used for this research.
- I understand that I can withdraw from this research at any time without giving a reason.
- I shall be paid £10 for this interview, which I shall be given on the day. This payment does not affect my rights explained above.

I therefore agree to take part in this research project.

Signed:

Please Print Name:

Date:

Appendix N: Semi-structured Interview Guide for all Interviewees

1. BACKGROUND INFORMATION – SETTING THE SCENE

(User Group Members)

- Can you tell me about any user groups you belong to?
- What are the aims of the group?
- How would you describe your role in the group? How long have you been involved in this?

(Professionals)

- Can you tell me briefly about your role/job here?
- What is your involvement with users or user groups as part of this role?
- Is this work supported/endorsed by your employer?

(User/Workers)

- Explore tensions between groups and work/issues of support/conflicts/benefits.

2. USER INVOLVEMENT/PARTICIPATION - CLARIFICATION AND DEFINITION

Because there's a lot of talk about user involvement and participation I want to ask about your thoughts on what these terms actually mean to you...

- So how would you define the term user involvement?
- Is the term meaningful to you? Is it your agenda?
- What does this mean to you in terms of actual practices? Give examples if possible?
- (For users) Were you involved in your treatment and care in your last admission for example?
- At what levels do you see the 'involvement' of service users working locally/where you work/live? At what levels should it work primarily?
- What do you think are the reasons why user involvement/participation is now on the agenda?
- Do you have any criticisms or concerns about the way user involvement happens in practice?

3. GUIDANCE OR TRAINING (PROFESSIONALS ONLY)

- Have you received any guidance on involvement of service users? If so what?
- What has informed your views on user involvement? Do you feel informed by academic or professional writings on the subject of involvement for example?

4. RELATIONSHIPS WITH PROFESSIONALS (USER GROUP MEMBERS ONLY)

- What kind of relationship does your group have with different professionals?
- Can you tell me about your experiences of working with professionals as a user group member?

5. RELATIONSHIPS WITH USERS (FOR PROFESSIONALS ONLY)

- How would you describe your relationships with the users or user group that you work with?
- Have you experienced any conflicts with users/user groups over any issues when collaborating with them? Can you tell me more?

6. DIFFICULTIES WITH COLLABORATION AND WITHIN GROUPS (FOR USER GROUP MEMBERS ONLY)

- Has your group experienced any conflict with professionals over issues of involvement and collaboration? If so over what kinds of issues?
- How do you think the professionals you know see user involvement and empowerment? Are there differences between users and professional's?
- Is conflict an issue within your group? If so, can you describe it for me?
- Are there any race, gender or other equality issues in your group? Can you describe these?

7. WHAT HINDERS/HELPS USER INVOLVEMENT AND PARTCIPATION?

- What are the barriers to 'real' user involvement/participation in your opinion?
- What helps user involvement take place/work? Probe rewards and incentives.

8. WHAT ARE THE RISKS AND REWARDS OF USER INVOLVEMENT?

- What challenges do you see user involvement presenting to professionals/yourself?
- Are there any risks do you think?
- What are the rewards of user involvement? Generally? Professionally? Personally?
  Ask professionals their views on risks for users and vice versa too.

9. THE FUTURE

- Do you believe there are real opportunities for partnership and power sharing between users and professionals?
- How do you see things changing in the next few years if at all? What would you like to see?

NOTE: PROBE ON LINKS TO POWER AND EMPOWERMENT THROUGHOUT INTERVIEW

Would you like to say anything else before we finish - anything I've left out?

Endings and Follow Up

- Thank you very much for your time.
- Payment and Consent Form - Are you happy for this to be used?
- I shall send you a copy of your research transcript - would you like the opportunity to comment on your research transcript? Make changes? What would be the easiest way of doing this? Shall I send it to you with a stamp-addressed envelope for return?
- If I do not receive it back I need to presume things are OK to go ahead so please contact me if not.
- A copy of the final research will be sent to you as part of my commitment to feedback to people who take part. Can you let me know if you change address?
- Can you recommend anyone else to interview who either shares your views or who has very different views?

THANK YOU AGAIN FOR YOUR TIME.